Patient-Reported Outcomes of Chronic Kidney Disease and Diabetes Treatments, including Transplantation.

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Declaration of Authorship

I Katherine Hann hereby declare that this thesis and the work presented in it is entirely my own. Where I have consulted the work of others, this is always clearly stated.

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Abstract

Mixed methods were used to investigate the impact of chronic kidney disease (CKD) and diabetes on quality of life (QoL) and other patient-reported outcome measures (PROMs). Study 1 followed up 127 participants from the Access to Transplantation and Transplant Outcome Measures (ATTOM) detailed PROMs sub-study, which included individualised condition-specific measures of QoL, and found QoL and other PROs improved 12-months post-kidney or simultaneous pancreas and kidney transplant (SPKT). Participants completed follow-up PROMs six/seven years after ATTOM. PROMs scores remained stable from 12-months follow-up in ATTOM to approximately six/seven-years post-kidney or SPK transplantation. Living-donor and deceased-donor kidney recipients were similar across the PROs. Study 2 involved a prospective longitudinal cohort observation of patients wait-listed for an SPKT. Analyses of 11 SPKT recipients found significant post-transplant improvements in generic QoL, diabetes-dependent QoL, treatment satisfaction, well-being, and health status. Health utilities and renal-dependent QoL did not significantly improve post-transplant. A sub-sample of participants from studies 1 and 2 took part in semi-structured qualitative interviews about their QoL. Those awaiting an SPKT often struggled with diabetes management and the combination of diabetes and CKD restricted QoL. Kidney and SPK transplant recipients experienced freedom to do and enjoy more; however, it was “not all rosy”. The qualitative interviews confirmed findings from the QoL PROMs. In study 3, interviews with partners of SPKT recipients revealed they had lived with pervasive worry prior to transplantation, and some had prioritised the patient’s well-being over their own. Post-transplant, partners experienced a great sense of relief and were able to refocus on their well-being. Overall, transplantation improved patients’ QoL and benefited partners, but patients are still often negatively impacted post-transplant. Patients need to be well informed on both positive and negative outcomes that they may experience post-transplant.

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15D	15 Dimension measure of health status and functioning.
ADDQoL	Audit of Diabetes Dependent Quality of Life, individualised measure of QoL and the impact of diabetes on QoL.
APD	Automated Peritoneal Dialysis.
ATTOM	Access to Transplantation and Transplant Outcome Measures research programme.
AWI	Average Weighted Impact.
BMI	Body Mass Index.
Brief IPQ	Brief Illness Perceptions Questionnaire.
CAPD	Continuous Ambulatory Peritoneal Dialysis.
CES-D	Centre for Epidemiological Studies – Depression measure.
CGM	Continuous Glucose Monitor.
CKD	Chronic Kidney Disease.
CSM	Common Sense Model of Self-Regulation
DAFNE	Dose Adjustment For Normal Eating, which is a training course for people with insulin-treated diabetes.
DASS-21	Depression, Anxiety, and Stress Scale – 21.
DBD	Donor after Brain Death.
DCCT	Diabetes Control and Complications Trial.
DCD	Donor after Cardiac Death.
DDKT	Deceased-Donor Kidney Transplant.
DDS	Diabetes Distress Scale.
DQOL	Diabetes Quality of Life measure designed for the DCCT.
DTSQs	Diabetes Treatment Satisfaction Questionnaire status version.
DTSQc	Diabetes Treatment Satisfaction Questionnaire change version.
EQ-5D-3L	EuroQoL-5 Dimension-3 level measure of health status and functioning.
EQ-5D-5L	EuroQoL-5 Dimension-5 level measure of health status and functioning.
EQ-VAS	EuroQoL Visual Analogue Scale single-item measure of health, modelled on a thermometer, included in the EQ-5D questionnaires.
GFR	Glomerular Filtration Rate.

GIQLI	Gastrointestinal Quality of Life Index.
GP	General Practitioner.
HADS	Hospital Anxiety and Depression Scale.
HD	Haemodialysis.
HLA	Human Leukocyte Antigens.
HRQoL	Health-Related Quality of Life.
KDQOL-SF	Kidney Disease Quality Of Life Short Form, kidney disease specific measure of health status/functioning.
KDQOL-36	Kidney Disease Quality Of Life 36 item measure, kidney disease specific measure of health status/functioning.
LDKT	Living-Donor Kidney Transplant.
NHSBT	National Health Service Blood and Transplant.
NICE	National Institute for Clinical Excellence – now named the National Institute for health and Care Excellence.
PAID	Problem Areas In Diabetes questionnaire.
PD	Peritoneal Dialysis.
PHQ-9	Patient Health Questionnaire 9-items.
PHQ-2	Patient Health Questionnaire 2-items.
PRO	Patient-Reported Outcome.
PROM	Patient-Reported Outcome Measure.
QoL	Quality of life.
RDQoL	Renal Dependent Quality of Life, individualised measure of QoL and the impact of renal failure on QoL.
RMQ	Renal Medication Questionnaire.
RRT	Renal Replacement Therapy.
RSSQ	Renal Service Satisfaction Questionnaire.
ReTransQoL	Renal Transplant Quality of Life questionnaire.
RHUL	Royal Holloway, University of London.
RTSQs	Renal Treatment Satisfaction Questionnaire status version.
RTSQc	Renal Treatment Satisfaction Questionnaire change version.
SEIQoL	Schedule for the Evaluation of Individual Quality of Life individualised interview method of measuring QoL.
SF-36	36-Item Short Form Survey measure of health status and functioning.
SF-12	12-Item Short Form Survey measure of health status and functioning.

SF-6D	6-Item Short Form Survey measure of health status and functioning.
SPKT	Simultaneous Pancreas and Kidney Transplant.
TxEQ	Transplant Effects Questionnaire of issues relevant to transplantation.
UK	United Kingdom.
VAS	Visual Analogue Scale.
W-BQ12	Well-Being Questionnaire 12 item version.
W-BQ16	Well-Being Questionnaire 16 item version.
WHO	World Health Organisation.
WHOQOL	World Health Organisation Quality Of Life measure.
WHOQOL-BREF	World Health Organisation Quality of Life BRiEF version

Chapter 1: Introduction and Literature Review

Introduction to Chronic Kidney Disease

The kidneys are two organs that filter the blood to remove otherwise harmful waste products and excess water, which is eventually excreted from the body. The Kidney Disease: Improving Global Outcomes (KDIGO) organisation defines chronic kidney disease (CKD) as the presence of kidney damage or abnormality lasting at least three months and resulting in decreased kidney functioning that has an impact on health (Stevens & Levin, 2013). CKD is a worldwide health problem with an estimated global prevalence of around 9% in 2017 (Bikbov et al., 2020). In 2011 it was estimated that approximately 2.6 million adults (aged ≥16 years) in England had stage 3-5 CKD and the prevalence is estimated to reach 4.2 million by 2036 (Public Health England, 2014). CKD directly resulted in around 1.2 million deaths worldwide in 2017 (Bikbov et al., 2020).

CKD Symptoms and Diagnosis. Diagnoses of CKD are often made by chance or once the patient has started experiencing severe symptoms (Webster, Nagler, Morton, & Masson, 2017). Symptoms of CKD can include fatigue, headaches, shortness of breath, difficulty concentrating, sleep problems, nausea, poor appetite, and weight loss. Patients often also experience changes to their urine, the frequency with which they need to urinate, and some patients stop urinating altogether. Swollen hands and feet can occur due to a build-up of excess water in the body (Webster et al., 2017).

CKD can be diagnosed from a blood test to investigate the glomerular filtration rate (GFR), an estimation of the amount of blood that passes each minute through the tiny structures in the kidneys, called the glomeruli. A second test involves measuring the levels of proteins in a sample of the individual's urine. High levels, known as albuminuria or proteinuria, suggest that the kidneys are not functioning effectively. Abnormalities of the kidneys can also be diagnosed using imaging tests or by a kidney biopsy (Webster et al., 2017). Currently CKD is diagnosed in five stages depending on the GFR associated with increasing impairment in kidney functioning, see Table 1.1. Once an individual reaches G5 CKD, often referred to as kidney failure or end stage kidney disease, they will need renal replacement therapy (RRT) such as dialysis or a kidney transplant (Levey & Coresh, 2012).

Table 1.1.

Stages of Chronic Kidney Disease by Glomerular Filtration Rate (GFR)

Stage	**G1**	**G2**	**G3a**	**G3b**	**G4**	**G5**
GFR ml/min per 1·73 m²	>90%	60-89%	45-59%	30-44%	15-29%	<15%
Kidney functioning	Normal	Mildly decreased	Mildly/ moderately decreased	Moderately/ severely decreased	Severely decreased	Kidney failure

Causes of CKD. CKD is a complex condition and may be the result of multiple risk factors. One of the leading causes of CKD is diabetic nephropathy due to inadequately controlled diabetes (Evans & Taal, 2015). Diabetes is a condition that results in an inability to maintain sufficiently normal levels of glucose in the blood. Frequent hyperglycaemia, when there is too much glucose in the blood, can cause damage to the blood vessels in the kidneys and as a result, decreases the organ's ability to properly filter the blood. Approximately 30-50% of diagnosed cases of CKD are due to diabetes (Webster et al., 2017). A second condition which can contribute to the development and progression of CKD is high blood pressure, also known as hypertension (Evans & Taal, 2015). Consistently high blood pressure can cause damage to blood vessels and organs, such as the kidneys and heart. Hypertension can also be a complication of kidney disease and is more common amongst those with diabetes. As obesity is a risk factor for both type 2 diabetes and hypertension, it is also a risk factor for CKD (Hall et al., 2014).

Individuals with a family history of CKD are at higher risk of developing kidney failure and several conditions caused by a single gene mutation can lead to kidney failure, although these are rare (Evans & Taal, 2015). Examples of genetic conditions include polycystic kidney disease (Bergmann et al., 2018), and Alport syndrome (Kruegel, Rubel, & Gross, 2013). Other diseases such as Lupus, and infections such as Human Immunosuppressant Virus (HIV), can cause kidney failure by damaging the cells in the lining of the glomeruli. This type of kidney damage is called glomerulonephritis (Evans & Taal, 2015).

CKD Treatment. Lifestyle changes such as eating a healthy diet, smoking cessation, regular exercise, and avoiding alcohol are often recommended to those with CKD. Medications can be prescribed to treat the conditions that cause CKD or to treat CKD complications, such as high blood pressure, high cholesterol, water retention, and anaemia. These lifestyle recommendations and medications will not necessarily cure CKD but may help to slow the progression of the disease (NICE, 2014).

Dialysis*.* Once an individual experiences kidney failure, they will need to begin RRT to maintain the balance of chemicals within the body and to remove excess water and waste products from the blood. The majority (around 70%) of individuals who start RRT for the first time in the UK receive haemodialysis (HD; UK Renal Registry, 2020). Patients starting on HD need surgery to insert a catheter in the large vein of their neck or groin, or a fistula in the wrist or arm, in order for their blood to be pumped out and through the HD machine, where waste products are removed before the blood is returned to the body. Patients on HD are usually required to attend a hospital or renal clinic up to three times a week for three to four hours at a time to have their blood filtered by a machine. Around 2% of patients have HD machines at home which they can use. HD is a burdensome treatment, not only due to the amount of time it takes to attend a clinic and receive treatment, but due to the amount of time taken to recover afterwards, as well as the potential side-effects and complications (Caplin, Kumar, & Davenport, 2011; Morfin et al., 2016). Patients on HD are also recommended to follow strict liquid and dietary requirements, such as consuming high amounts of protein, to replace those lost in the urine, and low amounts of foods high in phosphorous, potassium, and salt, as these can build up in the blood between HD sessions (Kalantar-Zadeh et al., 2015).

Around 20% of patients starting on RRT for the first time in the UK carry out peritoneal dialysis (PD; UK Renal Registry, 2020). PD is usually carried out by the patient in their own home. It requires the patient to fill the peritoneal cavity in their abdomen with a cleansing fluid (dialysate) under sterile conditions. Whilst the dialysate is in the peritoneal cavity, referred to as the dwell time, waste products and excess water from the blood move by osmosis through the peritoneal membrane into the dialysate. After several hours the dialysate is drained away and replaced with fresh dialysate to begin the process again. At least two weeks before starting PD, patients need to undergo surgery to insert a catheter in their abdomen

through which the dialysate can enter the peritoneal cavity (Figueiredo et al., 2010). Patients who manually change the dialysate throughout the day, known as continuous ambulatory peritoneal dialysis (CAPD), need to do so around three to five times each day but otherwise may carry out their usual activities. Alternatively, patients can use a machine to automatically change the fluid through the night whilst they sleep, known as automated peritoneal dialysis (APD). Unfortunately, PD can lead to some unpleasant complications such as infections of the peritoneum (peritonitis), catheter-related infections, dialysate leakage, hernias, and catheter-related mechanical problems that can prevent proper drainage of the dialysate (Stuart et al., 2009).

Transplantation. The first successful human kidney transplant was carried out in 1954 in the United States (Barker & Markmann, 2013). Kidney transplantation is often considered to be the best treatment for patients with renal failure in terms of medical outcomes as it continuously filters the blood naturally without the need for dialysis. A kidney can be taken from a donor after cardiac death (DCD), a donor after brain death (DBD), or a living donor and transplanted into the patient with renal failure. To receive a kidney transplant, patients must either find a willing and compatible living donor or be placed on the transplant waiting list. Under the UK Living Kidney Sharing Scheme, if a patient finds a willing donor who is not compatible with them, they can be added as a pair to a list of people in a similar situation in order to be matched to another pair or group of pairs with whom organs are better matched and can be swapped. This is referred to as paired and pooled donation (Barlow, 2017). Kidney transplants can be carried out pre-emptively, before the patient has started dialysis treatment. However, more commonly patients receive a transplant after having started dialysis due to the long waiting times for deceased-donor organs. Patients undergo rigorous physical health checks before being added to the transplant waiting list to ensure they are fit enough for the operation. There is no age restriction on being added to the waiting list; however, patients who have persistent cancer, an active infection, or a condition with a life expectancy of less than two years are not eligible. Patients may also be considered ineligible for a transplant if they are not expected to live longer than 5 years, have a high risk (>50%) of losing the new kidney within one year, are unlikely to take post-transplant immunosuppressant medications, or are at increased risk of developing a life-threatening illness from the immunosuppressant medications (Zalewska, 2016).

There is more demand for organs than there are organs available, with around 5000 patients on the UK kidney waiting list in 2018 (National Health Service Blood and Transplant [NHSBT], 2019). In the UK, from 2006 to September 2019, DBD kidneys were allocated by the National Allocation Scheme, whilst DCD kidneys were allocated by the National Sharing Scheme (Watson, Johnson, & Mumford, 2020; Zalewska, 2017). In September 2019, the policy was updated to offer both DBD and DCD kidneys under the same allocation scheme. The kidney allocation policy involves a points-based system whereby points are allocated to patients waiting for a kidney according to patient, donor, and transplant factors including waiting time, patient age (paediatric patients prioritised over adults), tissue type (human leukocyte antigens [HLA] match), donor-recipient age difference, location of patient relative to the donor, HLA-DR homozygosity, HLA-B homozygosity, and blood group match. Kidneys are offered first to patients on the waiting list with the highest points, which is calculated by an evidence-based computer algorithm (Zalewska, 2017). The updated scheme prioritises sensitised patients who have high levels of antibodies and usually have a longer waiting time (Watson et al., 2020).

The median waiting time for a kidney among adults is approximately 706 days, although waiting times also depend on factors such as ethnicity and blood group. Thousands of kidney transplants are carried out across the UK each year; for example between April 2018 and March 2019, 2399 deceased-donor kidney transplants (DDKT) and 999 living-donor kidney transplants (LDKT) were carried out (NHSBT, 2019). Unfortunately, due to the COVID-19 pandemic and the associated restrictions, fewer transplants than usual were carried out in 2020 (V. Sharma et al., 2020).

CKD and Kidney Transplant Prognosis. It is generally accepted that kidney transplantation is better for patient survival than dialysis (Kaballo et al., 2018; Molnar et al., 2016; Tonelli et al., 2011). Common causes of death among dialysis patients include cardiovascular disease (CVD), infection, and treatment withdrawal (Cozzolino et al., 2018; Methven, Steenkamp, & Fraser, 2017). In the UK, NHSBT (2019) report that kidney graft survival after a first DBD transplant is approximately 95%, 92%, 87% and 76% at one-, two-, five-, and 10-years post-transplant respectively, whilst patient survival is 97%, 94%, 88% and 77% at one-, two-, five-, and 10-years post-transplant. Similarly, graft survival after a first DCD kidney transplant is approximately 93%, 92%, 86% and 76% at one-, two-, five-, and 10-years post-transplant respectively, and patient survival is reported as 97%, 94%,

86% and 76% at one-, two-, five-, and 10-years post-transplant. Lastly, graft survival for LDKT recipients is reported to be 98%, 96%, 91% and 82% and patient survival is 99%, 98%, 95% and 90% at one-, two-, five-, and 10-years post-transplant respectively (NHSBT, 2019). However, this data is unadjusted and does not take into account the fact that patients who receive a LDKT are often younger than those who receive a DDKT, and more likely to receive a pre-emptive transplant (Gibbons et al., 2021).

Clinicians often argue that LDKTs are clinically more beneficial than DDKTs and some research appears to support this (Almasi-Hashiani, Mansournia, Rezaeifard, & Mohammad, 2018; Matas et al., 2008; Nemati, Einollahi, Pezeshki, Porfarziani, & Fattahi, 2014). However, one study found there were no significant differences in graft survival or function between DDKT and LDKT recipients who had their transplant more than five years (Lee et al., 2010). One of the main benefits of LDKTs is that they can often be planned and carried out prior to the patient starting dialysis or after a shorter time spent on dialysis, which has been associated with better graft and patient survival in several but not all studies (Abramowicz et al., 2016; Haller, Kainz, Baer, & Oberbauer, 2017; Helantera et al., 2014). It has been acknowledged that those who receive a pre-emptive kidney transplant are often already advantaged compared to those who do not have this opportunity and such factors have not always been controlled for in analyses (Abramowicz et al., 2016). For example, those who receive a pre-emptive transplant often have fewer comorbidities (Abramowicz et al., 2016)

Introduction to Diabetes

Diabetes is a worldwide health problem, with a global prevalence of around 9% (Saeedi et al., 2019) and almost 4 million people living with diagnosed diabetes in the UK (Diabetes UK, 2019). Diabetes is a condition that causes problems with maintaining a normal level of glucose in the blood, and chronically high blood glucose levels can cause long-term complications including CKD (Webster et al., 2017). There are two main types of diabetes. Type 1 diabetes is often diagnosed in childhood or adolescence and is caused by an autoimmune reaction which damages the pancreas resulting in insufficient insulin production (DiMeglio, Evans-Molina, & Oram, 2018). Those with type 1 diabetes are required to administer insulin to regulate the level of glucose in the blood. Patients with type 1 diabetes

and CKD can be given a simultaneous pancreas and kidney transplant (SPKT) to treat both conditions, meaning that patients no longer need to administer insulin or carry out dialysis (Dean, Kukla, Stegall, & Kudva, 2017). SPKTs are less common than kidney-only transplants. The current research aimed to evaluate this special type of treatment and investigate the impact of SPK transplantation on patients.

Type 2 diabetes is more often diagnosed in adulthood and results when the pancreas is unable to produce enough insulin (insulin deficiency) or the body is unable to react effectively to the insulin (insulin resistance; Chatterjee, Khunti, & Davies, 2017). Type 2 diabetes is more common, accounting for around 90% of all diabetes diagnoses, and is associated with lifestyle factors and obesity, as well as having a strong genetic component (Chatterjee et al., 2017). Whilst type 2 diabetes is a main cause of CKD, it is uncommon for a patient with type 2 diabetes to be offered a pancreas transplant because this will not treat insulin resistance. Instead, patients with type 2 diabetes and CKD are more often offered a kidney-only transplant.

Diabetes symptoms. If diabetes is not properly controlled patients can experience hyperglycaemia. Symptoms of hyperglycaemia can include thirst, irritability, trouble concentrating, headaches, dizziness, and blurred vision (Warren, Deary, & Frier, 2003). Hyperglycaemia can lead to diabetic ketoacidosis, which is a build-up of acidic ketones in the body that can be life-threatening if not treated properly (Misra & Oliver, 2015). In addition to CKD, various other complications can be caused by chronic hyperglycaemia in diabetes including eyesight problems, heart disease, and nerve damage, which may result in wound infection and even limb amputation (Harding, Pavkov, Magliano, Shaw, & Gregg, 2019). Patients with diabetes can also experience hypoglycaemia, when blood glucose is low. Hypoglycaemia can be very unpleasant as the individual may experience weakness, sweating, nausea, drowsiness, shakiness, clumsiness, difficulty speaking, and in extreme situations, they may lose consciousness or have a seizure (McAulay, Deary, & Frier, 2001). Not all people with diabetes experience symptoms; for example, one study found that approximately 20% of patients with type 1 diabetes had impaired awareness of hypoglycaemia, also known as hypoglycaemic unawareness (Geddes, Schopman, Zammitt, & Frier, 2008). Impaired awareness of hypoglycaemia can be detrimental to self-management of the condition and patients are at increased risk of experiencing severe hypoglycaemia, which requires assistance from another person (Graveling & Frier, 2010).

Diabetes treatment. Patients with type 1 diabetes and some with type 2 diabetes need to check their blood glucose levels and administer insulin to treat their condition. Individuals can check their blood glucose levels by carrying out a finger prick blood test using a lancet and applying a drop of blood to a glucose monitoring device. Alternatively, a Continuous Glucose Monitor (CGM) can be used to transmit interstitial fluid (fluid around the cells in the body) glucose readings to a separate device in real-time (with an approximate 4-10 minutes lag time) or information can be stored over time to be assessed retrospectively. CGMs used in real-time can alert patients when their glucose levels are getting too high or low. Alternatively, Flash Glucose Monitors (FGMs) require the patient to scan the sensor on the skin to get a reading (Rodbard, 2017; Slattery & Choudhary, 2017).

There are several treatment regimens for administering insulin (Neu et al., 2015). Some individuals may follow a biphasic regimen and inject a mixture of short acting and intermediate acting insulin twice a day. This is only suitable for individuals who tend to keep a consistent routine as there is no room for flexibility with mealtimes and snacks. Rather than adjusting the amount of insulin injected, patients on a fixed-dose insulin regimen will need to ensure that they eat the right amount of carbohydrates at mealtimes, depending on their blood glucose levels. Others may be on a basal-bolus regimen which involves administering a long or intermediate acting insulin once or twice a day plus short or rapid-acting insulin with each meal (DiMeglio et al., 2018). Whilst this regimen may involve administering insulin more often than twice a day, it does allow flexibility over when meals/snacks are eaten and doses can be varied depending on what is eaten. Patients on a flexible-dose regimen are taught how to adjust the amount of insulin they inject depending on how much carbohydrate they eat, allowing them to have more freedom in what and how much they eat. Patients may attend training, such as the Dose Adjustment For Normal Eating (DAFNE) programme, which helps patients understand how to adjust their insulin doses to the food that they eat (DAFNE Study Group, 2002). Some individuals with type 2 diabetes who do not produce enough of their own insulin may also follow an insulin regimen (NICE, 2015).

Some patients, particularly those with type 1 diabetes who have struggled with other insulin regimens, may be provided with an insulin pump that automatically delivers a continuous background dose of insulin into their body with extra boluses of insulin delivered by the patient pressing the button when they choose to eat. This method

of insulin delivery, also known as continuous subcutaneous insulin infusion, requires patients to carry a small device around with them which delivers the insulin through a cannula inserted under the skin (Pickup, 2012). CGMs and insulin pumps can be integrated so that the pump automatically delivers appropriate doses of insulin depending on the measured glucose levels and can stop insulin if the patient is reaching hypoglycaemia, but this technology is still very new. Evidence suggests that CGMs and insulin pumps can help to improve patients' diabetes management (Benkhadra et al., 2017; Slattery & Choudhary, 2017). However, it can still be difficult for patients to manage their blood glucose levels, for example the lag-time of CGM devices can be problematic (Slattery & Choudhary, 2017).

Transplantation. Patients who have type 1 diabetes or insulin-treated type 2 diabetes can undergo a pancreas transplant. If successful, a pancreas transplant should produce the insulin needed to naturally regulate blood glucose levels without needing to administer additional insulin (Dean et al., 2017; Mittal & Gough, 2014). Patients who have diabetes and CKD can receive an SPKT from a deceased donor to treat both conditions. Alternatively, patients might receive a kidney-only transplant, for example from a well-matched living-donor, and receive a deceased-donor pancreas transplant at a later date (Dean et al., 2017; Mittal & Gough, 2014). Very few pancreas-only transplants are carried out in the UK, for example there were only six pancreas-only and 12 pancreas-after-kidney transplants between April 2018 and March 2019 (NHSBT, 2019). The first successful SPKT was carried out in 1966 in the USA and the first pancreas transplant in the UK was carried out in 1972 (Casanova, 2017).

In order to be eligible for a pancreas transplant, patients must be considered to have debilitating hypoglycaemia and had at least two severe hypoglycaemic episodes in the past 24 months (Zalewska, 2018). To be eligible for an SPKT, patients with insulin-treated diabetes usually need to be on dialysis or have a GFR of 20mls/min. As previously discussed, criteria regarding the health of the patient is also taken into consideration. If a patient's health deteriorates after they have been added to the waiting list, they may be temporarily suspended from the waiting list. As with kidney transplantation, SPKTs are allocated using a points-based system based on patient, donor, and transplant factors. The median time spent on the transplant waiting list for an SPKT is approximately 346 days. There are usually around 200 patients on the waiting list for an SPKT, and between April 2017 and March 2018 168 SPKTs were carried out in the UK (NHSBT, 2018).

SPKT prognosis. In the UK, graft survival after a first DBD SPKT is reported to be around 89%, 84%, 81%, and 70% at one-, two-, five-, and 10-years post-transplant respectively, and patient survival is 97%, 94%, 87%, and 75% at one-, two-, five-, and 10-years post-transplant (NHSBT, 2019). Survival after an SPKT has improved since around the year 2000, most likely due to improvements in pancreas transplantation techniques and immunosuppressant medication regimens (Lindahl et al., 2016; Lindahl, Jenssen, & Hartmann, 2014). After a successful SPKT, the pancreas graft normalises blood glucose levels and this helps to protect the kidney graft from damage due to poorly controlled diabetes (Lindahl, Reinholt, et al., 2014). Evidence suggests that SPK transplantation has survival benefits compared to wait-listed patients (Ojo et al., 2001; van Dellen et al., 2013) and provides better graft and patient survival compared to kidney-only transplantation (C. M. Chan et al., 2016; Esmeijer et al., 2020; Lindahl, Jenssen, et al., 2014). A functioning pancreas transplant can help to halt or improve some diabetes complications, such as neuropathy, although findings related to retinopathy and CVD are less clear (Lindahl, Jenssen, et al., 2014; S. A. White, Shaw, & Sutherland, 2009).

Post-transplant Treatment – Immunosuppressant Medication

Organ rejection occurs when the body detects the transplanted organ(s) as a foreign object leading the immune system to attack it, causing damage, and resulting in loss of functioning. Initially after transplantation patients receive induction therapy, which involves the administration of powerful immunosuppressant medications to prevent early graft rejection. In the long-term, immunosuppressant medicines such as Tacrolimus, Cyclosporine, and Mycophenolic acid are prescribed (Neuwirt et al., 2019). Whilst kidney and SPK transplants are beneficial, patients are unlikely to experience perfect, symptom-free health. Anti-rejection medications can increase transplant recipients' risk of cancer (Billups, Neal, & Salyer, 2015; Coghill et al., 2016) and diabetes (Demirci et al., 2010; Shivaswamy, Boerner, & Larsen, 2016), and can make patients more susceptible to infections.

Measuring Patient-Reported Outcomes (PROs) in CKD and Diabetes

SPK and kidney transplants are not necessarily carried out to save lives because patients can survive with insulin injections and dialysis. Instead, these transplants are carried out to improve patients' health and functioning, prevent further damage to health, and to improve patients' lives. Patient-reported outcome measures (PROMs) are measures which ask patients about their subjective experience or their perspective on certain outcomes such as health, symptoms, functioning, quality of life (QoL), treatment satisfaction, and well-being. It is important that patient-reported outcomes (PROs) are recorded, particularly within clinical trials, as these outcomes can help to inform clinicians and patients about the impact of a particular treatment and can help to determine which treatments provide the best outcomes.

As healthcare has improved and the emphasis has moved away from providing treatments that aim mainly to prolong life and towards treatments that improve life, QoL has become a popular PRO (Moons, Budts, & De Geest, 2006). However, despite the fact that QoL is frequently referred to, it is a poorly defined concept for which there are multiple definitions and models but no real consensus on what it is (Post, 2014). One frequently referenced definition set out by the World Health Organisation (WHO) states that QoL is:

> …a person's perception of his/her position in life within the context of the culture and value systems in which he/she lives and in relation to his/her goals, expectations, standards, and concerns. It is a broad-ranging concept incorporating, in a complex way, the person's physical health, psychological state, level of independence, social relationships, personal beliefs, and relationship to salient features of the environment (WHOQOL Group, 1994).

In their critique of conceptualisations of QoL, Moons et al. (2006) concluded that satisfaction with life was the most appropriate conceptualisation as it fulfils six criteria that they set out: it is subjective; it is not focused on functioning or health; it can change over time but does not fluctuate day by day; it distinguishes between determinants and indicators; it can be positively or negatively influenced; and it favours overall QoL over health-related QoL (HRQoL). The authors also critiqued conceptualisations of QoL that they refer to as 'normal life', utility and social utility, happiness, achievement of personal goals, satisfaction with specific domains, affect,

and natural capacity, none of which met the previously mentioned six criteria. Barcaccia et al. (2013) also outline several definitions of QoL found in the literature and although they do not endorse any one definition, they do conclude that subjectivity is the most important aspect of QoL.

Perhaps due to the lack of clarity as to what QoL is, several of the questionnaires frequently used in QoL research do not actually measure QoL at all. For example, in a review of measures used in research on the QoL of diabetes patients, Speight, Reaney, and Barnard (2009) report that of the 10 most frequently used measures only three were judged to measure QoL, these were: the World Health Organisation QOL questionnaire (WHOQOL Group, 1994, 1998), the Diabetes Quality of Life questionnaire developed for the Diabetes Control and Complications Trial (DQOL, The DCCT Research Group, 1988) and the Audit of Diabetes-Dependent Quality of Life (ADDQoL; Bradley et al., 1999). Speight et al. (2009) argued that the remaining seven PROMs measured outcomes such as health status or psychological well-being. Terms such as QoL and HRQoL are often used interchangeably and to describe outcomes which are more accurately described as measures of perceived health status (Bradley, 2001; Moons et al., 2006). Furthermore, PROMs referred to as measures of QoL tend to cover a range of outcomes such as mental functioning, physical functioning, social functioning, symptoms, and well-being (Moons et al., 2006). Many of the measures used in research reporting to evaluate the QoL of those with health conditions have not involved patients in the development of the measure and so likely include elements that are not relevant (Carr & Higginson, 2001). Most PROMs used in 'QoL' research also do not take into account the fact that different aspects of life or elements of QoL will be important to various extents among different people, reducing their subjectivity (Carr & Higginson, 2001). It is important that researchers are clear on the type of outcomes they are measuring in PRO research and use appropriate measures so that results can be properly interpreted and are not misleading (Bradley, 2001). Several systematic reviews of PROMs used in research with CKD (Aiyegbusi, Kyte, Cockwell, Marshall, et al., 2017; Butt, Yount, Caicedo, Abecassis, & Cella, 2008; Ju et al., 2019; Manera et al., 2021) and diabetes patients (El Achhab, Chakib Nejjari, Chikri, & Lyoussi, 2008; Speight et al., 2009; Tang, Yusuf, Polonsky, & Fisher, 2017) have previously been carried out. There are a variety of different types of PROMs including general/generic, condition-specific, and even individualised measures. The different types of PROMs are explained in more detail below and some of the more popularly

used measures are described. (Brief details of measures mentioned throughout the thesis can be found in Appendix A, Table A1.)

Generic measures. Generic measures are ones which are not specific to any particular health condition and measure various outcomes such as physical, emotional, and social functioning, health, well-being, or general QoL. A review of the literature (Butt et al., 2008) found that the most frequently used measure in studies reporting to have assessed the QoL of kidney transplant recipients was the Medical Outcomes Study 36-item short form (SF-36; Ware & Sherbourne, 1992). The SF-36 is a generic measure that was designed to assess health status and function but is frequently referred to as a measure of QoL. The SF-36 assesses eight domains: physical functioning, social functioning, role functioning, emotional functioning, bodily pain, mental health, vitality, and perceptions of general health (Ware & Sherbourne, 1992). Results can be reported for each domain subscale, or overall physical and mental component scores can be calculated. Two brief adaptations of the measure are also available, the SF-12 and the SF-6D, which can also be used to calculate a health utility score.

The WHOQOL-100 (WHOQOL Group, 1994, 1998) is another frequently used generic measure, and it assesses six domains: physical health, psychological, independence, social relationships, environment, and spirituality/religion. A shortened version, the WHOQOL-BREF, measures four domains: physical health, psychological, independence, and social relationships. The measure was developed from focus groups and interviews with both healthy and unwell people and using input from healthcare professionals. Whilst the WHOQOL can be considered to be a measure of QoL and includes a single item measure of QoL (Speight et al., 2009), a single score reflecting QoL or how QoL is impacted cannot be calculated from the overall measure.

Another generic measure, the Well-Being Questionnaire (W-BQ; Bradley & Lewis, 1990) was originally designed as a 22-item measure suitable for assessing the psychological well-being of patients with diabetes as it avoids asking about somatic states that could result from the diabetes rather than depression. A total well-being score can be calculated from the 22-item measure, as well as four subscale scores: depression, anxiety, energy, and positive well-being. From the W-BQ22, a shorter version was developed and validated with 12 items assessing three subscales: Positive Well-Being, Negative Well-Being, and Energy (Riazi, Bradley, Barendse, &

Ishii, 2006). Although originally designed with people with diabetes in mind, the measure has been found to be suitable for use in other conditions such as macular degeneration (Mitchell & Bradley, 2001). A benefit of generic measures is that they can be used to compare outcomes across various groups of people with and without health conditions. However, it can be difficult to interpret the impact of a particular condition when using these measures as participants might be taking into consideration other aspects of life or comorbidities when completing the measure. Furthermore, generic PROMs may not be sensitive enough to identify variations between individuals with health conditions, such as diabetes, who are receiving different treatments or have different complications (Bradley, 2001). Generic measures may include items which are not relevant to patients with certain health conditions, or they may miss aspects which are important and negatively impacted. For example, diet is not covered in the SF-36 but is often a particularly important element of life that is impacted by diabetes (Bradley et al., 1999).

Utility measures. Utilities are preference value scores relating to various health states and are used in health economics to make decisions about the allocation of resources (Weinstein, Torrance, & McGuire, 2009; Whitehead & Ali, 2010). Utility scores are usually given between 0, a state equivalent to death, and 1, a state of perfect health, but minus scores are also sometimes used and represent a state worse than death (Whitehead & Ali, 2010). Utilities can be acquired by asking people to make judgements about various health states by completing certain tasks. For example, time-trade off tasks ask people to decide whether they would choose to live a certain number of years with a reduced health state or fewer years at full health. The task is continued until the individual becomes indifferent to the two options (Whitehead & Ali, 2010). These tasks can be carried out with the intended sample directly, or data can be collected from a sample of the general population and mapped on to scores from a generic measure which can be completed by the patient population of interest.

A very frequently used health measure, from which utility values can be calculated, is the EuroQoL-5 Dimension measure (EQ-5D; Brooks & the EuroQoL Group, 1996), developed by the EuroQoL Group task force. The EQ-5D measures five dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. There are two versions of this measure (Devlin, Shah, Feng, Mulhern, & van Hout, 2016), the EQ-5D-3L provides a 3-point response scale while the EQ-5D-5L provides a 5-point scale asking individuals to indicate the extent to

which each dimension is a problem. The 5L version was developed to improve the sensitivity of the EQ-5D, although the 3L version is still frequently used and preferred by NICE (2019). The EQ-5D also includes a visual analogue scale (VAS) which asks individuals to rate 'your health today' on a scale of 0-100, where 0 is 'the worst health you can imagine' and 100 is 'the best health you can imagine' (Herdman et al., 2011). Despite more accurately being described as a measure of health status, as both the EQ-5D and the VAS ask about 'your health today', the EQ-5D is often referred to as a measure of QoL or HRQoL. The raw scores are rarely analysed and instead the measure is most often used as an indirect utility measure

A utility score can be calculated from the EQ-5D by first converting participant responses into values established from data collected from the general population (Devlin et al., 2016). These values have been produced by asking members of the general population to complete multiple time trade-off tasks and discrete-choice experiment tasks, which involves choosing a preference between various hypothetical health scenarios. Therefore, the utility scores ultimately reflect the general population's perceptions of health states rather than that of the person who completed the measure. In the UK, the EQ-5D is frequently used to calculate quality adjusted life years (QALYs), as recommended by NICE (Ogden, 2017). QALYs are a cost-utility analysis which is calculated by multiplying the expected additional years of life due to a particular treatment by the utility score. QALYs are used to make decisions on which medical treatments are funded by the NHS in the UK; treatments costing ≤£20,000 per QALY are considered cost effective and will be provided to patients by the NHS (Ogden, 2017).

Utility scores and QALYs are controversial. The different tasks and measures used to acquire utilities often produce inconsistent results (Arnold, Girling, Stevens, & Lilford, 2009; Bleichrodt, 2002; Brazier, Roberts, Tsuchiya, & Busschbach, 2004). There are also various arguments for who should be asked to provide utility scores. Whilst people with the health condition in question will have the best insight into how it impacts on them, there are concerns that they may make strategically biased judgements (Whitehead & Ali, 2010). Alternatively, people from the general population will likely not truly understand what it is like to live with a certain condition or health state, but this may mean that they can give less biased judgements. In addition, taxpayers' money funds healthcare treatments provided by the NHS in the UK, so some argue that it is right for the general population to have an influence on

how the money is spent (Whitehead & Ali, 2010). Generic measures, such as the EQ-5D, which are used as indirect measures of utilities may be too simple and miss important elements that are relevant to living with a particular health condition. They often do not allow individuals to indicate positive impact (Arnold et al., 2009). While the aim of QALYs is to include both QoL and years gained, utilities do not really assess QoL as individuals are not asked about QoL in either the utility tasks or the utility measures. Other issues with utilities and QALYs have been highlighted but are beyond the scope of the current research (see Weinstein et al., 2009; Whitehead & Ali, 2010). The main issue considered in the current thesis is that measures of utilities or health status/functioning are frequently referred to in the literature as measures of QoL or HRQoL when they do not assess QoL.

Condition-specific measures. Condition-specific measures are PROMs which have been tailored especially for use with patients with a particular condition in order to cover topics/issues that are most relevant to these individuals and omit issues which are not relevant. Several measures have been designed specifically for use with patients with CKD or a kidney transplant (Aiyegbusi, Kyte, Cockwell, Marshall, et al., 2017). As with generic measures, these condition-specific measures are often used to calculate various domain scores rather than an overall score. One frequently used measure is the Kidney Disease Quality of Life (KDQOL; Hays, Kallich, Mapes, Coons & Carter, 1994) instrument which includes the generic SF-36 in addition to 43 kidney-specific questions which assess: symptoms and problems; effects of kidney disease; burden of kidney disease; work status; cognitive function; quality of social interaction; sexual function; sleep; social support; dialysis staff encouragement; and patient satisfaction. A shortened version of the measure is available in the form of the KDQOL-36, this only includes 36 questions covering: SF-12 physical component summary; SF-12 mental component summary; burden of kidney disease; symptoms and problems; and effects of kidney disease on everyday life. Some measures have been designed specifically for transplant recipients. For example, the Transplant Effects Questionnaire (TxEQ; Ziegelmann et al., 2002) is a 24-item measure that assesses five domains: worry about the transplant, guilt towards the donor, issues regarding disclosure about the transplant, adherence to medications, and responsibility to others.

There are also several measures specifically designed for use with patients with diabetes, and while these assess a variety of outcomes or domains they are often labelled as assessing HRQoL (El Achhab et al., 2008; Tang et al., 2017). The

Problem Areas In Diabetes (PAID; Polonsky et al., 1995) and Diabetes Distress Scale (DDS; Polonsky et al., 2005) are two frequently used measures that assess diabetes distress, which is the negative emotional response to diabetes and its management. The PAID is a 20-item measure from which an overall score can be calculated, whilst the DDS includes 17 items that measure four domains: emotional burden; physician-related distress; regimen-related distress; and interpersonal distress. Another commonly used measure is the DQOL, (The DCCT Research Group, 1988) which was developed following advice from healthcare professionals and patients with insulin-treated diabetes. The measure includes 46 questions, each with a 5-point Likert scale response option and can be scored to give a total DQOL score and/or sub-scale scores for satisfaction with treatment, impact of treatment, diabetes-related worry, and social/vocational worry. An additional 16 questions can be included when the measure is used with adolescents with diabetes to assess family relationships and school experiences. Although condition-specific measures such as the DQOL have been designed to be more relevant to patients, a limitation is that they assume that each item is equally important for each patient (Bradley et al., 1999). The fact that various measures which have often been labelled as measures of HRQoL assess different domains rather than sharing commonalities has also been criticised (Tang et al., 2017).

Other condition-specific measures relevant to the current research include the Renal Treatment Satisfaction Questionnaire (RTSQ; Barendse, Speight & Bradley, 2005) and the Diabetes Treatment Satisfaction Questionnaire (DTSQ, Bradley, 1994a) . The DTSQ consists of six questions with a 7-point scale response option, from which a total diabetes treatment satisfaction score can be calculated. The DTSQ also contains two additional single items (items 2 and 3) which ask the patient about their perceptions of the frequency with which their blood glucose levels are unacceptably high (hyperglycaemia) or low (hypoglycaemia). The development of the RTSQ was influenced by the DTSQ and interviews with patients with renal failure receiving various renal replacement therapies. The original RTSQ measure included 11 questions, each with a 7-point response scale, from which a total satisfaction score could be calculated (Barendse et al., 2005). The measure now has 13 items which can be used to calculate a total score.

Individualised measures. Whilst condition-specific measures tend to be more suitable for use with patients with health conditions compared to generic measures, they still assume to an extent that each aspect or domain is equally

relevant or important to each patient completing the measure when this may not always be the case. Individualised measures are ones that can be adapted in some way to suit the person completing the measure, this is especially beneficial for measuring QoL because not everyone values the same aspects of life to the same extent. One of the first methods of assessing generic QoL in an individualised way was the Schedule for the Evaluation of Individual Quality of Life (SEIQoL; McGee, O'Boyle, Hickey, O'Malley & Joyce, 1991). This is an interview-style method which involves asking the individual to identify five areas of their life which are most important to their QoL. The individual then rates their current state within each of these aspects of life on a VAS marked from 'as good as it could possibly be' to 'as bad as it could possibly be'. Finally, the individual completes a task so that the relative importance of each aspect of QoL can be assessed (O'Boyle, 1994). Whilst this interview-style assessment provides an individualised measurement of QoL, it involves a time-consuming process which is not practical for assessing QoL in a busy healthcare setting.

While the SEIQoL is a general measure and does not evaluate the impact of a health condition, it influenced the development of other individualised, condition-specific, questionnaire measures, namely the ADDQoL (Bradley et al., 1999) and the Renal Dependent Quality of Life measure (RDQoL; Bradley, 1997). These measures start by telling the patient: 'this questionnaire asks about your quality of life – in other words how good or bad you feel your life to be'. The questionnaire then asks the individual to rate their overall QoL on a 7-point scale from 'excellent' to 'extremely bad', and then asks them to consider how their QoL is affected by their diabetes or renal condition on a single overview item. The measures then ask about whether different aspects of life would be better, the same, or worse if they did not have the health condition and how important that aspect of life is to them. The aspects of QoL included in these measures were developed based on work with patients to identify the relevant elements to include. Furthermore, these measures allow individuals to indicate certain aspects of life as not applicable, rather than assuming that everyone will find every element of life included in the measure to be relevant to them (e.g. work; Bradley, 1997). Each item in the questionnaire can be investigated individually to see the impact of the condition on that part of life, or a single average weighted impact (AWI) score can be calculated to provide an overall score of how impacted that person's life is by their condition.

PROs in CKD and Kidney Transplantation

Generally, patients on dialysis have reported poorer perceived health status and functioning compared to the general population/population norms, but results on mental health variables are less consistent (de Wit, Merkus, Krediet, & De Charro, 2001; Fukuhara et al., 2003; Ogutmen et al., 2006; Ong et al., 2013; Pagels, Stendahl, & Evans, 2020). Comparisons between kidney transplant recipients and general population samples have found varied results on measures of health status/functioning, such as the SF-36 (Neipp et al., 2006; Villeneuve et al., 2016) and the 15D (Ortiz et al., 2014; Sintonen, 2001). Results tend to vary by domain/outcome and patient characteristics, with some reporting similar levels of functioning to the general population and others reporting worse outcomes. Most research, however, has focused on differences in PROs between those in receipt of different forms of RRT. These can be divided into studies that have compared differences in PROs based on dialysis modality, PROs after transplantation, and comparisons of LDKT and DDKT recipients.

Comparison of PROMs by dialysis modality. A few studies suggest that individuals with CKD who have not yet started on dialysis report better outcomes for physical (Auneau-Enjalbert et al., 2020) and mental health (Perlman et al., 2005) compared to patients on dialysis. A recent study found that individuals with stage 3-5 CKD had significantly better EQ-5D utility scores compared to patients on dialysis (Krishnan et al., 2020). However, other research found no significant difference in Patient Health Questionnaire-9 depression (PHQ-9; Kroenke, Spitzer, & Williams, 2001) and SF-36 scores between CKD patients who had and had not started dialysis yet (Abdel-Kader, Unruh, & Weisbord, 2009). Comparison of dialysis modalities is complicated because the type of dialysis a person receives is due to various factors including local availability and personal choice (Boateng & East, 2011). Systematic reviews and meta-analyses of studies comparing dialysis modalities have reported that the results are heterogeneous and a clear conclusion that one modality provides better outcomes than the other has not been reached (Boateng & East, 2011; Bonenkamp et al., 2020; Chuasuwan, Pooripussarakul, Thakkinstian, Ingsathit, & Pattanaprateep, 2020; Ho & Li, 2016; Liem, Bosch, Arends, Heijenbrok-Kal, & Hunink, 2007). Liem et al. (2007) conducted a meta-analysis controlling for age and diabetes diagnoses and reported that patients on PD had lower role physical scores on the SF-36 but otherwise did not differ

compared to those on HD. Similarly, Ho and Li (2016) concluded that patients on PD and HD did not differ significantly on a range of outcomes assessing physical and mental health, social outcomes, and symptoms. In a meta-analysis that did not control for potential confounders, individuals on PD had significantly better scores on some domains of the SF-36, EQ-VAS health status, and the symptoms, burden of kidney disease, and effect of kidney disease domains of the KDQOL compared to those on HD (Chuasuwan et al., 2020). Another recent meta-analysis concluded that home dialysis, including PD and home-based HD, was associated with better physical but not mental health outcomes compared to centre-based HD, particularly in studies conducted in Western Europe (Bonenkamp et al., 2020). Similarly, Ortiz et al. (2014) found that patients on home HD reported better scores on the 15D measure of functioning than patients on PD and patients visiting a centre for HD. In an uncontrolled comparison, patients on APD reported significantly better social functioning on the SF-36 compared to those on CAPD (de Wit et al., 2001). However, another study found no significant differences between APD and CAPD on the KDQOL-SF when adjustments were made for confounding factors such as age, gender, comorbidity, and GFR (Michels et al., 2011). As might be expected, because eligibility to receive a transplant requires the patient to be healthy enough to go through the operation, EQ-5D scores have been found to be better among HD patients on the transplant waiting list compared to those not on the list (Lowney et al., 2015).

PROs after kidney transplantation. Kidney transplantation is often considered to result in better outcomes than dialysis. A systematic review investigating utility-based outcomes of CKD treatments identified 11 studies which had used the EQ-5D, 155 studies that had used the SF-36, and 9 that had used the SF-12. A meta-analysis of some of these studies indicated that utility scores were better for kidney transplant recipients compared to patients on dialysis and patients not yet receiving RRT (Wyld, Morton, Hayen, Howard, & Webster, 2012). Since that review, two other large-scale studies also found that kidney transplant recipients had significantly better EQ-5D utility scores than patients on dialysis (Krishnan et al., 2020) and patients on the waiting-list for a transplant (Li et al., 2017). A meta-analysis of studies which used the SF-36 found that kidney recipients had significantly better scores compared to patients on PD and HD on all domains except mental health, but when age and diabetes diagnoses were controlled for, differences in vitality and social functioning scores were no longer significant. In addition, kidney recipients no longer had significantly better scores than HD patients

on physical functioning, role physical, or bodily pain (Liem et al., 2007). A more recent systematic review of studies using a variety of measures found that kidney recipients reported better physical function, freedom, and work outcomes compared to patients on HD or PD with small to large effects (Purnell et al., 2013). However, of the studies which properly adjusted for confounding variables, only 57% and 50% reported better outcomes for kidney recipients compared to patients on HD or PD, respectively. A study comparing kidney recipients and pre-dialysis patients with stable stage 3-4 CKD found no significant differences on the SF-36, but pre-dialysis patients did report significantly better HRQoL on a VAS measure (Stømer, Bergrem, & Gøransson, 2013). Other research found that kidney recipients reported better physical health component scores on the SF-36/SF-12 compared to patients on dialysis or awaiting transplantation (Czyżewski, Sańko-Resmer, Wyzgał, & Kurowski, 2014; Villeneuve et al., 2016), even after controlling for possibly confounding variables (Alvares, Cesar, Acurcio Fde, Andrade, & Cherchiglia, 2012). Balaska et al. (2016) also found that two years post-transplant, kidney recipients reported significantly better general health, role physical, role emotional, and vitality on the SF-36 than patients on HD. Some studies have not found a difference between dialysis and transplant patients on the mental component of the SF-36 (Alvares et al., 2012; Czyżewski et al., 2014; Liem et al., 2007) or on the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983; Müller et al., 2015) and this may reflect patients' ability to adapt mentally to their situation. In research using the WHOQOL-BREF, kidney recipients were found to report better scores on all four domains (physical, psychological, social relationships, and environmental) and on the overall QoL and health items compared to patients on HD (Ranabhat et al., 2020).

A limitation of this cross-sectional research is that comparisons are made between potentially very different groups of people on various CKD treatments and possibly confounding factors are not always controlled for in the analyses (Chuasuwan et al., 2020; Czyżewski et al., 2014; Ranabhat et al., 2020). Because there may be fundamental pre-existing differences between patients who receive a transplant and those who are on dialysis or remain on the waiting list, it can be difficult to interpret comparisons across groups. Large samples (around 100 per group) are generally needed for well-powered comparisons across different groups (Brysbaert, 2019) and this has not always been achieved in previous research (Purnell et al., 2013). Prospective collection of data pre- and post-transplantation is more difficult and costly to collect than cross-sectional study designs due to the unpredictable nature

of when patients on the deceased-donor waiting list will receive a transplant. However, comparisons of PROs completed by the same sample of patients before and after a transplant are very useful for improving our understanding of the impact of transplantation.

In longitudinal research, significant pre- to post-transplant improvements have been found on the KDQOL-SF including the symptoms, effect of kidney disease, general health, role physical, and vitality domains (Gil et al., 2020; Kostro et al., 2016; Lønning et al., 2018; von der Lippe et al., 2014). Clinically significant changes in general health, effects of kidney disease, and burden of kidney disease have also been reported (Lønning et al., 2018; von der Lippe et al., 2014). de Olivera et al. (2020) found significant improvements in KDQoL kidney disease effects and burden and SF-36 mental component scores, though it is unclear why the physical component scores worsened from pre- to post-transplant. Whilst participants were followed up at least three months post-transplant, it is unclear what the average length of time was and it is possible that some were still recovering from the transplant operation. Other research found significant improvements from pre- to post-kidney transplantation on both physical and mental component scores of the SF-36 (Griva, Davenport, Harrison, & Newman, 2012) and on the 15D survey (Ortiz et al., 2014). In a 10-year follow-up of patients on RRT, de Brito et al. (2019) found that those who had received a transplant reported significantly improved physical component scores on the SF-36 compared to those who remained on dialysis, including significantly better physical functioning, role physical, and general health. However, mental health component scores did not improve significantly compared to those who remained on dialysis. Another study found significant pre- to seven-months post-transplant improvements in the physical domain of the WHOQOL-BREF including improved pain, sleep, energy, and capacity to work (de Mendonça, Salvetti, Maia, Silva, & Torres, 2015). Similarly, Das, Srivastava, Tudu, and Hooda (2014) found LDKT recipients improved on all four physical, psychological, social, and environmental domains of the WHOQOL-BREF six-month post-transplant. Another study found significant pre- to one-year post-LDKT improvements in the physical and psychological domains of the WHOQOL-BREF, however there were no significant changes in the social or environmental domains (Lumsdaine et al., 2005). Significant improvements in distress measured on the General Health Questionnaire-12 (GHQ-12; Goldberg & William, 1988) have been reported from pre- to post-kidney transplant (de Vries et al., 2017; Schulz et al., 2017)

A study asking participants to rate their QoL on a scale of 0 (worse imaginable) to 100 (best imaginable) found that QoL significantly improved from pre- to post transplant in a sample of 33 kidney recipients (Smith et al., 2008). Furthermore, participants reported significant improvements from pre- to post-transplantation on the SF-12. However, the researchers had also asked participants to predict the impact of transplantation at baseline and found that patients significantly overestimated how much their QoL and SF-12 scores would improve. Transplant recipients also underestimated their pre-transplant QoL when asked to recall it around 12-months post-transplant (Smith et al., 2008). In a similar study, significant pre- to post-transplant improvements were found on VAS scores for physical, psychological, and social QoL (Schulz et al., 2014). Pre-transplant predictions of post-transplant QoL were significantly higher than actual post-transplant scores, particularly for those who had been on HD (Schulz et al., 2014).

Comparisons of LDKT and DDKT recipients. As previously mentioned, clinicians often believe that LDKTs are superior to DDKTs as they can be planned and carried out more quickly than is often possible when waiting for a DDKT. Some cross-sectional PROMs research has shown that LDKT recipients reported significantly better scores than DDKT recipients on the mental and environmental subscales of the WHOQOL-BREF but not on the social subscale (Gozdowska et al., 2016). LDKT recipients also reported better social involvement and happiness on a transplant recipient questionnaire designed for the study (Gozdowska et al., 2016). However, whilst only patients who had received dialysis prior to transplantation were included, the authors do not appear to have controlled for other potentially confounding variables despite stating that LDKT recipients were younger. In contrast, Müller et al. (2020) found no significant differences by transplant type on the HADS and SF-12, although the study only included 13 LDKT and 114 DDKT recipients and the analyses did not control for possibly confounding variables. In research which controlled for potentially confounding variables, no significant differences between LDKT and DDKT recipients were found on the SF-36/SF-12 (Griva et al., 2002; Zimmermann, Pabst, Bertram, Schiffer, & De Zwaan, 2016) the HADS (Zimmermann et al., 2016) or the Depression, Anxiety, and Stress Scale-21 (Lovibond & Lovibond, 1995; Lai, Neo, Vathsala, & Griva, 2020). However, Zimmerman et al. (2016) found that DDKT recipients >58 months post-transplant reported significantly less anxiety on the HADS and better mental component scores on the SF-36. In other research, after controlling for age, sex, and education level, LDKT recipients who had had their transplant for ≤5 years reported

significantly better role limitations, general health, and physical component scores on the SF-36 and better societal participation compared to DDKT recipients (de Groot et al., 2013). There were no significant differences in societal participation or on the SF-36 between LDKT and DDKT recipients transplanted >5 years before in analyses controlling for possible confounding variables (de Groot et al., 2013). Some studies have found that LDKT recipients report more guilt towards the donor on the TxEQ compared to DDKT recipients, but participants had similar scores on transplant worry and adherence domains (Griva et al., 2002; Lai et al., 2020; Zimmermann et al., 2016). A six-year longitudinal study of post-transplant outcomes found improvements in SF-36 mental component scores and a worsening of physical component scores, as well as increases in worry about the transplant and responsibility to do well on the TxEQ. Specifically, LDKT recipients had better baseline physical component scores than DDKT recipients but by the follow-up they were similar (Griva et al., 2011).

A limitation of these comparison studies is that they mostly involve cross-sectional post-transplant analyses of LDKT and DDKT recipients and do not control for possible pre-transplant differences in PROMs, although this would not be an issue for transplant-specific outcomes such as the TxEQ which can only be completed post-transplant. Suzuki et al. (2012) collected longitudinal data for LDKT and DDKT recipients and reported that whilst mental and physical component scores on the SF-36 initially worsened for DDKT recipients, by 3-year follow-up scores were better than pre-transplant. LDKT recipients reported improvements in mental and physical component scores from pre- to post-transplant. Although the authors argue that LDKTs are superior to DDKTs, they do not appear to have tested this statistically. Furthermore, the authors did not take into account differences between the groups, such as age, and the study only included 11 DDKT recipients compared to 80 LDKT recipients.

To summarise, cross-sectional comparisons indicate that kidney transplant recipients have better utility scores and functioning than patients on dialysis and/or on the transplant waiting list (Alvares et al., 2012; Czyżewski et al., 2014; Liem et al., 2007; Ogutmen et al., 2006; Wyld et al., 2012). However, there may be important differences between those who have received a transplant and those still waiting that are not always controlled for in analyses. When such factors are controlled for, some outcomes are no longer significantly different between the groups (Liem et al., 2007; Purnell et al., 2013). Research which has assessed

PROs pre- and post-transplantation in the same sample of patients is particularly useful. Such studies indicate that patients experience improvements in health and functioning outcomes on the SF-36 and KDQoL (Gil et al., 2020; Griva et al., 2012; Kostro et al., 2016; von der Lippe et al., 2014). Few studies have specifically asked about QoL, but those that have indicate that transplantation has a beneficial impact (Schulz et al., 2014; D. Smith et al., 2008). Whilst some studies indicate that LDKT recipients report better outcomes than DDKT recipients (Gozdowska et al., 2016), others suggest that, with a longer follow-up and/or when other possibly confounding factors are controlled for, the two groups are similar (Griva et al., 2002; Lai et al., 2020; Zimmermann et al., 2016). A main limitation of previous research is that a variety of measures, labelled as QoL or HRQoL, but which assess multiple different domains have been used. This makes it difficult to interpret whether transplantation improves patients' QoL. Furthermore, the majority of studies are cross-sectional and the long-term impact of CKD and transplantation is unclear. Therefore, more longitudinal research which uses true measures of condition-specific QoL is still needed to help patients know what to expect after transplantation. Research comparing condition-specific QoL of DDKT and LDKT recipients is also needed to aid patient decision making.

Qualitative Research on Experiences of CKD

Research that has focused on patients' qualitative experiences can help to improve our understanding of chronic health conditions and treatments, such as transplantation, as it provides additional details that PROMs may not cover. Systematic reviews of qualitative research have found that patients with CKD need to gain knowledge and weigh up their various treatment options, but often report feeling that they ultimately still lacked a choice about their treatment (Morton, Tong, Howard, Snelling, & Webster, 2010; Roberti et al., 2018). Individuals starting dialysis have reported feeling overwhelmed and under-prepared, and experienced a loss of personal identity, independence, and social connectedness (Monaro, Stewart, & Gullick, 2014). Furthermore, the management of CKD, including adherence to medications, dietary recommendations, fluid restrictions, and dialysis treatment, requires substantial effort by the patient (Karamanidou, Weinman, & Horne, 2014; Roberti et al., 2018). Although some patients may feel that they are able to maintain a good level of QoL despite CKD and dialysis, others struggle to do so because of progressively poor health (Elliott, Gessert, Larson, & Russ, 2014).

Patients have also reported distress and frustration because, despite dialysis being a life-saving treatment, it often prevents patients from carrying out their usual activities (D. J. Jones, Harvey, Harris, Butler, & Vaux, 2018; Sein, Damery, Baharani, Nicholas, & Combes, 2020). Patients waiting for a DDKT have often reported feeling uncertain about their situation and health, but also felt hopeful for the future and returning to a more 'normal' way of life after receiving a transplant (Burns, Fernandez, & Stephens, 2017; Burns, Fernandez, & Stephens, 2015; Karamanidou et al., 2014; Tong, Hanson, et al., 2015; Yngman-Uhlin, Fogelberg, & Uhlin, 2015). Support from hospital staff, the community, friends, and family can be beneficial for patients, although some may worry about becoming a burden (Burns et al., 2015; Roberti et al., 2018; Yngman-Uhlin et al., 2015).

Kidney recipients have often reported experiencing improved health, well-being and independence, and are more able carry out their usual activities post-transplant (de Brito, Paula, Grincenkov, Lucchetti, & Sanders-Pinheiro, 2015; Dos Santos, da Costa Viegas, Feijo, Fernanda, & Schwartz, 2016; Luk, 2004; Pinter et al., 2016). Patients often feel deeply grateful towards the donor and healthcare professionals for their transplant. In particular, patients who had previously received dialysis are happy to no longer need this treatment post-transplant (Lonargáin, Brannigan, & Murray, 2017; Pinter et al., 2016). However, whilst transplant recipients often strive for normality this can continue to be disrupted by ongoing health issues (Boaz & Morgan, 2014). Transplant recipients who need to continue to manage their condition, often experience side-effects from the immunosuppressant medications that they are expected to take, and have reported uncertainty and anxiety about graft loss (de Brito et al., 2015; Jamieson et al., 2016; J. Jones et al., 2020; Lonargáin et al., 2017; Luk, 2004; Pinter et al., 2016; Schmid-Mohler, Schäfer-Keller, Frei, Fehr, & Spirig, 2014). Recipients have described paradoxical experiences such as being both healthy but also feeling unwell or being vulnerable to sickness (Amerena & Wallace, 2009; Bogue Kerr, Soulière, & Bell, 2018). Therefore kidney transplant recipients may continue to experience stress/distress relating to their condition even after a successful transplant (J. Jones et al., 2020; J. K. Low, Crawford, Manias, & Williams, 2017).

PROs after SPK Transplantation

Research has assessed PROs after SPKTs. A review of literature published in the 1990s and early 2000s found a variety of measures had been used but outcomes

generally suggested that pancreas and SPK transplants were beneficial (Joseph, Baines, Morris, & Jindal, 2003). Kwiatkowski and colleagues (Kwiatkowski et al., 2005) found that all 19 SPKT recipients who took part in their survey study felt that they were more satisfied with life post-transplant. Despite this, 12 recipients reported being permanently afraid of graft loss and 14 still checked their blood glucose levels daily. SPKT recipients have reported better physical well-being, health satisfaction, and less depression compared to patients with diabetes on HD, but outcomes were not significantly different to kidney-only recipients with diabetes (Secchi et al., 1998). Several studies have used the SF-36 and mixed results have been found in comparisons of SPKT recipients and those on the waiting list or with a kidney-only transplant. A recent study compared 72 SPKT recipients to 47 patients with type 1 diabetes awaiting an SPKT and a matched group of 42 patients with type 1 diabetes but no CKD. Overall, there was no significant difference between wait-listed patients and SPKT recipients on the mental and physical components of the SF-36, although SPKT recipients reported better general health (Nijhoff et al., 2020). In further analyses only those who had received their SPKT <7 years prior reported significantly better physical functioning compared to wait-listed patients (Nijhoff et al., 2020). The SPKT recipients were found to have lower scores across several subscales of the SF-36 including general health, physical and social functioning, role physical, vitality, and bodily pain, compared to patients with type 1 diabetes and no CKD. However, it should be noted that it does not appear that the authors controlled for potentially confounding factors in these comparisons (Nijhoff et al., 2020). The authors also report that patients wait-listed for and in receipt of an SPKT reported worse scores on the Brief Symptom Inventory (BSI; Derogatis & Melisaratos, 1983) indicating more psychological symptoms than patients with diabetes and no CKD (Nijhoff et al., 2020). After controlling for potential confounders, Pera et al. (2009) found that SPKT recipients had better outcomes on all aspects of the SF-36 compared to dialysis patients on the SPKT waiting list. Nyumura et al. (2017) also found that SPKT recipients had significantly better physical and mental component scores on the SF-36 compared to patients on dialysis with diabetes, and less diabetes distress on the PAID compared to dialysis patients and those with a kidney-only transplant. Another study reported that SPKT recipients had better general health and vitality on the SF-36 compared to wait-listed patients and better general health compared to LDKT recipients. At follow-up three-years later, SPKT recipients reported significantly improved role-physical subscale scores but worse vitality, whilst other subscale scores remained stable (Sureshkumar, Patel, Markatos, Nghiem, & Marcus, 2005).

In a recent study, SPKT recipients reported significantly less diabetes distress and better scores on several KDQOL-SF domains including symptoms, effects of kidney disease, burden of kidney disease, general health, and physical, sexual, and social function compared to patients awaiting SPK transplantation (Posegger et al., 2020). Interestingly, SPKT recipients reported worse cognitive functioning than those awaiting transplantation. The authors report the study as a prospective pre- to post-SPKT design, however data collection was cross-sectional and different participants awaiting SPKT and in receipt of an SPKT were compared. In another study which used the KDQOL, SPKT recipients reported significantly better symptoms, effects of kidney disease, overall health, pain, and physical and cognitive functioning compared to kidney-only recipients with diabetes (Ziaja, Bozek-Pajak, Kowalik, Król, & Cierpka, 2009). However, the sample was small with 21 SPK and 17 kidney transplant recipients (Ziaja et al., 2009). SPKT recipients have also indicated better satisfaction on the DQOL compared to kidney-only recipients and wait-listed patients with diabetes (Sureshkumar et al., 2005). These cross-sectional studies do appear to suggest that SPKT recipients often report some better outcomes compared to those waiting for a transplant or with a kidney-only transplant. However, not all the studies controlled for other differences that may have impacted outcomes in the group comparisons.

As stated previously, longitudinal research investigating PROs pre- and post-transplantation in the same patients can be useful for improving our understanding of the impact of transplantation. Some studies have asked patients to complete measures retrospectively shortly after transplantation and then followed them up post-transplant. One such study found that SPKT and kidney-only recipients were significantly improved on all domains of the KDQOL-SF, except for work status, at one-year post-transplant, and SPKT recipients had significantly better sleep and work status scores than kidney-only recipients (Rajkumar, Mazid, Vucak-Dzumhur, Sykes, & Elder, 2019). Another recent study with retrospective pre-transplant data reported significant improvements in post-SPKT scores on the SF-36, including the mental and physical component scores (Scheuermann et al., 2020). In a study with true pre-transplant data, participants were asked to indicate their QoL on a 10-point scale (0 being ‘worst imaginable QoL’ and 10 being ‘best imaginable QOL’), SPKT recipients were also asked to retrospectively assess their pre-transplant QoL (Adang, Kootstra, Engel, van Hooff, & Merckelbach, 1998). Results showed that QoL significantly increased by around two points on the scale for patients with a

successful SPKT, with follow up at 5, 12 and 18 months. Results from the retrospective assessment of QoL indicated that patients had a tendency to underestimate their pre-transplant QoL. This suggests that people may either have poor recall of their past experiences or that they experience a response shift (Howard & Dailey, 1979), whereby individuals adapt when they are unwell and re-evaluate their experience once they improve (Adang et al., 1998). A similar longitudinal study which collected both retrospective and true pre-transplant data found that a sample of 20 participants reported improvements pre- to 6-12 months post-SPKT in all domains of the EQ-5D and the EQ-VAS, as well as improvements in symptoms, psychological status, and physical and social functioning domains of the Gastrointestinal Quality of Life Index (GIQLI; Eypasch et al., 1995; Martins et al., 2015). Retrospective pre-transplant scores were similar to the actual pre-transplant scores suggesting accurate recall of pre-transplant experiences (Martins et al., 2015).

In other prospective longitudinal research, SPKT recipients and patients with diabetes and a kidney-only transplant reported significantly improved mental and physical component scores on the SF-36 one-year post-transplant (Gross, Limwattananon, Matthees, Zehrer, & Savik, 2000). Kidney-only recipients reported improvements in all SF-36 domains except for physical functioning, and SPKT recipients reported improvements in pain, general health, social functioning, and vitality at one-year post-transplant. Significant pre- to one-year post-transplant improvements were also found on other measures of depression (Centre for Epidemiological Studies – Depression; CES-D; Radloff, 1977), well-being and life satisfaction (Index of Well-Being; Campbell, Converse, & Rodgers, 1976), and satisfaction with diabetes treatment (taken from DQOL). At the three-year follow-up, SPKT recipients' scores were still significantly improved on several outcomes, however the mental component, depression, and life satisfaction scores were no longer significantly better than at pre-transplantation (Gross et al., 2000). Similarly, kidney-only recipients no longer reported significantly improved physical component scores or role functioning at the three-year follow-up. However, both samples suffered attrition (22 SPKT and 33 kidney-only recipients at three years follow-up) and may have lost power at the three-year follow-up. A more recent study found significant improvements in physical component scores on the SF-36 from pre- to four-months, one-year, and two-years post-SPKT (G. C. Smith, Trauer, Kerr, & Chadban, 2010). Mental component scores improved from pre- to four months post-SPKT and then remained stable up to three years follow-up. Overall, results from

these studies do appear to suggest that patients report significant improvements on PROMs from pre- to post-SPKT. However, it is not clear what outcomes improve consistently and which remain stable, because of the various outcome measures that are used. As previously stated, the majority of research investigating PROs of kidney and SPK transplant recipients have used generic measures that more accurately assess health status and/or aspects of functioning rather than QoL, so the impact on QoL is still unclear.

Qualitative Research on Experiences with Diabetes and SPKT

Qualitative research exploring experiences of patients with diabetes have reported that it can be a difficult condition to keep under control and involves making numerous lifestyle and dietary changes. Young adults with type 1 diabetes have reported difficulties with diabetes management and that diabetes is always on their mind (Balfe et al., 2013). A meta-synthesis of qualitative research exploring experiences of uncontrolled type 1 diabetes found that this is a condition that causes considerable psychological distress, irritability, cognitive difficulties, and even aggressive behaviour (Vanstone, Rewegan, Brundisini, Dejean, & Giacomini, 2015). Patients often fear long-term complications and dread experiencing hypoglycaemia, and this concern can cause issues with sleep, work, driving, and leisure activities (Pera, Vasallo, Andreu, Brulles, & Rabasa, 2012; Vanstone et al., 2015). Conflict over diabetes management can negatively impact relationships (Morris, Parker, Booker, & Johnson, 2006; Stuckey et al., 2016; Trief, Sandberg, Dimmock, Forken, & Weinstock, 2013). Individuals with type 1 diabetes have reported experiencing stigma due to their condition and frustration at the inaccurate perceptions of others that (type 1) diabetes is a condition that is self-inflicted (Browne, Ventura, Mosely, & Speight, 2014). At the same time, people with diabetes may also feel guilt when they experience problems with their diabetes management (Balfe et al., 2013). Whilst patients may find technologies such as CGM devices and insulin pumps empowering, as they help patients to feel more independent and in control of their diabetes, they can also be burdensome to use and patients may feel self-conscious if the device is visible to others (Grose, O'Brien, & Castle, 2017; Messer, Johnson, Driscoll, & Jones, 2018).

Whilst there are many qualitative studies which have explored various aspects of living with diabetes, there is limited research which has focused specifically on the impact of having both diabetes and CKD. Patients with diabetes who have

developed CKD have reported experiencing a sudden realisation of the seriousness of their condition, a loss of normality, and feelings of uncertainty for their future health (K. Reid, Morris, Cormack, & Marchant, 2012). Individuals with both conditions often need to make further adjustments to their lifestyle and the management of their health conditions and may find certain aspects, such as following dietary recommendations, particularly difficult (Clemens et al., 2019; N. King, Carroll, Newton, & Dornan, 2002; Lo et al., 2016; Notaras & Conti, 2018; K. Reid et al., 2012). A limitation of these studies is that it is unclear whether patients were awaiting transplantation, and specifically SPK transplantation, which may have additional implications or impact on patients' perspectives. For example, Pera et al. (2012) found SPKT recipients experienced guilt prior to their transplant as they were aware of the connection between poorly controlled diabetes and CKD. Participants reported conflicting emotions regarding the possibility for an SPKT as they were anxious but also hopeful that the transplant would restore their health.

Similarly, there is limited qualitative research which has reported specifically on the experiences of SPKT recipients. Pera et al. (2012) found that SPKT recipients regarded their transplant as a miracle and felt that they had been reborn as they were able to return to a more normal way of life. SPKT recipients have reported more independence, motivation, physical ability, and dietary freedom post-transplant (Dahl & Moen, 2017). Some kidney and SPK transplant recipients have reported improvements in aspect of life such as sexual functioning and relationships; however, others have reported continued or worsening sexual dysfunction due to symptoms, such as fatigue, and anti-rejection medications (Martell, Rice, Crooks, Ko, & Muehrer, 2015). As found with kidney-only transplant recipients, SPKT recipients have reported being fearful of graft loss and some continue to suffer from diabetes complications and/or unpleasant side-effects from the immunosuppressant medications (Dahl & Moen, 2018; Pera et al., 2012). Some recipients reported struggling with their feelings about the transplanted organs and of having a transplant from a deceased donor (Pera et al., 2012). SPKT recipients have also described experiencing symptoms of hypoglycaemia; and some still test their blood glucose levels post-transplant due to concerns about organ rejection (Dahl & Moen, 2018).

Factors Associated with PROs in CKD/Post-Transplant

Researchers have also investigated other factors that might help to predict outcomes reported by CKD patients. These include clinical and demographic characteristics and illness perceptions.

Clinical and demographic characteristics. One clinical characteristic that has been assessed for its impact on PROs post-transplant is length of time on dialysis. Von der Lippe et al. (2014) found greater improvements in kidney disease burden on the KDQOL for patients who had been on dialysis for ≥12 months compared to those who had been on dialysis for less time (von der Lippe et al., 2014). Another study found that young patients (<65 years) had poorer mental and physical component scores on the SF-36 the longer they had spent on dialysis prior to transplantation (Weber et al., 2014). Similarly, Gentile et al. (2013) found that long-term dialysis (>3 years) was associated with poorer mental and physical health on the ReTransQoL, a French condition-specific measure (Gentile et al., 2008). Lønning et al. (2018) also found that time on dialysis was associated with worse outcomes on several domains of the KDQOL. Whether patients received HD or PD prior to transplantation was not found to significantly impact KDQOL(-SF) outcomes post-transplant in two studies (Kostro et al., 2016; von der Lippe et al., 2014), although Scheuermann et al. (2020) found physical component scores on the SF-36 were better in SPKT recipients who had been on PD compared to HD. Kidney-transplant recipients with comorbidities, such as diabetes, have been found to report significantly poorer outcomes than those with fewer or without comorbidities (Dukes, Seelam, Lentine, Schnitzler, & Neri, 2013; Szeifert et al., 2010; Weber et al., 2014). Comorbid mental health problems have also been associated with worse physical functioning on the SF-36 after SPKT (Smith et al., 2010). Other predictors of poorer outcomes on measures such as the ReTransQoL and SF-36/SF-12 include age, ethnicity, income (Chisholm & Spivey, 2007), female gender (Bohlke et al., 2009; G. C. Smith et al., 2010), living alone, and medication side-effects (Gentile et al., 2013). Szeifert et al. (2010) found that being single, having comorbidities, a poor financial situation, and estimated GFR were significantly associated with depression in kidney recipients. Other research suggests social support is associated with better mental and physical component scores on the SF-36, whilst medication side-effects are associated with poorer scores in patients <40 years old with a kidney transplant (Rosenberger et al., 2010).

Common-Sense Model of Self-Regulation (Leventhal, Nerenz, & Steele, 1984). The way a person perceives their illness is also thought to be important to how they respond and cope with the illness, which can influence outcomes such as well-being. The Common-Sense Model (CSM) of Self-Regulation theorises that individuals hold illness perceptions or representations about the identity (symptoms), cause, timeline (acute, chronic, cyclical), consequences, and control/curability of health conditions (Leventhal, Brissette, & Leventhal, 2003; Leventhal et al., 1984). These illness perceptions, and the emotional response to the health threat, are thought to influence individuals' behavioural response or coping and, in turn, patient outcomes. For example, the model suggests that if a person believes their condition has been caused by an unhealthy lifestyle, they might be more likely to change their unhealthy behaviours than if they believed it was caused by genetics. Research suggests that illness perceptions have a direct association with outcomes, such as well-being and functioning, as well as indirect relationships through coping (Hagger, Koch, Chatzisarantis, & Orbell, 2017). In general, perceptions of greater control are associated with better well-being and functioning, whilst perceptions of greater illness consequences, identity, and emotional representations are associated with worse well-being and functioning (Hagger et al., 2017). Chronic timeline perceptions have generally been found to be negatively associated with well-being (Hagger & Orbell, 2003). Some research has previously investigated the illness perceptions of patients with CKD and diabetes and found associations with psychological well-being (Chilcot, 2012; Hudson, Bundy, Coventry, & Dickens, 2014; Knowles et al., 2016; Muscat, Chilcot, Weinman, & Hudson, 2018). For example, when controlling for clinical factors, perceptions of greater illness consequences and less personal control and coherence significantly predicted depression in patients on HD (Chilcot, Wellsted, Davenport, & Farrington, 2011). Another study found that patients' timeline perceptions were positively associated with physical component scores on the SF-36. Personal control perceptions were positively associated with mental component scores, and emotional representations were associated with both (Covic, Sica, Gusbeth-Tatomir, Gavrilovici, & Goldsmith, 2004).

The CSM also suggests that illness perceptions and coping behaviours can change when individuals make reappraisals of the health condition. In line with this, some illness perceptions have been found to differ across the CKD illness trajectory (Jansen et al., 2013; Pagels, Söderquist, & Heiwe, 2015) and by treatment (Griva, Jayasena, Davenport, Harrison, & Newman, 2009; Timmers et al., 2008). One study

found that the illness perceptions of individuals on dialysis changed after kidney transplantation so that timeline perceptions became more acute, perceptions of control improved, and participants identified fewer symptoms and consequences from CKD (Griva et al., 2012). Multiple regression analyses showed that change in perceptions of the illness consequences were associated with mental component scores on the SF-36 (Griva et al., 2012). It has been suggested that illness perceptions, and especially perceptions of control, could be targeted in psychological interventions to help improve patient outcomes such as psychological well-being (Hagger et al., 2017; Hudson, Moss-Morris, Game, Carroll, & Chilcot, 2016; Petrie & Weinman, 2006). However, there appears to be limited research on associations between illness perceptions and outcomes for patients with a kidney or SPK transplant, and a lack of research investigating associations between illness perceptions and genuine measures of QoL in this patient population. Associations between illness perceptions and QoL need to be investigated before interventions which target illness perceptions can be suggested as a way to improve this outcome. The current thesis aimed to partly address this gap by investigating whether illness perceptions change after SPK transplantation and whether illness perceptions are associated with outcomes including condition-specific QoL.

Impact of Diabetes and CKD on the Family

Family members often provide practical and emotional support that can help patients with a chronic condition like CKD both directly and indirectly by having a buffering effect (S. Cohen & Wills, 1985; S. D. Cohen et al., 2007). Research with caregivers or persons close to patients with CKD or diabetes usually include adult children and partners/spouses, as these individuals are usually closest to the patient and may become informal caregivers. Research reveals that providing support and experiencing stressors associated with diabetes (Messina et al., 2018; Whittemore, Delvy, & McCarthy, 2018) and CKD (J. Low, Smith, Burns, & Jones, 2008) can have a negative impact on family members. However, there is a lack of research with the partners/caregivers of patients who have both diabetes and CKD. Research also suggests that partners/caregivers may benefit when the person with CKD receives a kidney transplant. For example, caregivers of individuals on PD or HD reported significantly worse anxiety, depression, sleep quality, and carer burden than caregivers of kidney recipients (Avşar et al., 2013; Avşar et al., 2015). Rodrigue et al. (2010) found that spouses of kidney recipients reported significantly better

Quality of Life Inventory (Frisch, 1994) scores than spouses of wait-listed patients; however, mental and physical component scores on the SF-36 and measures of mood, caregiver strain, and caregiver benefit did not significantly differ. Over 50% of the participants were classed as reporting high levels of caregiver strain before and after the partners transplant, which the authors argue was because they continued to support the patient with their treatment and/or other comorbidities (Rodrigue et al., 2010). Whilst there is some research with family members of kidney-only transplant recipients, it has mostly involved quantitative assessments and lacks in-depth detail of the experiences of family members. There is also a lack of research investigating the experiences of partners of patients after SPK transplantation specifically. Qualitative research could usefully investigate the experiences of partners of SPKT recipients to find out about the wider impact that diabetes, CKD, and SPK transplantation has on families. This could help to evaluate SPKTs further and identify the needs of patients' families. The current research aimed to address this by carrying out qualitative interviews with partners of SPKT recipients to explore their personal experiences before and after transplantation.

The Access to Transplantation and Transplant Outcome Measures (ATTOM) Programme of Research

Although most previous research has been cross-sectional and focused on outcome measures such as health status and functioning, the Access to Transplantation and Transplant Outcome Measures **(**ATTOM) programme aimed to address these limitations. The main aim of the research programme was to examine access to renal transplantation in the UK and learn how best to optimise transplant outcomes. The research programme had five work-streams; 1) examining factors that influence access to transplantation (Calestani et al., 2014; Gibbons et al., 2017; Pruthi et al., 2020; D. M. Taylor et al., 2019; Wu et al., 2017); 2) examining factors that affect survival on dialysis and after transplantation (Wu et al., 2020); 3) examining differences in QoL and other PROMs in patients undergoing dialysis or transplantation (Gibbons et al., 2021; Gibbons et al., 2020); 4) conducting health economics analyses of alternate approaches to organ allocation (Li et al., 2020); and 5) using the survival, health status, QoL, treatment satisfaction, and costs to determine an optimal organ allocation policy for the UK. Between November 2012 and March 2013, 6360 patients with CKD were recruited to the ATTOM programme by 72 renal units across the UK. Three cohorts of patients were included: incident

dialysis (patients who recently started dialysis), incident transplant (patients who recently received a kidney or SPK transplant), and a matched-control group of prevalent patients on the transplant waiting list. The control group was matched to the incident dialysis and incident transplant groups by age within five years, time spent on the transplant waiting list, the type of transplant (LDKT, DDKT or SPKT), and whether they had started dialysis. Full details of the methods used in the original ATTOM programme can be found in Oniscu et al. (2016).

A sub-set of 651 ATTOM participants were invited to take part in the work-stream which focused on PROMs. Participants completed questionnaires measuring health status, health utilities (EQ-VAS and EQ-5D-5L; Herdman et al., 2011), and well-being (W-BQ12; Bradley, 2000) at recruitment. Participants also completed measures of generic and renal-dependent quality of life (RDQoL; Bradley, 1997), and renal treatment satisfaction (RTSQ; Barendse, Speight & Bradley, 2005) at three months post-recruitment/post-transplant. Patients who also had diabetes or an SPKT were asked to complete a measure of diabetes-dependent QoL (ADDQoL; Bradley et al., 1999) and diabetes treatment satisfaction (DTSQ; Bradley, 1994a). All measures were completed again approximately 12 months after recruitment/transplantation. A subsample of participants who were recruited as wait-listed participants received a transplant before the 12-month follow-up. For these participants, the initial measures were completed while they were still wait-listed for a transplant, giving a pre-transplant measure, and the second set of measures was completed 12-months post-transplant. These data allowed for pre- and post-transplant analyses to be conducted. The research used a mixed methods design, as qualitative interviews were also carried out with a sub-sample of participants at 12-month follow-up to examine in more detail patients' QoL post-transplant.

In cross-sectional analyses of 12-month post-transplant PROMs LDKT recipients reported significantly better generic QoL, renal-dependent QoL, well-being, and renal treatment satisfaction compared to DDKT recipients, when controlling for group differences. Patients on the waiting list had significantly worse scores across all measures compared to the transplant recipients (Gibbons et al., 2021). However, the analyses of longitudinal data from the sub-sample of 26 LDKT and 41 DDKT recipients who provided pre- and 12-month post-transplant data indicated that LDKT and DDKT recipients had similar scores on most measures. DDKT recipients' health status, renal-dependent QoL, and treatment satisfaction significantly improved from pre- to post-transplant but utilities, well-being, and generic QoL remained stable.

Although the LDKT recipients' scores improved across all the PROMs, they only scored significantly higher on treatment satisfaction compared to DDKT recipients when pre-transplant scores were taken into account. The wait-listed participants' QoL and treatment satisfaction scores remained stable across the two time points, but well-being, health status, and utilities worsened (Gibbons et al., 2021). Gibbons et al. (2021) argued that the research highlights the importance of taking into account group differences and pre-transplant PROMs data in comparisons of LDKT and DDKT recipients.

Analysis of data from SPKT recipients showed that at 12-months follow-up SPKT recipients had significantly better generic QoL, well-being, health status, and renal treatment satisfaction, and less impacted renal-dependent QoL compared to those on the waiting list, when controlling for sex, education, and previous renal treatment. Differences were not found between the two groups on the diabetes-dependent measures (ADDQoL and DTSQs). In addition, longitudinal data was collected from 22 SPKT recipients with pre- and 12-month post-transplant data. When compared to 19 participants still on the waiting list, the groups did not significantly differ on the PROMs at baseline. Whilst outcomes remained stable over time for those on the waiting list, SPKT recipients reported significantly improved generic QoL, well-being, health status, and renal treatment satisfaction, and significantly less impacted renal-dependent QoL at 12-months follow-up compared to pre-transplant and those still on the waiting list (Gibbons et al., 2020). No significant changes were detected in diabetes-dependent QoL or diabetes treatment satisfaction from pre- to post-SPKT, although results on a change version of the DTSQ indicated patients were more satisfied with their treatment post-SPKT (Gibbons et al., 2020).

Qualitative interviews were carried out with a sub-sample of the ATTOM detailed PROMs study participants in order to supplement findings from the quantitative data (Gibbons et al., 2021; Gibbons et al., 2020). Both kidney and SPK transplant recipients reported that they had gained more independence, dietary freedom, and were more able to have a better lifestyle post-transplant. However, both kidney-only and SPK transplant recipients appeared to have unmet expectations, which was distressing for some. SPKT recipients reported still being negatively impacted by diabetes complications such as eye-sight and mobility problems, which may help to explain why no significant improvement in diabetes-dependent QoL was found on the ADDQoL from pre- to post-transplant or when comparing to the wait-listed group (Gibbons et al., 2020). SPKT recipients were concerned about how long their

transplanted organs would last and several reported still restricting their diet or checking their blood glucose levels unnecessarily. Some LDKT recipients reported feeling guilty and concerned about the well-being of their living-donor, especially those who had received their transplant from adult offspring (Gibbons et al., 2021). Responses from the transplant recipients in the qualitative research indicated that at 12 months follow-up some participants may still have been adjusting to life with the transplant, for example some had not returned to work and/or were still experiencing physical difficulties. The findings suggested that a longer follow-up was needed to ascertain whether PROs changed further or remained stable post-transplant

Conclusions and Aims

Transplant recipients often report better PROs compared to dialysis patients or those wait-listed for a transplant, particularly on utility measures or physical functioning (Purnell et al., 2013; Wyld et al., 2012). However, patients who receive a transplant may be different from those who do not, and confounding variables need to be taken into account. Importantly, improvements in some PROs have been reported from pre- to post-transplant in longitudinal research (Gross et al., 2000; Lønning et al., 2018; Martins et al., 2015; G. C. Smith et al., 2010; von der Lippe et al., 2014). Whilst clinicians often believe that LDKTs are superior to DDKTs, research using PROMs to investigate this have found variable results and it is not clear that this bias is substantiated (de Groot et al., 2013; Griva et al., 2002; Lai et al., 2020; Zimmermann et al., 2016). Much of the research which has reported measuring QoL or HRQoL has used measures such as the SF-36, which are more accurately described as measures of health status or functioning. This can lead to difficulties in interpreting findings and misleading conclusions (Bradley, 2001). Further longitudinal research that measures QoL is therefore needed to clarify the impact of CKD, diabetes, and transplantation on QoL.

The ATTOM detailed PROMs study was the first to use individualised measures of condition-specific QoL as well as measures of health status, well-being, and treatment satisfaction to assess outcomes after kidney and SPK transplantation. Although cross-sectional analyses indicated that LDKT recipients reported better outcomes than DDKT recipients, analyses of a sub-sample of participants showed that when controlling for pre-transplant PROMs scores and other confounding variables, LDKT recipients only reported better renal treatment satisfaction than

DDKT recipients. LDKT recipients improved across all the included PROMs from pre- to post-transplant, whilst DDKT and SPKT recipients improved on health status, renal-dependent QoL, and renal treatment satisfaction. As some participants interviewed at 12-months follow-up were still adjusting to life with a transplant, it was anticipated that patients might experience further improvements in time. Alternatively, it is also possible that the long-term accumulation of medication side-effects and/or complications relating to CKD and transplantation may negatively impact patients. There is limited longitudinal research which has investigated long-term PROs after transplantation and none that have used the measures of QoL, treatment satisfaction, and well-being included in the ATTOM detailed PROMs study.

Therefore, in study 1, the current research aimed to investigate longitudinal PROs of individuals receiving treatment for CKD and diabetes by carrying out a further follow-up approximately six years after the original ATTOM detailed PROMs sub-study ended. The current thesis defines QoL as 'how good or bad a person considers their life to be' and uses the previously described individualised condition-specific measures of QoL and other PROs to gain a better understanding of the impact of CKD and diabetes. The sample included patients who were recruited to the original ATTOM detailed PROMs study shortly after receiving a kidney-only or SPK transplant. Follow-up data collected from these patients provides insight into the long-term outcomes of transplantation and the impact of CKD on patients' QoL. Other participants were originally recruited as matched controls on the transplant waiting list but may have received a transplant since recruitment to the original study. Therefore, these participants will have provided pre- transplant data and follow-up would provide insight into the impact of transplantation from pre- to post transplant. Furthermore, the study aimed to compare LDKT and DDKT recipients' follow-up PROMs data to test the commonly held belief that LDKTs provide superior outcomes. Study 1, presented in Chapter 3, aimed to answer the following research questions:

- Do PROs including QoL, treatment satisfaction, health status, utilities, and well-being change from pre- to post- kidney transplantation?
- Do PROs including QoL, treatment satisfaction, health status, utilities, and well-being change several years post-transplant?
- Do PROs differ between LDKT and DDKT recipients at follow-up?

- Are patients satisfied with the renal service that they receive several years post-transplant?

The study provides data that could help patients know what to expect after a kidney or SPK transplant and may help patients to make decisions about which type of transplant to have (LDKT or DDKT).

SPK transplantation is still a relatively new treatment and there are only a few studies which have investigated PROMs both pre- and post-transplantation (Adang et al., 1998; Martins et al., 2015). Whilst some pre- and post- transplant data were collected during the original ATTOM study, this only happened when those recruited as waiting list controls received a transplant within the first year of the study and the sample was small. The aim of study 2 of the current research was to investigate the impact of SPK transplantation by recruiting a new sample of patients wait-listed for SPKTs in order to collect PROMs data pre- and post-transplant. The study included the individualised condition-specific measures of QoL, and other condition-specific and generic measures to assess treatment satisfaction, well-being, and health status to provide information on a range of outcomes. The study also aimed to assess illness perceptions to investigate whether perceptions changed from pre- to post-SPKT and whether perceptions were associated with QoL, well-being, and treatment satisfaction. Therefore study 2, presented in Chapter 4, aimed to answer the following research questions:

- What impact does CKD, diabetes, and SPK transplantation have on PROs including QoL, treatment satisfaction, health status, utilities, and well-being?
- Are patients satisfied with the renal service that they receive pre- and post-SPKT?
- What are patients' perceptions of their renal condition and diabetes, and do perceptions change after SPK transplantation?
- Are illness perceptions associated with QoL, treatment satisfaction, and well-being?

The study evaluates SPK transplantation and informs patients on what to expect. Information on illness perceptions could help to inform interventions aimed at improving patient outcomes.

Whilst quantitative research using PROMs can provide an overview of patient outcomes and statistical analyses can be conducted to investigate significant changes in outcomes or differences between groups, qualitative research can

provide additional details and a deeper understanding of patients' experiences. There is limited qualitative research with patients in the UK who have both CKD and insulin-treated diabetes and a lack of research on the experience of waiting for SPKT specifically. To understand the impact of transplantation on patients, we need first to understand their experiences prior to transplantation. Therefore, a sub-sample of participants from study 2 was invited to take part in an interview about their experiences and the impact of having diabetes and CKD on QoL. The qualitative research, presented in Chapter 5, aimed to answer the following questions:

- How does diabetes, CKD, and wait-listing for an SPKT impact QoL?
- How do patients cope with their health conditions?

The qualitative research helps to clarify findings from the PROMs and can provide further information about how patients' QoL is impacted.

Previous qualitative research suggests that kidney and SPK transplantation benefit patients (Dahl & Moen, 2018; de Brito et al., 2015; Orr, Willis, Holmes, Britton, & Orr, 2007; Pera et al., 2012; Pinter et al., 2016). However, transplant recipients may still struggle with health issues and fear of graft rejection, which can negatively impact their lives and well-being (Boaz & Morgan, 2014; Dos Santos et al., 2016; Schipper et al., 2014). There is still limited research conducted with SPKT recipients, especially with UK-based patients. Interviews with kidney and SPK transplant recipients who completed PROMs for studies 1 and 2 were carried out to supplement the quantitative research and explore post-transplant experiences and QoL. The research, presented in Chapter 6, explored transplant recipients' responses to the QoL measures included in studies 1 and 2 and aimed to answer the following questions:

- How is QoL positively and negatively impacted after SPK and kidney-only transplantation?
- How have patients coped with health-related issues since transplantation?

Lastly, there is evidence to suggest that having a partner and social support is associated with better outcomes in people with chronic health conditions such as diabetes and CKD (S. D. Cohen et al., 2007; Joensen, Almdal, & Willaing, 2013; Lilympaki et al., 2016; Mollaoglu, 2006). Research also indicates that diabetes and CKD can negatively impact on patients' family members (Lawton et al., 2014; Stuckey et al., 2016; Whittemore et al., 2018). Whilst there is some evidence to

suggest that family members also benefit when patients receive a kidney transplant (Avşar et al., 2013; Avşar et al., 2015), there is a lack of existing research on the experiences of partners or caregivers of SPKT recipients. Therefore study 3 aimed to investigate the pre- and post-transplant experiences of partners of SPKT recipients to establish what impact these conditions have on family members. Overall, the current research aimed to provide a better understanding of the wider impact of CKD, diabetes, and transplantation on patients and their families. The research, presented in Chapter 7, aimed to answer the following questions:

- If and how partners are impacted by diabetes, CKD, and wait-listing for SPKT?
- How do partners support the patient with diabetes and CKD?
- What impact does SPK transplantation have on partners?
- How do partners cope throughout the experience of wait-listing and transplantation?

Overall, findings from the current research should help to inform patients who are considering having a kidney or SPK transplant about what to expect post-transplant and should help patients make more informed treatment decisions. Figure 1.1 presents a map of the thesis to help guide the reader. Chapter 2 outlines the methodology and methods of the research in more detail.

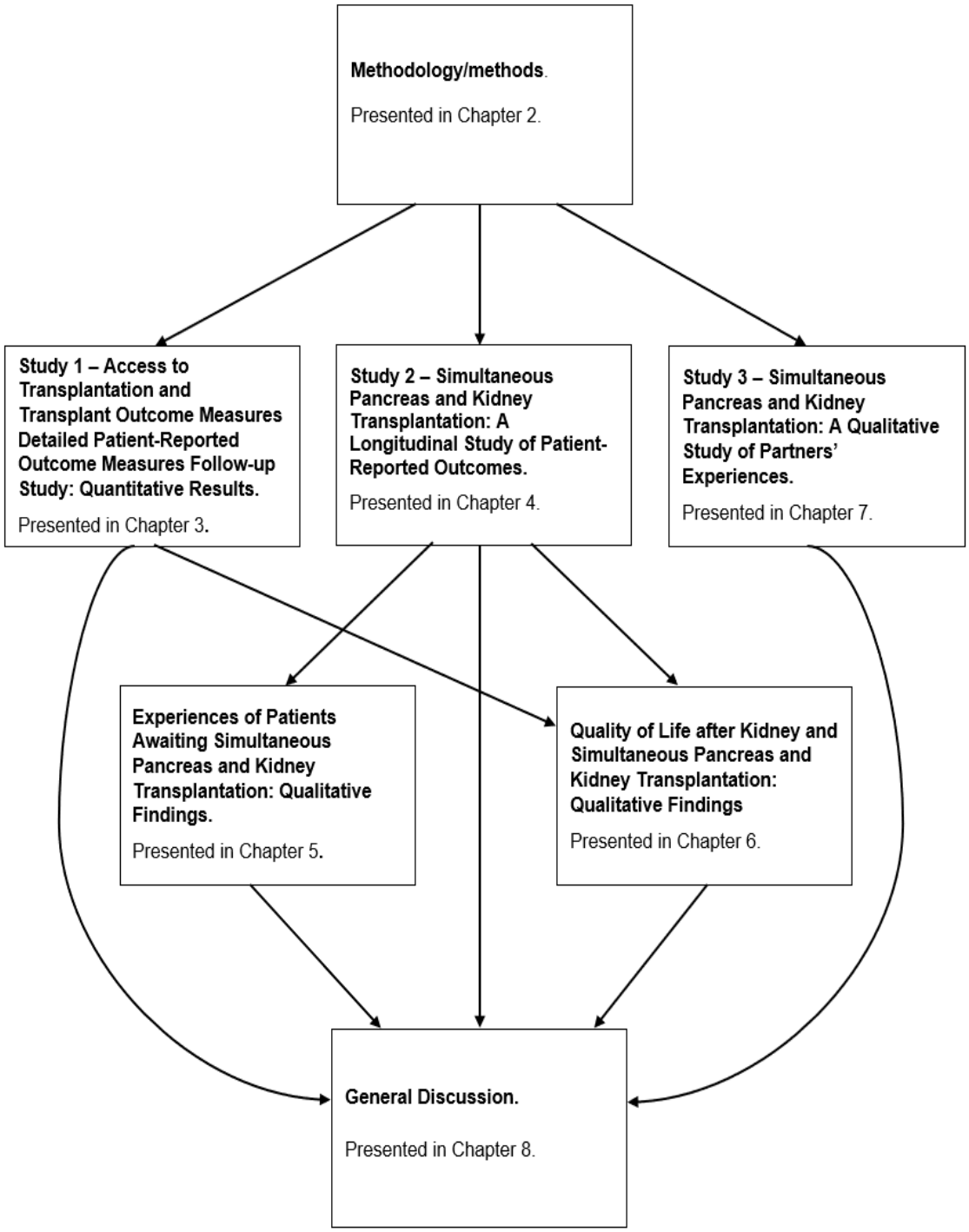

Figure 1.1. Conceptual map of the thesis.

Chapter 2: Research Methodology/Methods

Theoretical Approach

An overall pragmatic approach was taken towards the current research; this is recommended as the most appropriate for mixed methods (Burke Johnson & Onwuegbuzie, 2004; Denscombe, 2008; Dures, Rumsey, Morris, & Gleeson, 2011). Often a positivist approach is taken towards quantitative research, this is the belief that 'reality' can be quantitatively measured, and knowledge is objective; alternatively post-positivism recognises that knowledge can be subjective. However, qualitative research usually involves a constructivist or contextualist approach. Constructivism argues that there is not just one 'reality' that can be measured, and knowledge is socially constructed, subjective, and influenced by factors such as culture and politics. Similarly, contextualism is a less extreme version of constructivism which also argues that there is not just one 'reality' and knowledge is context-specific and will be valid in some contexts but not all (Braun & Clarke, 2013; Dures et al., 2011; Madill, Jordan, & Shirley, 2000). Pragmaticism is a moderate, 'common-sense' approach that sits between positivism and constructivism and is a 'practical and outcome oriented' approach (Burke Johnson, & Onwuegbuzie, 2004, p.17). Knowledge is both socially constructed and based on 'reality'. With a pragmatic approach both quantitative and qualitative methods can be used together to investigate research questions.

Study 1: Access to Transplantation and Transplant Outcome Measures (ATTOM) - Detailed Patient-Reported Outcome Measures (PROMs) Follow-up Study

Objectives. The objective of the study was to follow up participants of the ATTOM detailed PROMs sub-study and investigate changes in PROs, including QoL, treatment satisfaction, health status, and well-being. The study aimed to compare LDKT and DDKT recipients across the PROMs at follow-up. Qualitative interviews were used to explore further the experiences of transplant recipients, and how their QoL was impacted by CKD, diabetes, and transplantation.

Design. The study used a mixed methods research design including a cohort observation that involved a longitudinal follow-up of PROMs. Some PROMs

were collected during the ATTOM study at recruitment as a matched control, shortly after transplantation, or shortly after commencement of dialysis, and others at three-month follow-up. These measures were assessed together as recruitment/three-month follow-up measures. All PROMs were completed again 12 months after recruitment/transplantation. As NHSBT usually report patient and graft survival at one, two, five-, and 10-years post-transplant the aim of the current study was to follow participants up five years post-recruitment/transplant. Due to logistical reasons the current follow-up was carried out closer to six/seven years post-recruitment. Regardless, this timeframe will have allowed for participants to adjust to life with a transplant and post-transplant treatment and therefore they will have been able to consider any impact of the medications, as well as the transplant, on their QoL. As ≥70% of kidney and SPK transplants survive 10 years, the majority of participants who received a transplant during the ATTOM study would still have a working graft at six/seven years post-transplant (NHSBT, 2019).

Qualitative interviews were used to supplement the quantitative data to provide in-depth information on patients' experiences and how QoL was impacted, with a focus on transplantation. Rather than collecting all of the quantitative PROMs data first, and then beginning to collect all of the qualitative data, collection of the quantitative and qualitative data were conducted concurrently to avoid too much time elapsing between the time when participants completed the PROMs and when they were interviewed. A maximum of six months was allowed between collection of a participant's PROMs data and that participant's qualitative interview. The qualitative interviews were carried out before the PROMs data were analysed. The qualitative analysis did not aim to compare LDKT and DDKT recipients, although these groups were compared in the analyses of the quantitative PROMs data.

The mixed methods design was utilised to provide a more complete understanding of patients' experiences and how and why QoL is impacted. Quantitative and qualitative research methods each have their own strengths and weaknesses, when combined the strengths of each can offset their weaknesses (Plano Clark & Ivankova, 2017). For the current research, the mixed-method study design was beneficial because the quantitative data provided more generalisable findings, allowed for (statistical) group comparisons to be made (e.g. between LDKT and DDKT recipients), and provided information on whether outcomes changed over time. The qualitative element of the study provided additional detail that could not be captured by the PROMs alone and allowed for exploration of the processes of how

and why QoL was impacted. Through triangulation, the combination of different research approaches or methods can help to produce more accurate and reliable conclusions (Plano Clark & Ivankova, 2017). By establishing whether findings from the quantitative research were consistent with patients' detailed reports of their experiences, stronger conclusions could be drawn.

Study population. Eligible participants were individuals living in the UK who had CKD for which they received treatment (including dialysis and/or transplantation) and had previously been involved in the ATTOM detailed PROMs sub-study. All participants were ≥18 years old and able to give informed consent to participate in the research. The original ATTOM sub-study only included individuals who were fluent in English as the resources needed to include non-English speakers were not available, therefore follow-up participants were all fluent in English.

A sub-sample of LDKT, DDKT, and SPKT recipients also took part in qualitative interviews. Participants were purposively selected for interview in order to recruit both men and women who had a range of scores (low, moderate and high) on the RDQoL measure. Participants were interviewed within six months of having completed the follow-up PROMs as it was anticipated that no major changes would have occurred in relation to their QoL in this time.

Sample size. Six-hundred and fifty-one patients were recruited to the original ATTOM detailed PROMs sub-study and approximately 490 participants completed PROMs at 12-months post-recruitment or post-transplant. Eighteen UK renal centres were involved in data collection for the original sub-study but only 13 agreed to aid recruitment of participants to the follow-up and were able to provide sufficient information. Therefore, the initial potential sample size for this follow-up study was 383 patients, including dialysis patients and SPK and kidney-only transplant recipients. GPower was used to estimate the sample sizes needed to carry out analyses (Faul, Erdfelder, Lang, & Buchner, 2007). To carry out *t*-tests to compare two groups (e.g. LDKT and DDKT recipients), to detect a medium effect (dz = 0.50) with 80% power, approximately 64 participants were needed in each group (total n = 128). For ANCOVAs comparing two groups whilst controlling for up to five covariates, to detect a medium effect (f = 0.25) with a power of 80%, 269 participants were needed. For paired t-tests to compare changes across two time points, to detect a medium effect (dz = 0.50) with 80% power, 34 participants were

needed. To compare data across three time-points with a repeated ANOVA with a medium effect size (f = 0.25) and power of 80%, 28 participants were needed. Alternatively, Brysbaert (2019) has argued that to run a study with 80% power and detect an effect size of *d* = 0.40, 50 participants are needed for repeated measures designs and 100 participants are needed in each group in between-group comparisons.

It was planned that approximately 15 participants (5 LDKT recipients, 5 DDKT recipients, and 5 SPKT recipients) would be interviewed for the qualitative analysis, although more could be interviewed if needed (see Chapter 6). The number of participants included in qualitative research is often decided during the data collection and analysis phases in an attempt to reach data saturation, which is generally considered to be the point at which no new information would be gained from further data collection (Braun & Clarke, 2019b). The idea of data saturation and what this actually means in regards to the number of interviews or participants needed for qualitative research has been hotly debated by researchers (Braun & Clarke, 2019b; J. Low, 2019). Some researchers have suggested that samples of 6-12 participants can achieve a high level of data saturation (Guest, Bunce, & Johnson, 2006; Young & Casey, 2019). Braun and Clarke (2019b) and J. Low (2019) have argued that data saturation is problematic because new information or insight can always be gained if data collection or analysis continues, and there is no clear endpoint. Instead of aiming for data saturation some researchers have aimed for 'theoretical sufficiency' by obtaining sufficient depth of information, for example, to build a theory (Dey, 1999, as seen in Braun & Clarke, 2019b). Malterud, Siersma, and Guassora (2016) outlined the concept of 'information power' in qualitative research and argued that there is more power and fewer participants are needed in research with a narrow aim, a specific sample, when theory is applied, if the interview dialogue is rich, and if the focus is on cases. Therefore, the number of participants 'needed' in a qualitative study depends on several factors, and inevitability practical factors such as time limitations and availability of appropriate participants will also influence sample size. In the current research, interviews were carried out until sufficient data had been collected to achieve the aim of understanding patients' experiences of transplantation and how QoL was impacted. As the qualitative element of the current research was carried out to supplement and support the quantitative PROMs research, it is possible that fewer participants were needed than if it was a stand-alone study.

Recruitment and procedure. PROMs data were collected between December 2018 and February 2020. Collaborators at 13 renal centres that were originally involved in recruitment to the ATTOM detailed PROMs sub-study provided information detailing: (1) whether any participants recruited through their site had died since taking part in ATTOM; (2) which participants, if any, did not provide consent to be contacted about future research; (3) whether contact details held for each participant were correct. Surviving participants who completed PROMs at 12-month follow-up in the original ATTOM study and who consented to be contacted about future research were then invited to take part in this follow-up study by the same method that they were contacted previously (via telephone, post, email). Where possible individuals were contacted by telephone first and invited to take part. Collaborators at each of the participating sites sent a study invitation letter (see Appendix B) to individuals who had changed contact details since ATTOM or where the research team at Royal Holloway, University of London (RHUL) had missing details. The research team included the PhD student researcher (KH) and two supervisors within the Health Psychology Research Unit at RHUL. Along with the invitation letter, these individuals were provided with a stamped-addressed envelope and reply slip which they could complete and return to the researcher (KH) at RHUL (see Appendix C). Individuals who expressed willingness to take part in this follow-up (either when contacted by phone/email or by returning a reply slip indicating willingness) were sent a study invitation letter (see Appendix D and E), the participant information sheet (see Appendix F and G), consent form (see Appendix H and I), and PROMs in the post. A stamped-addressed envelope was provided with the pack so that completed PROMs and consent forms could be returned to the researcher (KH). Potential participants were informed that they could also complete the questionnaires over the telephone if they preferred, in which case consent to participate could either be given in writing as usual or over the telephone and recorded.

On the study information sheet, participants were also informed about the prospect of taking part in a telephone interview and were asked to consent to be contacted for an interview and to the interview being audio-recorded if they took part. SPKT recipients were informed about the additional study with transplant recipients' partners, asked to give consent for their partner to be contacted about taking part in a telephone interview, and asked to provide contact details for their partner (see Appendix J). A selection of those participants who indicated a willingness to take

part in an interview were contacted by telephone by the researcher (KH) to invite them to participate and to organise a time and date that was suitable.

Qualitative research has traditionally been conducted through face-to-face interviews, leading some to believe that this is the 'gold standard'. However, there is little or no evidence to suggest that telephone interviews are any less useful than face-to-face interviews (Novick, 2008). The original ATTOM detailed PROMs study found that participants were willing to be interviewed over the telephone and spoke in-depth about their personal experiences (Gibbons et al., 2021; Gibbons et al., 2020). Other researchers have also described positive experiences with qualitative telephone interviews and consider it to be equivalent to face-to-face interviewing for producing detailed, in-depth qualitative data (Cachia & Millward, 2011; Holt, 2010; Sturges & Hanrahan, 2004; Trier-Bieniek, 2012; Ward, Gott, & Hoare, 2015). Some argue that the anonymity offered by telephone interviewing can result in more honest discussions, particularly if a topic is embarrassing (Sturges & Hanrahan, 2004; Trier-Bieniek, 2012). A common critique of telephone interviews is the loss of visual cues, which some researchers argue inhibits rapport between the interviewer and interviewee and leads to less detailed data (Novick, 2008). However, Cachia and Millward (2011) argue that people generally have the skills necessary to communicate effectively over the telephone and interviewers and interviewees are aware of the need to verbalise any communication rather than rely on visual cues. For example, interviewers often explicitly ask participants about their emotional experiences in a telephone interview rather than relying on visual cues and this can help to provide rich data. Furthermore, non-verbal communication, which might be noted during a face-to-face interview, is often not used in the analysis (Cachia & Millward, 2011).

Telephone interviews were adopted in the current research because it provided increased flexibility to work around how the participants were feeling and allowed interviews to be rescheduled easily at short-notice or stopped and restarted at another time if needed. The use of telephone interviews removed the need for participants to travel to an agreed location or for the interviewer to enter participants' homes, which could be intrusive for the participant or unsafe for the researcher. The flexibility and convenience of the telephone interviews was particularly important for the current research as some participants were quite unwell and had reduced mobility and/or impaired vision. The use of telephone interviews also enabled the inclusion of participants from a wider geographical area across the UK, including

individuals from Scotland, which would not otherwise have been practical. The interviews followed a semi-structured schedule, described below, and were audio-recorded so that they could be transcribed verbatim in preparation for analysis. Interviews with ATTOM follow-up participants took place between June 2019 and February 2020.

Quantitative measures. Participants were asked to complete a general questionnaire to provide details on their date of birth, gender, marital status, education level, employment status, ethnicity, height and weight (so that body mass index could be calculated), details of current CKD treatment and diabetes treatment (if applicable), information on previous transplants, comorbidities, and whether they were registered as visually impaired or disabled (see Appendix K). Participants who had received an SPKT were asked to indicate on a five-point scale from 1 (always) to 5 (never) whether since receiving their transplant they worry about their blood sugar levels being too high and whether they restrict their diet/avoid sugary foods and drinks. SPKT recipients were also asked to indicate whether since having the SPKT they have monitored their blood sugar levels and, if so, how often in the past four weeks.

Renal-Dependent Quality of Life (RDQoL). The RDQoL is an individualised measure of renal-dependent QoL (Bradley, 1997). The development of the RDQoL was influenced by the SEIQoL assessment of QoL and informed by discussions with healthcare professional and interviews with 40 renal patients on HD, PD, or with a transplant (Bradley, 1997). The measure starts with a statement: this questionnaire asks about your quality of life – in other words how good or bad you feel your life to be. This is followed by a single-item measure of Generic QoL, scored on a 7-point scale from ‘excellent’ to ‘extremely bad’ (+3 to -3). It also includes a Renal-Dependent QoL Overview item which asks participants ‘if I did not have a renal condition my quality of life would be’, and is scored on a 5-point scale from ‘very much better’ to ‘worse’ (-3 to +1). Twenty-one domain-specific items follow, covering aspects of life such as work, leisure activities, social life, and freedom to eat as you wish (see Appendix L). Individuals are asked to indicate on a five-point scale whether each aspect of life would be very much better or worse (-3 to +1) if they did not have a renal condition. The measure also asks that participants indicate the importance of each domain using a four-point scale from ‘very important’ to ‘not at all important’ (+3 to 0). There are six domains that may not be applicable to all individuals completing the questionnaire. For example, if the patient

does not have any family, they can indicate this in response to a preliminary question about applicability and skip the rest of the item about family life. Weighted impact scores can be calculated for each aspect of life by multiplying the impact rating and importance rating, to give a score from -9 (most negative impact) to +3 (positive impact). A score of 0 indicates that the domain is not impacted and/or not important. Average weighted impact (AWI) scores can be calculated by summing all applicable weighted impact scores and dividing by the number of applicable items, to give a score from -9 (most negative impact on QoL) to +3 (most positive impact on QoL). The RDQoL was used in the original ATTOM study and psychometric analyses were carried out with wait-listed patients, kidney-only transplant recipients, and SPKT recipients. Some items were not found to load well onto a one factor structure but with the removal of items 2 (work), 4 (holidays), 14 (spiritual/religious life), and 19 (others fussing) the RDQoL was found to have an acceptable one factor structure and good reliability (Cronbach's $\alpha > 0.90$) within all three patient groups (Gibbons et al., 2020; Gibbons et al., 2021). Reliability was retained (Cronbach's $\alpha > 0.70$) with up five items missing within SPKT recipients and up to seven items missing for non-transplant patients and kidney transplant recipients, excluding non-applicable items.

Audit of Diabetes-Dependent Quality of Life (ADDQoL). The ADDQoL is an individualised measure of how diabetes impacts QoL (Bradley et al., 1999; Wee, Tan, Goh, & Li, 2006). The development of the ADDQoL was also influenced by the SEIQoL and knowledge of pre-existing measures used in diabetes research, input from healthcare professionals, and interviews with 12 individuals with diabetes (Bradley et al., 1999). The ADDQoL starts with the same statement on QoL as the RDQoL followed by a single-item measure of diabetes-dependent QoL that asks participants to rate on a five-point scale whether their QoL would be very much better or worse (-3 to +1) if they did not have diabetes. A further 19 domain-specific items follow this overview item (see Appendix M). Domains cover the same aspects of life as the RDQoL but omits two domains: spiritual/religious life and others fussing. The measure is scored in the same way as the RDQoL; five items have a not-applicable option and relevant items can be rated for their impact on QoL and importance to the individual, from this AWI scores can then be calculated (-9 to +3). The ADDQoL has previously been found to have good reliability and validity (Bradley & Speight, 2002; Bradley et al., 1999; Wee et al., 2006). The measure was adapted for use with SPKT recipients during the original ATTOM study because individuals often felt that they no longer had diabetes post-transplant, although they

might still be impacted by the complications of diabetes. Each question in the ADDQoL for SPKT recipients begins with 'If I had never had diabetes' rather than the original 'If I did not have diabetes' (see Appendix N for sample). Analyses of data from the ATTOM study found the ADDQoL for SPKT recipients loaded acceptably onto one factor, with item loadings all >0.40. The measure was found to have excellent reliability (Cronbach's α = 0.92) and AWI scores could be calculated with up to seven missing items, excluding the non-applicable items, and retain an α of >0.70 (Gibbons et al., 2020).

Renal Treatment Satisfaction Questionnaire status version (RTSQs). The 13-item RTSQs was developed to measure satisfaction with any treatment for CKD (Barendse et al., 2005). The measure asks respondents to consider such aspects as how convenient and flexible their treatment is, whether they feel satisfied with the treatment, and how well their condition is controlled. Each item is rated from 6 (e.g. very satisfied) to 0 (e.g. very dissatisfied; see Appendix O). Total scores can be calculated by adding the item scores, giving a range of 78 to 0. The original 11-item measure has been found to have acceptable reliability and discriminant validity for patients on dialysis or with a kidney transplant (Barendse et al., 2005). The 13-item version of the RTSQs was used in the ATTOM detailed PROMs study. Analyses found that items could load onto one factor with item loadings ≥0.31 for SPKT recipients, ≥0.52 for kidney recipients, and ≥0.45 for non-transplant patients. The RTSQs was found to have good reliability within SPKT recipients (Cronbach's α = 0.84) and excellent reliability within kidney recipients and non-transplant patients (Cronbach's α ≥ 0.90). Reliability was retained with up to four items missing for SPKT recipients and up to five missing for kidney recipients or non-transplant patients; missing items can be replaced with average scores in order to calculate a total score for the measure (Gibbons et al., 2020; Gibbons et al., 2021).

Diabetes Treatment Satisfaction Questionnaire status version (DTSQs). The DTSQs is an 8-item measure of treatment satisfaction for people with diabetes (Bradley, 1994a; Bradley & Lewis, 1990). The measure asks individuals to rate each item on a scale of 6 (e.g. very satisfied) to 0 (e.g. very dissatisfied; see Appendix P). Six items (1 and 4-8) can be summed to produce an overall treatment satisfaction score between 36 (very satisfied) to 0 (very dissatisfied). Items 2 and 3 measure perceived frequency of hyperglycaemia and hypoglycaemia respectively, on a scale from 6 (most of the time) to 0 (none of the time). This measure has been validated with tablet-treated and insulin-treated patients and has been found to have good

internal consistency, construct validity, and sensitivity to change (Bradley, 1994a; Bradley & Gilbride, 2008). Analyses of data from SPKT recipients in the original ATTOM detailed PROMs study found that the six items loaded onto one factor (each item ≥0.59) and the measure had excellent reliability (Cronbach's α = 0.89) (Gibbons et al., 2021). Up to two scores can be missing to maintain an α > 0.70; missing scores can be replaced with average scores to calculate the overall total.

EuroQoL-5 Dimension-5 Level (EQ-5D-5L) and Visual Analogue Scale (EQ-VAS). The EQ-5D-5L (Herdman et al., 2011) measures five dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression (see Appendix Q). Individuals self-rate their status for each domain by selecting one of five response options indicating that they have: 'no problems' (0), 'slight problems' (1), 'moderate problems' (2), 'severe problems' (3), or 'extreme problems' (4). The measure also includes a visual analogue scale (EQ-VAS) on which the individual indicates their overall 'health today' on a scale from 0 (worst health you can imagine) to 100 (best health you can imagine). The EQ-5D-5L (and a version with a 3-level response option) has been used extensively in clinical research across several countries (Herdman et al., 2011; Rabin & Charro, 2001). Responses on the EQ-5D-5L can be recoded in order to calculate utility scores between zero (death) and 1.0 (perfect health). The rating also allows for the possibility of a negative score to -0.281, which is considered to reflect states worse than death (Devlin et al., 2016). The values allocated to each response option on the EQ-5D-5L when recoding for the utility score were calculated from responses of 996 members of the English general population on a series of time trade-off and discreet choice experiment tasks (Devlin et al., 2016). This scoring was used to calculate the utility scores in the original ATTOM detailed PROMs study.

Well-Being Questionnaire 12 (W-BQ12). The W-BQ12 was developed from a longer 22-item measure originally designed and validated within a sample of individuals with diabetes to assess Depression, Anxiety, and Positive Well-Being (Bradley, 1994b; Bradley & Lewis, 1990). The measure does not include any diabetes-specific items and uses positively and negatively worded items. The current W-BQ12 includes 12 items with four items for each subscale assessing Negative Well-Being, Energy, and Positive Well-Being (Mitchell & Bradley, 2001; Pouwer, Snoek, van der Ploeg, Adèr, & Heine, 2000; Pouwer, Van Der Ploeg, Ader, Heine, & Snoek, 1999; Riazi et al., 2006). The measure asks respondents to rate how often they feel each statement has applied to them in the past few weeks from

3 (all the time) to 0 (not at all; see Appendix R). Overall well-being scores on the W-BQ12 range from 0 to 36, with higher scores indicating better well-being. Subscale scores for Negative Well-Being, Energy, and Positive Well-Being can also be calculated with scores ranging from 0 to 12. Several validations of the W-BQ12 have been published for different patient groups including diabetes and macular degeneration (Mitchell & Bradley, 2001; Pouwer et al., 2000; Pouwer et al., 1999; Riazi et al., 2006) and the measure was used in the original ATTOM detailed PROMs study.

Renal Service Satisfaction Questionnaire (RSSQ). The RSSQ is a 34-item measure of renal patients' satisfaction with the care they receive from their renal unit or hospital (Bradley, unpublished). Items address satisfaction with a variety of aspects of care including the information provided about their care, how they are treated by staff, satisfaction with the time available in consultations, and advice and support received (see Appendix S). Each item can be marked as not applicable or scored on a 5-point scale from -2 (dissatisfied) to +2 (very satisfied). A final question asks individuals to report any other sources of satisfaction or dissatisfaction with their care. Each item is considered individually.

Renal Medication Questionnaire (RMQ). The RMQ (Bradley, unpublished) asks participants to list each immunosuppressant medication prescribed to them and to indicate: a) whether they take the medication; b) how often they are meant to take it; c) when they are meant to take it; d) how often they have taken the medication exactly as recommended on a 7-point scale from none of the time to all of the time (0 to 6); and (e) how often they find it inconvenient or difficult to take the medication as recommended on a 7-point scale from none of the time to all of the time (0 to 6). The first three questions are to orient the patient to consider the particular medication and the last two are used as single-item measures of adherence and difficulty with the medication (see Appendix T).

Qualitative materials. A semi-structured interview schedule was used to guide the qualitative interviews (see Appendix U and V). The interview schedule was informed by the schedule used in the original ATTOM study interviews. The focus of the interviews was on patients' experiences of renal failure (and diabetes), of being on the waiting list, and receiving a transplant. Open-ended questions and prompts were used. The interviews began by asking participants about their experiences of CKD (and diabetes) prior to transplantation in order to aid in the

understanding of how quality of life changed from pre- to post-transplantation. The interviews went on to ask about participants' experiences of being added to the transplant waiting list, their feelings about being on the list, and their experiences of transplantation. The rest of the interview focused around the impact transplantation had on their lives and some of their responses to the QoL and treatment satisfaction questionnaires that they completed beforehand. Items on the QoL measure were selected for discussion based on those that were most impacted and most important to the individual. Participants were asked about how they had adjusted and coped with their health condition, such as sources of support. Lastly participants were asked if they had had any expectations prior to transplantation and whether these had been met.

Quantitative analyses. The quantitative data were analysed in IBM SPSS statistics 21. Missing data were dealt with as recommended in the scoring instructions for each measure. For example, for kidney recipients, RDQoL AWI scores could be calculated with missing data on up to seven items and up to five missing items on the RTSQ can be replaced with average scores to then calculate total scores. The data were checked for normality by assessing skew and kurtosis, data were considered non-normally distributed if skew or kurtosis divided by the standard error were >1.96 (Field, 2013). Histograms and Kolmogorov-Smirnov tests were also considered. When data were found to be non-normally distributed non-parametric tests or bootstrapping were used. Bootstrapping is a technique which can be used on non-normal data whereby repeated random samples are taken from the data (with replacement) to estimate the sampling distribution of a statistic and more robust significance tests and 95% confidence intervals are calculated (Field, 2013). For the current research 1000 biased-corrected bootstraps were used. However, bootstrapping is not available for all analyses in SPSS version 21, for example repeated measures ANOVAs, in which case non-parametric Friedman's ANOVAs were used.

Repeated-measures ANOVAs were used to investigate changes in the PROMs across the three post-transplant time points for kidney-only and SPK transplant recipients; from recruitment to the original ATTOM study, to 12-months follow-up, and the current follow-up approximately six/seven-years later. For significant ANOVAs, Bonferroni corrected pair-wise comparisons between the paired time-points were reported. Paired-samples t-tests were used to investigate whether kidney transplant recipients reported significant changes across the PROMs from

pre- to post-transplantation. Effect sizes *r* were calculated for parametric and non-parametric analyses following instructions provided by Field (2013). The effect size *r* was calculated for pair-wise comparisons of significant repeated (Friedman's) ANOVA tests as this is more informative than reporting an overall effect size for the ANOVA (Field, 2013). The effect size *r* was calculated for consistency across the various parametric and nonparametric tests to aid comparison. Effect sizes around 0.10, 0.30, and 0.50 are considered to be small, medium, and large effects respectively (Field, 2013; Rosnow, Rosenthal, & Rubin, 2000).

Chi-squared tests or Fisher's exact tests, and independent samples t-tests were carried out to compare DDKT and LDKT recipients across background demographic characteristics. Correlations were carried out to identify variables which were significantly associated with the PROMs. Uncontrolled t-tests followed by ANCOVAs were carried out to compare DDKT and LDKT recipients across the PROMs whilst controlling for associated variables. Covariates were chosen based on demographic or clinical variables that significantly correlated with the outcome variable, $p < .05$. Further ANCOVAs were carried out to compare a smaller sub-group of DDKT and LDKT recipients who had received their transplant during or since the original ATTOM research programme and had provided pre-transplant data. In these ANCOVAs the pre-transplant PROMs scores were included as a covariate, along with other potentially confounding variables. Effect size *r* was calculated for the independent t-tests to remain consistent and aid comparison with previous analyses. Partial eta squared (η_p^2), provided by SPSS, has been reported for the ANCOVAs. Results of the quantitative analyses of PROMs from the ATTOM follow-up are presented in Chapter 3.

Qualitative analysis. The qualitative data were analysed using reflexive thematic analysis, as described by Braun and Clarke (Braun & Clarke, 2006, 2013, 2019a; Clarke & Braun, 2015). This is a flexible method of qualitative analysis that follows six stages which the researcher can shift between as necessary: familiarisation; data coding; generating initial themes from the coded data; developing and reviewing themes; refining and defining themes; and producing the report (Braun & Clarke, 2006; Braun & Clarke, 2020). Coding can be deductive, based on previous research findings and/or theory/models, and/or inductive, driven by ideas and concepts raised in the data. A theme is a multi-faceted 'analytic output' with 'patterns of shared meaning' and a 'central organising concept' (Braun & Clarke, 2019a, p. 593-594). Themes can be surface level, known as semantic

themes, or they can reveal underlying meaning, known as latent themes (Braun & Clarke, 2006; Braun & Clarke 2020). Reflexive thematic analysis was selected because of its flexibility which suited the aim of the research, to explore participants' experiences of transplantation and responses to the QoL measure.

A tool to assess the quality of thematic analysis manuscripts, developed by Braun and Clarke (2020), was used to help guide the reports of the qualitative research. To improve the rigor of the analysis ideas were discussed and themes were developed together with the supervisor (AG), who had also become familiarised with several of the transcripts and had in-depth knowledge of the topic. Some types of thematic analyses may use codebooks or inter-rater reliability in an attempt to make the analysis more objective and 'less biased'; however, Braun and Clarke (2020) argue that this is not necessary for reflexive thematic analysis and that qualitative research is subjective. Furthermore, the current mixed methods research already utilised more objective methods through the collection of quantitative PROMs data. A contextualist epistemology was taken towards the thematic analysis (Clarke & Braun, 2015; Madill et al., 2000; Tebes, 2005). As previously stated, this epistemology suggests that knowledge is context-specific. The researcher therefore acknowledges that the information provided by participants about their experiences is true for them and their situation, and that participants' experiences have been shaped by contextual factors such as the culture in which they live. The qualitative analysis was carried out using QSR International's NVivo 11 software. Findings from the qualitative interviews of post-transplant experiences are reported in Chapter 6.

Study 2: Simultaneous Pancreas and Kidney Transplantation: A Longitudinal Study of Patient-Reported Outcomes

Objectives. The objective of study 2 was to investigate the impact of insulin-treated diabetes, CKD, and SPK transplantation by examining PROs, including measures of condition-specific QoL, treatment satisfaction, well-being, and health status. Qualitative interviews were carried out to support the PROMs research and to explore further the experiences of patients with diabetes and CKD both pre- and post-SPKT.

Design. The study used a mixed methods design including a longitudinal cohort observation study of PROMs and qualitative interviews, which were

conducted concurrently. The qualitative interviews were used to supplement the PROMs data to gain a deeper understanding of participants' experiences.

Study population. Over a 15-month period from May 2018 to August 2019, participants were recruited from three UK transplant units: Addenbrooke's Hospital; Guy's Hospital; and The Royal Infirmary of Edinburgh. Patients were eligible to participate if they were ≥18 years old; had diabetes and CKD for which they had been placed on the waiting list for an SPKT; had the mental capacity to provide informed consent and complete the PROMs; and were able to read or understand/speak fluent English. Those who could not read/understand English could not be included in the research as the resources needed to include non-English speakers were not available. A sub-sample of participants who had been on the SPKT waiting list for at least 12 months or had been living with an SPKT for at least 12 months were invited to take part in a qualitative interview.

Sample size. Prior to the commencement of the study, it was estimated that there were approximately 75 patients active on the waiting list, 59 patients suspended from the waiting list, and approximately 116 new patients would be wait-listed over a 12-month period across the three transplant units. As previously mentioned, GPower was used to estimate sample sizes needed for certain analyses (Faul et al., 2007). To carry out t-tests comparing two groups (e.g. SPKT recipients and those still wait-listed at 12 month follow-up), to detect a medium effect (dz = 0.50) with 80% power, approximately 64 participants were needed in each group (total n = 128). For ANCOVAs comparing two groups whilst controlling for covariates, to detect a medium effect (f = 0.25) with a power of 80%, 269 participants were needed. For paired t-tests to compare changes across 2 time points, to detect a medium effect (dz = 0.50) with 80% power, 34 participants were needed.

It was planned that a sub-sample of 10 participants would also be interviewed including 5 pre-transplant and 5 post-transplant patients, although more would be recruited if needed. As discussed, the final sample size for the qualitative research was decided during the data collection and analysis stages and depended on availability of participants and whether sufficient data had been collected to achieve the research aims.

Recruitment and procedure. Clinic staff at the three transplant units identified eligible patients under their care (see Appendix W for recruitment guide and study invitation letter template). Patients who were wait-listed for an SPKT were invited to take part in the research by the renal transplant team who posted the invitation letter along with the study information sheet (see Appendix X), consent form (see Appendix Y), first questionnaire pack, and a stamped-addressed envelope so that completed consent forms and questionnaires could be sent back to the researcher (KH) at RHUL. Those patients who were temporarily suspended from the waiting list when recruitment started were invited to participate in the study once they became active on the waiting list again. Patients wait-listed for the first time during the course of the study were either sent the study pack in the post or approached by a member of the renal transplant team when they attended for an appointment at the unit and provided with the study pack if they indicated a willingness to participate. Contact details for the research team at RHUL were provided so that patients could ask questions before deciding to take part. Patients were informed that they could complete the PROMs over the telephone if they preferred, for example, if they had an eyesight problem that would otherwise prevent them from taking part. Participants were asked to provide their contact details (see Appendix Z) to the researcher (KH) by completing a form included with the study pack so that they could be contacted for follow-up.

Consent was sought from the participants to allow the researcher (KH) to inform the relevant transplant unit if they decided to take part in the study and to allow the transplant unit to share information with the researcher (KH) about their treatment and circumstances (e.g. whether they were suspended from the waiting list, changed treatment/received a transplant, or if their transplant failed). This information was used to help determine if and when to contact participants for follow-up. Where possible, the clinic staff at each site attempted to contact potential participants (in person, on the phone or by letter) to remind them about the study approximately one month after initial invitation to the study if they had not returned the first study pack to the researcher (see Appendix AA for letter template and response form for participants to return to the researcher). Participants who had not yet received a transplant were asked to complete further PROMs at six- and 12-months post-recruitment, and those who received an SPKT were asked to complete measures approximately 12-months post-transplant. Where possible, participants were contacted by telephone by the researcher (KH) prior to posting follow-up questionnaire packs to check if there were any questions and to confirm with them

their address and current treatment. If follow-up questionnaire packs were not returned after approximately one month, the researcher (KH) attempted to contact the participant to find out whether the questionnaires had arrived, and if the participant had any questions or required help. Follow-up data were collected up to January 2021.

As in study 1, participants were also informed in the study information sheet about the prospect of taking part in a telephone interview and were asked to indicate whether they consented to being contacted for an interview and for the interview to be audio-recorded. As 12-month follow-up data were returned, participants who had given consent to be contacted about the interviews were contacted by telephone by the researcher (KH) to see if they would still be willing to take part and to arrange a convenient time for the interview. The telephone interviews followed a semi-structured interview schedule, described below. With participants' consent, the interviews were audio-recorded and transcribed verbatim for analysis. The interviews took place between June 2019 and August 2020. The telephone interviews were able to continue during the COVID-19 pandemic as they did not pose a risk to the participants or the researcher. Participants were also informed of the partner study in the information sheet and, if they had a partner, they were asked to provide contact details (see Appendix Z) and give consent for their partner to be contacted about the study.

Quantitative measures. All participants were asked to complete a general information questionnaire (see Appendix BB) including questions about their date of birth, gender, ethnicity, employment, marital status, height and weight (to calculate BMI), current CKD and diabetes treatments, diabetes complications, comorbidities, and whether participants were registered as visually impaired or disabled. At each follow-up participants were asked to complete a shorter general information questionnaire to update their current treatment, weight, experience of diabetes complications or new comorbidities, employment, and marital status.

Baseline PROMs. The primary outcome of interest was QoL measured using the single-item measure of Generic QoL and the ADDQoL and RDQoL questionnaires. At recruitment, participants were also asked to complete secondary outcome measures of: diabetes treatment satisfaction (DTSQs); renal treatment satisfaction (RTSQs); health utilities and health status (EQ-5D-5L & EQ-VAS); well-being (W-BQ16); renal service satisfaction (RSSQ); and illness perceptions (Brief

Illness Perceptions Questionnaire; Brief IPQ; Broadbent, Petrie, Main, & Weinman, 2006). The Brief IPQ was adapted to ask patients about their perceptions of their renal condition and a separate version was included to ask about perceptions of diabetes. Full details of these measures are listed above and descriptions of the W-BQ16 and Brief IPQ are provided below.

Well-Being Questionnaire 16 (W-BQ16). The W-BQ16 has four additional items to assess Stress and is otherwise the same as the W-BQ12 (Bradley & Lewis, 1990; see Appendix R). Overall well-being scores on the W-BQ16 range from 0 to 48, with higher scores indicating better well-being. Subscale scores for Negative Well-Being, Energy, Positive Well-Being, and Stress can also be calculated with scores ranging from 0 to 12. The W-BQ16 and Stress subscale have been validated in a sample of individuals with diabetes and found to have good reliability; Cronbach's $\alpha > 0.70$ (Speight, Khagram, & Davies, 2012).

Brief Illness Perceptions Questionnaire (Brief IPQ). The Brief IPQ is a measure of individuals' perceptions about their illness (Broadbent et al., 2006) and is a shortened version developed from the full-length Revised Illness Perceptions Questionnaire (Moss-Morris et al., 2002). The Brief IPQ includes 9 items that measure illness consequences, timeline, personal control, treatment control, illness identity, concern, emotional representations, illness comprehensibility or understanding, and perceived causes. Each item is rated by the respondent on a scale of 0 to 10, with the exception of the causal item which asks the respondent to indicate in order what they think the top three causes of their illness are. The causal item is analysed by categorising the responses. The other items can either be analysed individually or an overall score can be calculated by reverse scoring items 3, 4, and 7 and adding these to the five other scores; the higher the overall score (between 0 to 80) the more threatening the illness is perceived to be. This measure has been found to have good reliability, concurrent validity, and discriminant validity for a number of patient groups including renal patients (Broadbent et al., 2006) and has been used across various conditions (Broadbent et al., 2015). The measure was adapted for this study by referring to participants' 'renal condition' or 'diabetes' rather than 'illness', as recommended. An additional item was included that asks: 'How much do you experience symptoms from your renal treatment (including medications)?' The new item was added because it was understood that patients often experience symptoms that are due to their treatment rather than the renal condition itself. For consistency and because patients may also experience

symptoms from their diabetes treatment, the additional item was also added to the Brief IPQ for diabetes (see Appendix CC and Appendix DD).

Follow-up PROMs. Participants still on the SPKT waiting list six months post-recruitment were asked to complete a short subset of PROMs including the Diabetes-Dependent QoL Overview item, single-item measures of renal and diabetes treatment satisfaction (item one from RTSQs and DTSQs), as well as the EQ-5D-5L and EQ-VAS, W-BQ16, and the full RDQoL. Participants were asked to complete this shorter subset of PROMs in an attempt to capture pre-transplant outcomes closer to the time of transplantation but without over-burdening the participants.

At 12 months post-recruitment or, for those who received a transplant during the study, 12 months post-SPKT, participants were asked to complete the full set of questionnaires again: ADDQoL; RDQoL; DTSQs; RTSQs; EQ-5D-5L and EQ-VAS; W-BQ16; RSSQ; and the Brief IPQ relating to the patients' renal condition (and diabetes if still on the waiting list). Participants who received a transplant were asked to complete the SPKT version of ADDQoL instead of the usual ADDQoL and they were asked to report on their immunosuppressant medications by completing the RMQ. At 12-months follow-up all participants were also asked to complete change versions of the RTSQs and DTSQs measures (RTSQc and DTSQc) (Bradley, Plowright, Stewart, Valentine, & Witthaus, 2007; Howorka et al., 2000). These measures include similar questions and follow a similar format as the original status versions; however, they ask participants to indicate the extent to which satisfaction with their treatment has changed over the past 12 months or since before the SPKT was received (see Appendix EE and FF). Participants were asked to indicate their response to each question on a seven-point scale from +3 (much more satisfied) to -3 (much less satisfied), if there was no change in satisfaction participants were instructed to indicate 0. The change measures were included to deal with the potential ceiling effects of the DTSQs and RTSQs. The change versions were included in the 12-month follow-up of the ATTOM detailed PROMs study but not included in the current follow-up of ATTOM participants because it was felt that too much time had elapsed since the last follow-up or since most participants changed treatment. Psychometric analysis of the RTSQc data from ATTOM indicated that items loaded acceptably onto one factor with loadings ≥0.41 for SPKT recipients, ≥0.46 for kidney recipients, and ≥0.60 for non-transplant recipients. The reliability of the RTSQc was excellent (Cronbach's $\alpha > 0.90$). Up to 6

items can be missing whilst retaining reliability (Gibbons et al., 2020); missing items can be replaced by an average score and an overall total score can be calculated. Analysis of SPKT recipients' data found that the items of the DTSQc loaded onto one factor with each item loading ≥0.65. The DTSQc was found to have excellent reliability (Cronbach's α = 0.90). Up to two items can be missing and can be replaced by the average of the remaining six scores to calculate an overall score (Gibbons et al., 2020).

Qualitative materials. A sub-sample of pre-transplant and post-transplant participants took part in qualitative telephone interviews. A semi-structured interview schedule, similar to the one described in study 1, was used to guide the interviews (see Appendix GG). The focus of the interviews was on participants' experiences of diabetes and renal failure and of wait-listing for an SPKT. Individuals who had received an SPKT were asked about their experience of transplantation and post-transplant QoL. The interview guides incorporated participants' responses to the QoL and treatment satisfaction questionnaires completed beforehand.

Quantitative analyses. The data were analysed using SPSS version 25. The skew and kurtosis of the data were assessed for normality, where skew or kurtosis divided by the standard error >1.96 data were considered to be non-normally distributed (Field, 2013). Kolmogorov-Smirnov tests and histograms were also considered. Where data were not normally distributed non-parametric methods of analyses were used. Independent samples t-tests were carried out to compare PROs between dialysis and pre-dialysis participants at baseline and wait-listed participants and SPKT recipients at follow-up. Paired samples t-tests were used to assess differences over time in PROMs from recruitment to 12-months post-transplant or 12-months post-recruitment. Effect size *r* were calculated for each of the analyses. Correlation analyses were carried out to assess the relationships between illness perceptions (Brief IPQ) and QoL, treatment satisfaction, and well-being. Further details of the specific analyses used, and the results of the quantitative analyses are reported in Chapter 4.

Qualitative analysis. Reflexive thematic analysis was used to analyse the qualitative interview data (Braun & Clarke, 2006, 2019a). NVivo 11 was used to organise the qualitative analysis. Interviews with participants on the waiting list for an SPKT and dialogue about pre-transplant experiences from interviews with participants approximately 12-months post-SPKT were analysed together and the

findings are reported in Chapter 5. Post-transplant interviews from study 1 and study 2 were analysed together as similar themes were identified, although care was taken to highlight any differences in themes, for example SPKT recipients' references to diabetes-specific issues. The findings from the post-transplant interviews are reported in Chapter 6.

Study 3: Simultaneous Pancreas and Kidney Transplantation: A Qualitative study of Partners' Experiences

Objectives. The objective was to provide a better understanding of the wider impact of diabetes, CKD, and SPK transplantation on families by interviewing patients' partners and investigating: If and how partners are impacted by diabetes, CKD, and wait-listing for SPKT? How do partners support patients with diabetes and CKD? What impact does SPK transplantation have on partners? And how do partners cope throughout the experience of wait-listing and SPK transplantation?

Design. The study used a cross-sectional qualitative design involving semi-structured telephone interviews with partners of SPKT recipients recruited via participants from studies 1 and 2. A qualitative design was chosen in order to explore the experiences of partners of someone with an SPKT as this has not been done previously and there is also limited qualitative research with the family members of kidney recipients.

Study population. Individuals were eligible to participate if they were ≥18 years old, able to provide informed consent, and were the partner of an SPKT recipient for at least 12 months (although partners who had been in the relationship prior to the SPKT were preferred). Although SPKT recipients were interviewed for studies 1 and 2, study 3 focused solely on partners' experiences rather than couples as the aim was to understand the wider impact of diabetes, CKD, and transplantation on partners, rather than the impact on the relationship specifically. Interviews with partners rather than couples were also chosen to avoid participants' responses from being influenced/biased by the presence of the partner with the health condition. This also avoided other possible ethical issues of interviewing couples together (Lowton, 2018) or confidentiality issues of matching/linking participants' data.

Recruitment and procedure. SPKT recipients from study 1 and participants in study 2 were informed on their study information sheet about the additional research involving interviews with partners and were asked to provide consent and details for the researcher (KH) to contact their partner (if they had one) about the study. Where possible, partners were contacted by telephone directly to establish whether they would be willing to take part and would like to be sent the information sheet, consent form, and the brief questionnaires or whether they would be happy to complete these over the telephone. If initial contact could not be made by telephone, the information sheet (see Appendix HH), consent form (see Appendix II), and short questionnaire pack were sent to eligible individuals along with a stamped-addressed envelope so that completed consent forms and questionnaires could be returned. Partners were asked to complete a short questionnaire to provide some background information. Individuals who consented to be interviewed were contacted by telephone to arrange a convenient time and date for the interview. The interviews were guided by a semi-structured schedule and were conducted between July 2019 and January 2021. With consent from the participants, the interviews were audio-recorded so that they could be transcribed verbatim for analysis.

Materials/measures. Participants were asked to complete a general information questionnaire to provide data on their date of birth, gender, education level, employment, and whether they had any illnesses themselves (see Appendix JJ). Participants were also asked to complete the W-BQ16, EQ-5D-5L, EQ-VAS, and the single-item measure Generic QoL (taken from RDQoL, rated on a 7-pont scale from ‘excellent’ to ‘extremely bad’). These measures were included to provide a better understanding of the sample.

A semi-structured interview schedule was used to guide the interviews (see Appendix KK). Broad open-ended questions were used at first and prompts were used to elicit further information. The interviews started by asking participants to describe their experience with their partner’s diabetes and the development of CKD, including ways in which they supported their partner and the impact of the conditions and of wait-listing on their lives. The interviewer then went on to ask about the time when their partner received the SPKT and the impact that this has had on their lives. Participants were asked about how they coped and adjusted throughout the experience and whether they felt any expectations that they had prior to transplantation had been met.

Analysis. The qualitative interviews were analysed thematically, as described above, following instructions provided by Braun and Clarke (Braun & Clarke, 2006, 2013, 2019a). The software NVivo 11 was used to organise the analysis. The results of this study are reported in Chapter 7.

Ethical Considerations

The research plan for study 1, the ATTOM detailed PROMs follow-up, was assessed and approved by the East of England – Cambridge Central Research Ethics Committee (REC reference: 18/EE/0256). The research plan for study 2, the longitudinal SPKT study, was reviewed and given ethical approval by the London - Queen Square Research Ethics Committee (REC reference: 18/LO/0134). As SPKT recipients' partners were recruited through participants in both studies 1 and 2 the research plan was reviewed and given ethical approval by both the East of England – Cambridge Central Research Ethics Committee (REC reference: 18/EE/0256) and the London - Queen Square Research Ethics Committee (REC reference: 18/LO/0134). An NHS email account was set up for the research and used in all communication about participants with hospital staff. Participants' personal identifiable data, such as contact details, will be stored safely for up to five years after the completion of the research as participants have been asked to consent to be contacted about possible future follow-up research. Research data will be stored for up to 10 years after completion, when it will be destroyed/deleted.

Quantitative research ethics. The research team at RHUL did not have access to any patient records for any of the studies. For the ATTOM follow-up study, staff at each of the renal/transplant units informed the researcher (KH) about whether participants had consented to be followed up in future. Only those who had given consent were contacted about the follow-up. Staff at the renal/transplant units provided information on whether contact details held by the research team from the original ATTOM programme were correct. If they were not correct, participants were sent a study invite by the renal unit with a reply slip that could be sent to the researcher (KH) to indicate if they were interested in participating. All potential participants for study 2 were invited to take part in the research by the staff at the transplant units and individuals who were willing to take part and to be followed up provided their contact details to the researcher (KH).

Potential participants were given a detailed information sheet to explain the purpose of the study, what participation would involve, and how their data would be used. Participants were informed that the studies formed part of a PhD research project and that the research team was based at RHUL. Individuals were made aware that participation was voluntary and whether they took part or not would not impact on their treatment. Participants were made aware that participation was not anticipated to have any negative consequences, however completing questionnaires or taking part in an interview about their health conditions might be upsetting. Information was provided so that participants could contact the research team to ask questions about the research. In addition, information for UK-based charities that provide helplines for patients and their families were provided on the information sheets. Informed consent was obtained from participants in writing or, in some circumstances, when participants completed the PROMs over the telephone, consent was taken over the telephone and audio-recorded. When consent was taken over the telephone, participants were sent a copy of the consent form and information sheet for their records. Participants were not required to make any additional trips to the transplant unit/hospital and they were provided with stamped-addressed envelopes to return completed questionnaires. In study 2, participants were asked to give consent for nurses at the renal unit to provide updated information on their treatments so that they could be contacted at appropriate times. This also meant that the researcher (KH) could be informed when a participant died so that no further attempts to contact that patient were made.

When PROMs were completed over the telephone at the participant's request, care was taken to listen out for signs that the participant may have been becoming upset. A distress protocol, outlining what the interviewer should to do if a participant became upset during an interview, was prepared and at hand during interviews (see Appendix LL). If participants became fatigued whilst completing PROMs over the telephone the call was ended and reconvened the following day or at the nearest available time that was convenient for the participant. Participants' data were anonymised using participant identification codes and participants' names and addresses were stored in password protected documents on a computer at RHUL. Anonymised PROMs data were stored separately. Hard copies of the questionnaires completed by participants were stored in a locked filing cabinet in a locked office at RHUL and were kept separately from the consent forms. Data were only accessible to the research team, which included the PhD student researcher and supervisors.

Qualitative research ethics. Participants who completed PROMs were also asked to consent to take part in a qualitative interview and for the interview to be audio-recorded if they took part in one. Only individuals who provided consent were invited to take part in an interview. Initially the REC for study 2 required that, where practical in terms of geographical location, participants were offered the option to be interviewed by telephone or in-person and were asked to indicate a preference. Of 12 participants recruited through Guy's Hospital (which included participants within a geographical area who could be interviewed in-person) who consented to be contacted to take part in an interview, 10 indicated no preference and two indicated a preference for telephone interviews. Therefore, for consistency, all interviews were completed over the telephone.

Participants were informed that the interview would be transcribed for analysis and that quotes would be used in reports and publications, but identifiable information would be removed from the transcripts and quotes. Interviewees were given opportunities to ask questions about the research before and after the interview. During interviews the interviewer listened out for signs that the participant was becoming upset (e.g. what was being said, prolonged pauses, changes in tone, or crying) and was prepared to implement the distress protocol if necessary. The distress protocol was at hand during interviews in case the participant became upset (see Appendix LL) but did not need to be enacted during any of the interviews. Interviews with both the patient and their partner were avoided; however, where both the patient and partner took part in individual interviews, the data were not matched to help preserve confidentiality. The researcher did not discuss anything that either partner had disclosed in their interview. At the end of interviews participants were asked about how they were feeling and whether they were satisfied with how the interview went. Participants were reminded that they could contact the research team if they wanted to ask any questions or discuss the research in future. To avoid over-burdening participants who had already completed PROMs and a telephone interview, transcripts were not returned to participants for comment. The interviews were transcribed by the researcher (KH) and only the research team had access to these. Identifiable information was removed from the transcripts and participant identification codes were used to anonymise the transcripts and any quotes reported.

Chapter 3: Access to Transplantation and Transplant Outcome Measures (ATTOM) - Detailed Patient-Reported Outcome Measures (PROMs) Follow-up Study: Quantitative Results

Introduction and Aims

Transplantation is considered to be the best treatment for patients with kidney failure and is associated with better survival compared to dialysis (Tonelli et al., 2011). Clinicians often believe that LDKTs are medically superior to DDKTs. There is some evidence to suggest that LDKTs result in better patient and graft survival compared to DDKTs (Almasi-Hashiani et al., 2018; Matas et al., 2008; Nemati et al., 2014). One of the main benefits of LDKTs is that they can be planned to take place before the patient has started on dialysis or after a shorter time spent on dialysis compared to those awaiting a DDKT, which has been associated with better clinical outcomes (Abramowicz et al., 2016; Liem & Weimar, 2009). However, those who receive LDKTs or pre-emptive transplants are usually already better off than those who don't, for example they tend to have fewer comorbidities (Abramowicz et al., 2016).

As outlined in Chapter 1, PROMs can be useful tools for investigating the impact of chronic health conditions and treatment (Black, 2013) and there are several types of PROMs including generic, condition-specific, and individualised measures. Whilst generic measures can aid comparison between different groups of patients or with healthy controls, they may contain inappropriate items and may not be sensitive to changes in treatment for a chronic condition. Much of the research reviewed in Chapter 1 has claimed to have investigated QoL in CKD but have often used generic measures of health status and/or functioning, which can result in misleading conclusions (Bradley, 2001). For example, the SF-36, which assesses aspects of mental, physical, and social functioning, and the EQ-5D, which assesses health status and utilities, have frequently been used in research claiming to investigate the QoL or HRQoL of patients with CKD (Chuasuwan et al., 2020; Wyld et al., 2012). The KDQoL, which has also been frequently used in research of CKD patients (Chuasuwan et al., 2020), includes some condition-specific domains as well as the generic SF-36 domains, but a single score of QoL or the impact of CKD on QoL cannot be calculated from the KDQoL. Despite this, findings from previous

qualitative research and research using PROs generally suggest that kidney and SPK transplantation are beneficial.

The ATTOM detailed PROMs study was the first to use individualised condition-specific measures of QoL to assess the impact of CKD and diabetes on wait-listed patients and kidney and SPK transplant recipients. Cross-sectional analyses at 12-months post-transplant showed that kidney and SPK transplant recipients had better outcomes compared to those still wait-listed when controlling for confounding variables (Gibbons et al., 2021; Gibbons et al., 2020). LDKT recipients reported significantly better generic QoL, renal-dependent QoL, well-being, and renal treatment satisfaction at 12-months follow-up, when controlling for age, pre-transplant treatment, education, and having a history of mental health problems. However, analyses of a sub-sample of participants with pre- and post-transplant data showed that when pre-transplant outcomes were controlled for, LDKT recipients only reported significantly better renal treatment satisfaction at follow-up compared to DDKT recipients (Gibbons et al., 2021). DDKT recipients' health status, renal-dependent QoL, and treatment satisfaction significantly improved from pre- to post-transplant. LDKT recipients' scores improved across all the PROMs from pre- to post-transplant (Gibbons et al., 2021). SPKT recipients reported significantly improved generic QoL, well-being, health status, and renal treatment satisfaction and significantly less impacted renal-dependent QoL compared to pre-transplant (Gibbons et al., 2020).

Qualitative interviews with SPK and kidney transplant recipients at 12-months follow-up of the original ATTOM study found that participants' independence and lifestyle had improved. However, several participants were still negatively impacted by having had a renal condition (Gibbons et al., 2021) and possibly even more so by having had diabetes, which could help to explain why significant pre- to post-SPKT improvements were not seen for diabetes-dependent QoL (Gibbons et al., 2020). It is possible that at 12-months follow-up participants may still have been adjusting to life post-transplant as some were still struggling with physical problems and had not yet returned to work (Gibbons et al., 2020; Gibbons et al., 2021). It is possible that patients may have experienced further improvements past 12-months follow-up. At the same time, aspects of treatment may mean that QoL could have worsened over time. Further longitudinal follow-up of PROMs would help to improve our understanding of the long-term impact of transplantation and could help to inform patients about what to expect. However, no studies have conducted a longer follow-

up than 12 months using genuine individualised measures of condition-specific QoL. It is also not known whether LDKT and DDKT recipients differ on these measures of individualised condition-specific QoL, treatment satisfaction, and well-being in the longer-term.

Therefore, the aim of the current study was to follow-up the ATTOM detailed PROMs study participants to investigate whether QoL and other PROMs changed over time since data collection for the original ATTOM detailed PROMs study to approximately six/seven years follow-up. Participants' satisfaction with the renal service they have received was also assessed. As it was expected that several more participants wait-listed for a transplant who were recruited to ATTOM as matched controls or incident dialysis patients may have received transplants, the current research also aimed to investigate changes in QoL and other PROMs from pre- and post-transplantation. Lastly, the current research aimed to investigate if there were any significant differences between DDKT and LDKT recipients across the PROMs at this longer follow-up time point.

Summary of Methods

Design. The study involved a longitudinal cohort observation follow-up of PROMs from participants who received treatment for CKD (and diabetes) and took part in the original ATTOM detailed PROMs study. The original ATTOM study collected some PROMs data at recruitment shortly after transplantation/three-month follow-up and 12-months post-recruitment/transplant. These data were compared to the data collected as part of the current study, approximately six/seven-years post-transplant/recruitment. For full details of the methods used in the original ATTOM detailed PROMs study see Gibbons et al. (2020) and Gibbons et al. (2021).

Recruitment and procedure. Participants were recruited from across the UK with the help of 13 of the original 18 renal centres that were involved in recruitment to the original ATTOM detailed PROMs study, these were: Cambridge, Addenbrooke's Hospital; London, Guy's Hospital; London, St Mary's Hospital; Manchester Royal Infirmary; Newcastle, Freeman Hospital; Nottingham, City Hospital; Plymouth, Derriford Hospital; Sheffield, Northern General Hospital; Birmingham, Queen Elizabeth Hospital; North Midlands, Royal Stoke University Hospital; University Hospital of Wales; the Royal Infirmary of Edinburgh; Belfast City Hospital. The remaining centres involved in recruitment to the original ATTOM

detailed PROMs study either declined to take part in this follow-up research or were unable to provide sufficient information to allow participant follow-up. Collaborators assisted with recruitment by providing information regarding whether ATTOM study participants were still alive, had consented to future follow-up, and whether the contact details for participants held by the research team were still correct. Where the research team did not have current contact details, collaborators sent study invitation letters along with a reply slip to potential participants. These individuals were provided with a stamped-addressed envelope so that they could return the response slip and inform the researcher (KH) at RHUL on whether or not they were interested in taking part.

Where possible, individuals were contacted by telephone to invite them to take part in the follow-up study. Individuals who indicated willingness to take part in the research were sent a study pack including an information sheet about the research, consent form, and the PROMs. Where possible, individuals who did not return the consent form and PROMs were contacted by telephone approximately one month after being sent the study pack to remind them about the study and to establish whether the study pack had arrived. This also gave participants the opportunity to ask questions about the research or receive help in completing the PROMs if needed. Data were collected between December 2018 and February 2020.

Measures. Participants were asked to complete a general information questionnaire so that demographic data could be updated. The questionnaire pack also included the primary outcome measures: Generic QoL (single item measure in the RDQoL), and the Renal-Dependent QoL questionnaire (RDQoL; Bradley, 1997). Participants who had an SPKT were asked to complete the Audit of Diabetes Dependent QoL (ADDQoL; Bradley et al., 1999; Wee et al., 2006) for SPKT to assess whether having had diabetes still impacted their QoL. Secondary outcome measures included: the Renal Treatment Satisfaction Questionnaire (RTSQs; Barendse, Speight, & Bradley, 2005), the Diabetes Treatment Satisfaction Questionnaire (DTSQs; Bradley & Lewis, 1990; Bradley, 1994a), the EQ-5D-5L (Herdman et al., 2011), the Well-Being Questionnaire 12 (W-BQ12; Bradley & Lewis, 1990; Bradley, 2000), and the Renal Service Satisfaction Questionnaire (RSSQ). Individuals who had received a transplant were asked to complete the Renal Medications Questionnaire (RMQ) to identify their anti-rejection/immunosuppressant medications. Details of these PROMs are provided in Chapter 2.

Participants. Figure 3.1 below presents a flow diagram showing recruitment to the study. After excluding those participants who had died, not consented to take part in future follow-up research, or those with insufficient information to follow up, there was a possible sample of 295 individuals who could be invited to take part in the follow-up study. A total of 199 study packs were posted to potential participants and 117 were returned. A further ten questionnaire packs were completed over the telephone. The response rate for the study was 43% of the potential participants. Data provided by one individual who completed and returned the PROMs at the end of June 2020 were not included in the following report as this was several months into the COVID-19 pandemic in the UK. These data were excluded because the responses may have been negatively biased by the events of the pandemic in a way that none of the other participants' data would have been.

The follow-up sample included 91 kidney recipients (48 DDKT and 43 LDKT) and 18 SPKT recipients with a working pancreas and kidney. Two participants had received an SPKT but their pancreas grafts were no longer working, although their kidney grafts were still functioning (data not shown). The sample also included 10 individuals on hospital-based HD and four individuals on home-based HD. No participants were on PD at follow-up. Surprisingly, one individual recruited to the original ATTOM programme of research as a matched control was still pre-dialysis at the current follow-up (data not shown).

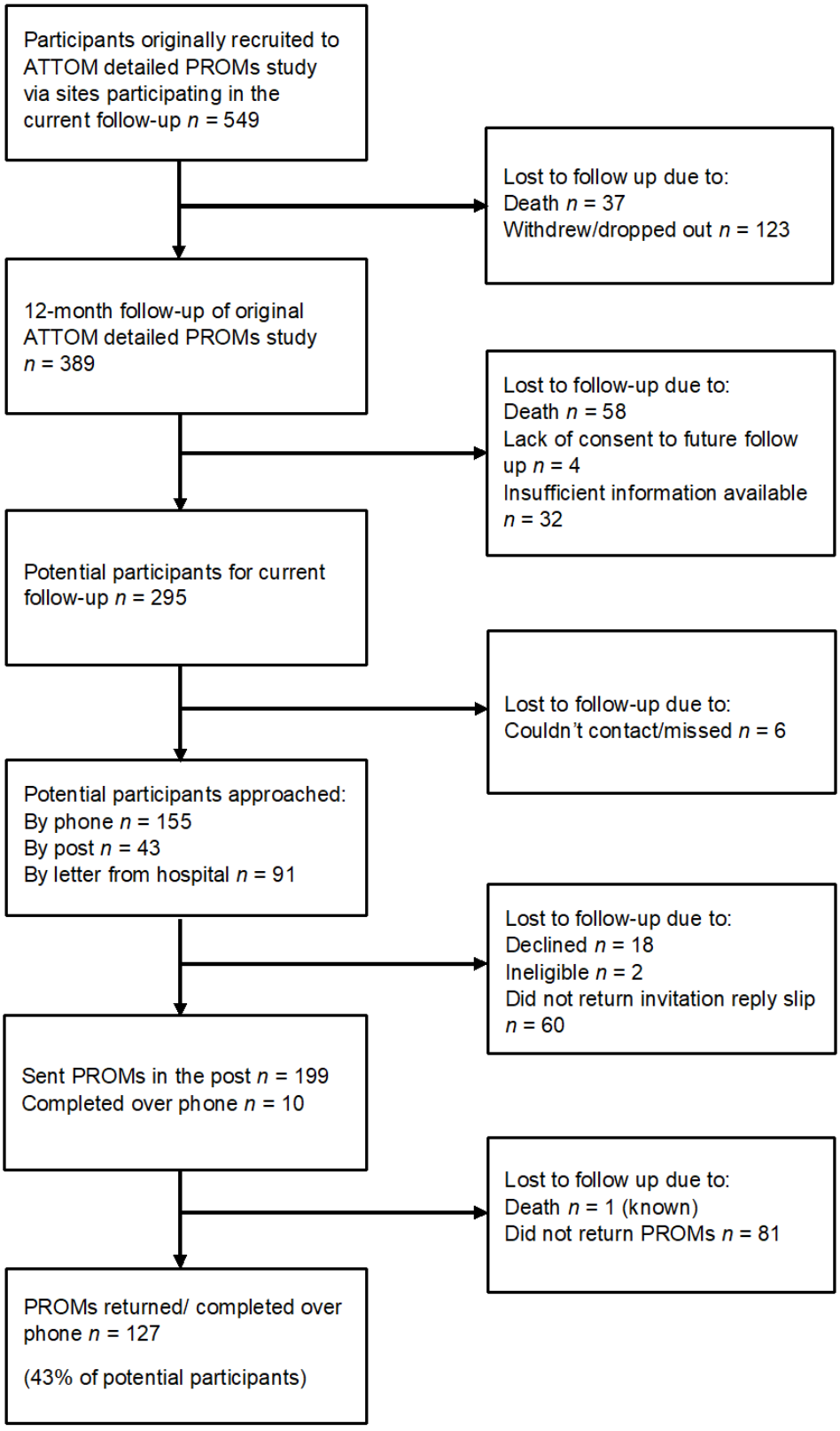

Figure 3.1. Flow diagram of recruitment to ATTOM detailed PROMs follow-up study.

Analyses. The data were analysed using IBM SPSS 21. Missing data on the PROMs questionnaires were treated according to the recommendations outlined in the guidelines for each questionnaire (see Chapter 2). Descriptive analyses were carried out to provide information on the demographics of each of the samples. As the sample of participants on HD was small and participants were in receipt of various treatments at the different time points, only descriptive analyses of follow-up demographics and PROMs data were carried out on this group; these are presented in the appendices (see Appendix MM, Table MM1). Descriptive data are provided for the RMQ and the RSSQ, which have been designed to be reported item by item. The five highest and lowest rated items on the RSSQ have been reported; additional items have been reported where there were more than one item with the same score. Data from kidney transplant recipients were used to calculate Cronbach alpha for the RDQoL, RTSQ, W-BQ12, and the three well-being subscales. The scales all showed excellent reliability scores, ranging from 0.84 to 0.94.

For each of the following analyses the distribution of the data were checked for normality by assessing the skew and kurtosis, data were considered not normal where the skew or kurtosis divided by the standard error was >1.97 (Field, 2013). Kolmogorov-Smirnov tests and histograms were also considered. Potential outliers were checked for errors but were otherwise kept in the analyses. Data from one LDKT recipient was excluded from analyses as they indicated that their transplant was not working but they were not yet on dialysis.

Comparisons of responders and non-responders. Fisher's exact tests, chi-squared tests and independent samples t-tests were carried out to compare individuals who responded to the current follow-up (responders) and those who were invited but did not take part (non-responders) on demographic and PROMs data collected during the original ATTOM study at recruitment/three-month follow-up and 12-months follow-up.

Analyses of SPKT and kidney-only transplant recipients' PROMs data over time. To investigate whether transplant recipients experienced changes in PROs over time, a series of repeated ANOVAs were carried out to compare PROMs across the three post-transplant time points from recruitment/three-month to 12-months to six/seven-years follow-up. Non-parametric Friedman's ANOVA tests were used when the data were not normally distributed. Where the repeated measures

ANOVAs returned significant results, pairwise comparison tests were used to identify differences between the three time points. Both unadjusted and Dunn-Bonferroni adjusted *p* values are reported to take into account multiple testing. The effect size *r* was calculated for each pairwise comparison for significant ANOVAs (Field, 2013), effect sizes of around .10, >.30, and >.50 were considered small, medium, and large (J. Cohen, 1988). Whilst a sufficient sample of kidney-only transplant recipients were recruited for these analyses, fewer than 28 SPKT recipients were recruited and therefore the SPKT analyses are underpowered.

Analyses of pre- to post-kidney transplant PROMs data. To compare PROMs from pre- to post-kidney transplantation, paired samples t-tests were carried out on data from the sub-sample of kidney recipients who provided pre-transplant data at recruitment/three-month follow-up during the original ATTOM study and post-transplant data at the current follow-up. Where data were not normally distributed the t-tests were bootstrapped using 1000 Bootstraps. Bias-corrected and accelerated 95% confidence intervals (BCa 95% CI) are reported. The effect size *r* was calculated for each t-test (Field, 2013). The sample size was sufficient according to the GPower calculations, which indicated that a sample of 34 participants would be needed for within-subjects t-tests.

***Comparisons of DDKT and LDKT recipients*.** T-tests, Chi-square tests, and Fisher's exact tests were carried out to compare DDKT and LDKT recipients' demographic and clinical characteristics. Independent samples t-tests were first used to compare DDKT and LDKT recipients' current follow-up PROMs scores without controlling for other variables. Next, Pearson's *r* correlations were carried out between the PROMs and potential confounding variables including age, months since transplantation, BMI, number of self-reported comorbidities, gender (male or female), ethnicity (dichotomised to white and other ethnic groups), pre-transplant treatment (pre-dialysis or dialysis), having a previous failed transplant (yes/no), marital status (having a partner or not), education (no qualifications or having qualifications) and self-reported mental health problems (yes/no). Where data were not normally distributed Kendall's tau correlations were used. ANCOVAs were conducted to compare DDKT and LDKT recipients across the PROMs whilst controlling for variables that were found to significantly correlate with the outcome variables. Where data were not normally distributed the t-tests and ANCOVAs were Bootstrapped using 1000 bootstraps; bias-corrected and accelerated 95% confidence intervals (BCa 95% CI) are reported. The effect size *r* was calculated for

each t-test (Field, 2013). Partial eta squared effect sizes have been reported for ANCOVAs. The desired sample size of 269 participants (needed for ANCOVA analyses comparing two groups with up to five covariates as calculated using GPower, see Chapter 2) was not achieved, so it is likely that the analyses are underpowered.

Comparisons of DDKT and LDKT recipients with pre- and post-transplant data. A sub-sample of kidney recipients received their transplant during the original ATTOM study or since the original study ended and provided pre-transplant data at recruitment/three-months and post-transplant data at the current follow-up. Independent samples t-tests, Chi-square tests, and Fisher's exact tests were carried out to compare the demographic and clinical characteristics of the DDKT and LDKT recipients. Independent samples t-tests were first carried out to compare the DDKT and LDKT recipients across the PROMs without controlling for other variables. Pearson's *r* and Kendall's tau correlations were carried out between the PROMs and possibly confounding variables including: age, months since transplantation, BMI, number of self-reported comorbidities, gender, ethnicity, pre-transplant treatment, having a previous failed transplant, marital status, education, and self-reported mental health problems. Variables that were significantly correlated, with a $p < .05$, were included in the relevant ANCOVAs, as well as the pre-transplant PROM score. Where data were not normally distributed the t-tests and ANCOVAs were Bootstrapped using 1000 bootstraps; bias-corrected and accelerated 95% confidence intervals (BCa 95% CI) are reported. The effect size *r* was calculated for each t-test (Field, 2013), and partial eta squared (n_p^2) effect sizes are reported for ANCOVAs.

Results

Comparisons of follow-up responders and non-responders. Follow-up responders ($n = 127$) and non-responders ($n = 160$) did not differ significantly on age at recruitment to the original ATTOM study, gender, BMI, marital status, or whether they were recruited to the original ATTOM study as a matched control, incidence dialysis patient, or transplant recipient (see Appendix MM, Table MM2). Responders and non-responders also did not differ significantly at recruitment/three-months on the EQ-VAS, EQ-5D-5L utility, W-BQ12, Renal-Dependent QoL Overview item, or RTSQs total scores (see Appendix MM, Table MM3).

However, a Fisher's Exact test indicated that responders were significantly more likely to be of white British ethnicity (92%) compared to non-responders (79%), $p = .003$. Responders were significantly more likely to have a degree or higher as their highest qualification (27%) compared to non-responders (16%), and non-responders were more likely to have GCSEs/A levels as their highest level of education (67%) compared to responders (33%), $X^2(3) = 9.99$, $p = .019$. Responders were also more likely to be in full-time employment (44%) than non-responders (24%), $p = .010$. A bootstrapped t-test indicated that responders (M = 1.09, SE = 0.10) reported better Generic QoL scores than non-responders (M = 0.81, SE = 0.11) at recruitment/three-months, $t(233) = -1.94$, $p = .048$. There was a trend for responders (M = -3.41, SE = 0.19) to report less negatively impacted RDQoL AWI scores than non-responders (M = -3.93, SE = 0.19) at recruitment/three-months, $t(232) = -1.94$, $p = .054$. It should be noted that there was considerably more missing data for non-responders (missing data on Generic QoL n = 36 and RDQoL AWI n = 36) than responders (missing data on Generic QoL n = 16 and RDQoL AWI scores n = 17).

Comparisons between responders and non-responders at 12-month follow-up during the original ATTOM study were also carried out (see Appendix MM, Table MM4). Responders reported significantly better scores than non-responders in: Generic QoL (M = 1.35, SE = 0.11 and M = 0.94, SE = 0.10), $t(283) = -2.73$, p = .006; RDQoL AWI (M = -2.63, SE = 0.18 and M = -3.44, SE = 0.18), $t(284) = -3.22$, $p = .004$; EQ-VAS health status (M = 77.12, SE = 1.52 and M = 71.75, SE = 1.62), $t(279.72) = -2.45$, $p = .019$; EQ-5D-5L utility (M = 0.84, SE = 0.02 and M = 0.75, SE = 0.02), $t(276.87) = -3.23$, $p = .003$; overall W-BQ12 (M = 25.07, SE = 0.64 and M = 22.26, SE = 0.64), $t(284) = -3.08$, $p = .003$; Positive Well-Being subscale (M = 8.34, SE = 0.25 and M = 7.08, SE = 0.23), $t(284) = -3.61$, $p = .001$; and Negative Well-Being subscale (M = 2.02, SE = 0.23 and M = 2.74, SE = 0.23), $t(281.43) = 2.26$, $p = .026$. There were no significant differences between responders and non-responders on the Energy subscale, the Renal-Dependent QoL Overview item, or RTSQs total scores.

PROs after SPKT. Table 3.1 presents the demographic characteristics of the 18 participants who reported having a working SPKT at the six/seven-year follow-up. Of the 18 SPKT recipients: 15 were recruited to the original ATTOM study as SPKT recipients; one was recruited as a matched control and received an SPKT during the original ATTOM study; and two were recruited as matched controls and

received their transplant after data collection to the original ATTOM study ended. At follow-up the average age of the SPKT recipients was 52 years, over half of the sample were women (56%) and all were of white ethnicity. Nine (50%) SPKT recipients reported having a basic education whilst eight (44%) had a higher education. The majority of the sample were married or living with a partner (78%) and were employed either part-time (28%) or full-time (44%). Three (17%) SPKT recipients reported having had a previous other transplant and most reported having a comorbid condition (61%), such as high blood pressure (44%). Eight (44%) indicated that they still check their blood glucose levels post-transplant. Two (11%) reported 'always' worrying about their blood sugar levels, whilst five (29%) 'sometimes' worried, and 10 (59%) rarely or never worried. Three recipients (17%) reported 'often' restricting their diet, whilst six (35%) 'sometimes' did, and eight (47%) 'rarely' or 'never' restricted their diet. One participant did not give a response.

Medications. One SPKT recipient did not report their anti-rejection medications. Seventeen SPKT recipients reported being prescribed the anti-rejection medication Tacrolimus, thirteen reported also taking Mycophenolic acid, three were on Azathioprine, and four were prescribed the steroid Prednisolone. Self-reported adherence, whether participants took each medication exactly as recommended, was assessed on a scale of 0 (none of the time) to 6 (all of the time). A high level of adherence was defined as a score of 5 or 6. SPKT recipients often reported a high level of adherence: Tacrolimus (65% scored 6, 29% scored 5, with 1 missing); Mycophenolic acid (54% scored 6, 46% scored 5); Azathioprine (67% scored 6, 1 missing); and Prednisolone (100% scored 6). Overall, participants also reported that it was generally not inconvenient/difficult to take their medications as recommended, which was defined as a score of 0 or 1: Tacrolimus (59% scored 0, 24% scored 1, with 1 missing); Mycophenolic acid (54% scored 0, 38% scored 1); Azathioprine (67% scored 0, with 1 missing); and Prednisolone (100% scored 0). (See Appendix MM, Table MM6 for full details.)

Table 3.1.

Demographic Characteristics of SPKT recipients at Current Follow-up

Variable	**SPKT recipients** (*n* = 18)
Age in years *M* (*SD)*	51.67 (7.72)
BMI *M* (*SD)*	25.05 (5.48)
Months since transplant *M* (*SD)**	77.06 (10.42)
Sex: male *n* (%)	8.00 (44.44)
Ethnicity: white *n* (%)	18.00 (100.00)
Marital status *n* (%)	
Married/civil partnership/ living with partner	14.00 (77.78)
Separated/divorced	2.00 (11.11)
Single	1.00 (5.56)
Widowed	1.00 (5.56)
Education *n* (%)	
No formal qualifications	1.00 (5.56)
Basic	9.00 (50.00)
Higher	8.00 (44.44)
Employment status *n* (%)	
Full-time	8.00 (44.44)
Part-time	5.00 (27.78)
Retired	1.00 (5.56)
Unemployed	4.00 (22.22)
Number of comorbidities *M* (*SD)*	1.44 (1.46)
Comorbidity *n* (%)	11.00 (61.11)
Anaemia	1.00 (5.56)
High blood pressure	8.00 (4.44)
Joint problems	2.00 (11.11)
Lung problems	1.00 (5.56)
Stroke	1.00 (5.56)
Circulatory problems	4.00 (22.22)
Memory problems	1.00 (5.56)
Mental health problems	3.00 (16.67)
Chronic viral infection	0.00
Cancer	0.00
Liver disease	0.00
Heart problems	0.00
Other	5.00 (27.78)
Still monitors blood sugar levels *n* (%)**	8.00 (47.06)
Previous other transplant *n* (%)	3.00 (16.67)

Variable	**SPKT recipients** (*n* = 18)
Registered as disabled *n* (%)	6.00 (33.33)
Registered as visually impaired *n* (%)	3.00 (16.67)

Note. M: mean; *SD*: standard deviation; BMI: body mass index.
*Fifteen participants recruited to original ATTOM study as SPKT recipients and three received the transplant since. **Missing data for one participant.

Renal service satisfaction. One SPKT recipient did not complete the RSSQ (*n* = 17), and two participants indicated that most or all items were not applicable. Overall, SPKT recipients reported the highest satisfaction scores for: 'the treatment for your renal condition (including medication, dialysis or transplant and any diet/fluid recommendations)' (*M* = 1.87, *SD* = 0.35); 'care taken by staff over hygiene (e.g. washing hands before examining patients)' (*M* = 1.80, *SD* = 0.41); 'surgical procedures (e.g. catheter insertion, fistula or transplant)' (*M* = 1.79, *SD* = 0.43); 'privacy' (*M* = 1.69, *SD* = 0.70); 'ease in making or changing appointments' (*M* = 1.67, *SD* = 0.49); and 'discussing with staff any problems you may have' (*M* = 1.67, *SD* = 0.49). Overall, the lowest rated item was 'social worker advice and support' (*M* = 0.00, *SD* = 1.22); although twelve participants indicated that this item was not applicable, two (40%) reported being slightly dissatisfied/dissatisfied. Other lowest-rated items included: 'psychological advice and support' (*M* = 0.18, *SD* = 1.40); 'ease of getting to the hospital (including public transport and/or parking)' (*M* = 0.27, *SD* = 1.33); 'time spent waiting at the renal clinic/unit' (*M* = 0.33, *SD* = 1.05); and 'availability of resources (including preferred treatment, beds etc.)' (*M* = 0.54, *SD* = 0.97). Five participants (33%) indicated being slightly dissatisfied/dissatisfied with 'ease of getting to the hospital/unit' and 'time spent waiting'. Four (36%) were slightly dissatisfied/dissatisfied with 'psychological advice and support' (see Appendix MM, Table MM7 for details of highest and lowest rated items).

PROs after SPKT from recruitment/three-months to 12-months and six/seven-years follow-up. PROMs data for 15 participants who were recruited to the original ATTOM study as SPKT recipients and still had both working grafts at the current follow-up were compared across the three time points from recruitment/three-months to 12-months post-SPKT and approximately six/seven-years follow-up. Table 3.2 presents the results of the repeated ANOVAs. Results of the pairwise comparisons, including effect sizes (*r*), are reported in the text. Due to missing data at various time points, the sample size ranges from 11 to 13 across the PROMs. In the analyses of RDQoL AWI, ADDQoL AWI, and EQ-5D-5L utility scores

the assumption of sphericity was found to have been violated and therefore Greenhouse-Geisser corrected tests are reported.

Quality of life. Non-parametric Friedman's repeated-measures ANOVA tests indicated that Generic QoL and the Renal-Dependent QoL Overview item scores did not differ significantly across the three time points. There were also no significant differences in the RDQoL AWI and ADDQoL AWI scores across the three time points. Overall, the results suggest that generic QoL, renal-dependent QoL, and diabetes-dependent QoL remained stable from three-months post-SPKT to six/seven-years follow-up.

Treatment satisfaction. RTSQs total scores did not change significantly over time. However, the Friedman's ANOVA indicated that DTSQs total scores did differ significantly over time. Pairwise comparisons indicated that DTSQs total scores improved from three-months to 12-months follow-up; however, after Dunn-Bonferroni adjustment for multiple testing the difference was not statistically significant, z = -2.13, p = .033, (adjusted p = .099), r =-.45. DTSQs total scores did not change significantly from 12-months to six/seven-years follow-up, z = 1.07, p = .286 (adjusted p = .859), r = .27, or overall, when comparing three-months to six/seven-years follow-up, z = -1.07, p = .286 (adjusted p = .859), r = -.27. At 12-months post-SPKT the mean DTSQs total score had reached its maximum (36) and this remained stable up to the six/seven-year follow-up.

Health status. There was a significant change in the EQ-VAS scores over time. Pairwise comparisons showed that there was an improvement in EQ-VAS scores from recruitment to 12-months follow-up with a large effect, z = -3.16, p = .002 (adjusted p = .006), r = -.65. The difference between EQ-VAS scores at 12-months and six/seven-years post-SPKT follow-up was not significant, z = 1.74, p = .083 (adjusted p = .248), r = .35. Although the EQ-VAS scores at six/seven-years follow-up were higher than at recruitment shortly after transplantation the scores did not differ significantly, z = -1.43, p = .153 (adjusted p = .459), r = -.29. The results suggest that health status improved from recruitment to the original ATTOM study to 12-months post-transplant and remained stable up to the six/seven-year follow-up. In contrast, the EQ-5D-5L utility scores did not differ significantly across the three time points.

Well-being. Overall W-BQ12 scores, Positive Well-Being, Negative Well-Being and the Energy sub-scale scores did not significantly differ across the three time points, suggesting that well-being remained stable over time.

Table 3.2.

ANOVA and Friedman's Repeated Measures ANOVA Comparisons of PROs from Recruitment/three-months to 12-months and Approximately Six/Seven-Years Post-SPKT Follow-up

Measure	**Recruitment/ 3-month follow-up**		**12-month follow-up**		**6/7-year follow-up**				
	M (SE)	**Range**	***M (SE)***	**Range**	***M (SE)***	**Range**	***F***	***df***	***p***
Renal-Dependent QoL Overview (*n* = 12)	-1.67 (0.19)	-3.00, -1.00	-1.33 (0.31)	-3.00, 0.00	-1.67 (0.33)	-3.00, 0.00	0.71	1.28, 14.02	.447
RDQoL AWI (*n* = 12)	-3.03 (0.59)	-5.88, -0.41	-2.56 (0.48)	-4.59, -0.12	-2.98 (0.87)	-8.47, 0.12	0.42	1.29, 14.20	.581
EQ-5D-5L Utility (*n* = 13)	0.71 (0.07)	0.18, 0.95	0.79 (0.07)	0.11, 1.00	0.72 (0.10)	-0.17, 1.00	1.73	2.00, 24.00	.198
	Mdn (IQR)	**Range**	***Mdn (IQR)***	**Range**	***Mdn (IQR)***	**Range**	X_F^2	***df***	***p***
Generic QoL	1.00 (1.00)	0.00, 3.00	1.00 (1.50)	-3.00, 3.00	2.00 (2.50)	-2.00, 3.00	3.94	2.00	.140
ADDQoL AWI (*n* = 12)	-2.63 (2.09)	-7.00, -1.21	-3.95 (3.12)	-8.37, -1.05	-2.89 (4.64)	-7.71, -0.89	0.50	2.00	.779
RTSQs total (*n* = 12)	67.00 (7.50)	55.00, 77.00	69.50 (10.25)	56.00, 76.00	72.00 (9.00)	54.00, 78.00	5.17	2.00	.076
DTSQs total (*n* = 11)	33.00 (3.00)	28.00, 36.00	36.00 (1.00)	35.00, 36.00	36.00 (5.00)	28.00, 36.00	6.35	2.00	**.044**
EQ-VAS[a] (*n* = 12)	63.50 (28.75)	10.00, 85.00	86.00 (23.75)	30.00, 100.00	80.00 (59.00)	20.00, 100.00	10.71	2.00	**.005**

	Recruitment/ 3-month follow-up		12-month follow-up		6/7-year follow-up				
Measure	***Mdn (IQR)***	**Range**	***Mdn (IQR)***	**Range**	***Mdn (IQR)***	**Range**	X_F^2	***df***	***p***
W-BQ12 (*n* = 13)	22.00 (13.50)	8.00, 32.00	26.00 (8.00)	5.00, 35.00	26.00 (12.50)	10.00, 36.00	2.04	2.00	.360
Positive W-B (*n* = 13)	7.00 (7.00)	0.00, 12.00	9.00 (5.00)	4.00, 12.00	8.00 (5.50)	4.00, 12.00	2.98	2.00	.226
Negative W-B (*n* = 13)	1.00 (2.50)	0.00, 7.00	2.00 (3.00)	0.00, 10.00	1.00 (4.00)	0.00, 8.00	1.85	2.00	.396
Energy (*n* = 13)	6.00 (6.50)	0.00, 10.00	7.00 (4.00)	0.00, 12.00	6.00 (6.00)	0.00, 12.00	1.76	2.00	.414

Note. M: mean; *SE*: standard error; *Mdn:* median; *IQR:* interquartile range; ADDQoL AWI: Audit of Diabetes Dependent Quality of Life average weighted impact score (-9- +3, indicates maximum negative impact/importance to maximum positive impact/importance); DTSQs: Diabetes Treatment Satisfaction Questionnaire status version (0-36, higher scores indicate better satisfaction); Energy: Energy subscale of W-BQ12 (0-12, higher scores indicate better energy); EQ-5D-5L utility: EuroQoL-5 Dimension-5 Level utility score (-0.28- +1, state worse than death to optimal health state); EQ-VAS: EuroQol Visual Analogue Scale of perceived health status (0-100, higher scores indicate better perceived health); Generic QoL: Generic Quality of Life (-3- +3, indicates extremely bad to excellent quality of life); Negative W-B: Negative Well-Being subscale of W-BQ12 (0-12, higher scores indicate worse negative well-being); Positive W-B: Positive Well-Being subscale of W-BQ12 (0-12, higher scores indicate better positive well-being); RDQoL AWI: Renal Dependent Quality of Life average weighted impact score (-9- +3, indicates maximum negative impact/importance to maximum positive impact/importance); Renal-Dependent QoL Overview: overview item of impact of the renal condition on quality of life (-3- +1, indicates maximum negative impact to positive impact); RTSQs: Renal Treatment Satisfaction Questionnaire status version (0-78, higher scores indicate better satisfaction); W-BQ12: Well-Being Questionnaire 12-item version (0-36, higher scores indicate better general well-being).

[a] indicates significant differences between scores at recruitment/3-months and 12-months follow-up after Dunn-Bonferroni correction, $p < .05$.

PROs after kidney transplantation. Table 3.3 presents the demographic characteristics of the kidney-only transplant recipients with working transplants. Of the 90 kidney-only transplant recipients: 47 (22 DDKT and 25 LDKT) were recruited to the original ATTOM study as transplant recipients; 17 (9 DDKT and 8 LDKT) were recruited as matched controls/incident dialysis patients and received a transplant during the original ATTOM study and so provided pre- and post-transplant PROMs data. Twenty-two (15 DDKT and 7 LDKT) were recruited as matched controls/incident dialysis and received their transplant after the original ATTOM study ended; and four received a transplant during the original ATTOM study and received another transplant since as the previous graft failed.

The kidney transplant recipients included 53 men and 37 women with a mean age of 56 years (*SD* = 11.93). The average length of time since transplantation was 68 months (approximately 5.5 years), ranging from 14.50 to 95 months. The majority of participants were of white ethnicity (92%), had higher level qualifications (51%), and were in full-time (42%) or part-time (16%) employment, or retired (34%). Seventy-four participants reported having some other comorbid condition such as high blood pressure (58%), diabetes (24%), mental health problems (13%), or 'other' conditions (25%). Other conditions included lymphedema, Crohn's disease, glaucoma, epilepsy, hernia, back pain, and skin problems.

Medications. There were missing RMQ data for five participants, and one participant indicated that they were on Prednisolone but gave no further details. Seventy-seven kidney transplant recipients reported taking Tacrolimus, 50 reported taking Mycophenolic acid, 11 were on Azathioprine, four were on Sirolimus, and two were on Cyclosporine. Fifty-one also reported taking the steroid Prednisolone. Kidney recipients often reported a high level of adherence to their anti-rejection medications, defined as scores of 6 or 5: Tacrolimus (70% scored 6, 23% scored 5, with 4 missing); Mycophenolic acid (70% scored 6, 30% scored 5); Azathioprine (45% scored 6, 45% scored 5, with 1 missing); Sirolimus (75% scored 6, 25% scored 5); Cyclosporine (50% scored 6, 50% scored 5), Prednisolone (74% scored 6, 14% scored 5, with 6 missing). Participants also indicated that it was generally not inconvenient/difficult to take their medications as recommended, defined as scores of 0 or 1: Tacrolimus (56% scored 0, 13% scored 1, with 4 missing); Mycophenolic acid (64% scored 0, 12% scored 1); Azathioprine (55% scored 0, 9% scored 1); Sirolimus (50% scored 0, 25% scored 1); Cyclosporine (50% scored 1), Prednisolone (69%

scored 0, 8% scored 1, with 6 missing). (See Appendix MM, Table MM8 for more details.)

Renal service satisfaction. Eighty-six kidney transplant recipients completed the RSSQ. Overall, the best rated renal service satisfaction item was 'how you are treated as a person by the staff' (*M* = 1.79, *SD* = 0.49). Other highly rated items included: 'information given to you by the staff regarding your results' (*M* = 1.77, *SD* = 0.42), 'the extent to which staff are caring and supportive' (*M* = 1.69, *SD* = 0.47), 'the treatment for your renal condition (including medication, dialysis or transplant and any diet/fluid recommendations) (*M* = 1.67, *SD* = 0.58), and 'the value to you in talking to staff' (*M* = 1.63, *SD* = 0.60). Overall, 'social worker advice and support' was the worst rated of the RSSQ items (*M* = 0.31, *SD* = 1.02) and eight participants indicated they were slightly dissatisfied/dissatisfied; however, 41 participants indicated that this item was not applicable. Other items given a low rating include: 'ease of getting to the hospital/unit (including public transport and/or parking)' (*M* = 0.55, *SD* = 1.27), 'psychological advice and support' (*M* = 0.69, *SD* = 1.08), 'information about and opportunities to use new developments' (*M* = 0.83, *SD* = 0.90), and 'time spent waiting at the renal clinic/unit' (*M* = 0.86, *SD* = 1.26). Whilst some participants indicated these items were not applicable, twenty-one (25%) were slightly dissatisfied/dissatisfied with the 'ease of getting to the renal unit/clinic, and 15 (18%) and nine (13%) were slightly dissatisfied/dissatisfied with 'time spent waiting' and 'psychological advice and support', respectively. (See Appendix MM, Table MM9 for more details.)

Table 3.3.

Demographic Characteristics of Kidney Transplant Recipients at Current Follow-up and Comparisons of LDKT and DDKT Recipients

Variable	**All kidney-only** (*n* = 90)	**DDKT** (*n* = 48)	**LDKT** (*n* = 42)	***p***
Age in years *M* (*SD)*	56.11 (11.93)	58.92 (11.04)	52.90 (12.24)	**.016**
BMI *M* (*SD)**	26.86 (4.59)	27.18 (3.89)	26.50 (5.31)	.514
Months since transplant *M* (*SD)*	67.58 (21.40)	63.94 (22.50)	71.75 (19.49)	.081
Sex: male *n* (%)	53.00 (58.89)	31.00 (64.58)	22.00 (52.38)	.240
Ethnicity: white *n* (%)	83.00 (92.22)	41.00 (85.42)	42.00 (100.00)	**.013**
Marital status *n* (%)				.179
Married/civil partnership/ living with partner	60.00 (66.67)	27.00 (56.25)	33.00 (78.57)	
Separated/divorced	13.00 (14.44)	9.00 (18.75)	4.00 (9.52)	
Single	12.00 (13.13)	8. 00 (16.67)	4.00 (9.52)	
Widowed	5.00 (5.56)	4.00 (8.33)	1.00 (2.38)	
Education *n* (%)				.077
No formal qualifications	11.00 (12.22)	9.00 (18.75)	2.00 (4.76)	
Basic	30.00 (33.33)	13.00 (27.08)	17.00 (40.48)	
Higher	46.00 (51.11)	23.00 (47.92)	23.00 (54.76)	
Other	1.00 (1.11)	1.00 (2.08)	0.00 (0.00)	
Missing	2.00 (2.22)	2.00 (4.17)	0.00 (0.00)	
Employment status *n* (%)				**.029**
Full-time	38.00 (42.22)	15.00 (31.25)	23.00 (54.76)	
Part-time	14.00 (15.56)	6.00 (12.50)	8.00 (19.05)	
Retired	31.00 (34.44)	21.00 (43.75)	10.00 (23.81)	
Unemployed	7.00 (7.78)	6.00 (12.50)	1.00 (2.38)	
Number of comorbidities *M* (*SD)*	2.15 (1.77)	2.11(1.57)	2.19 (1.98)	.830
Comorbidity *n* (%)**	76.00 (86.36)	41.00 (85.42)	36.0 (85.71)	.636
Diabetes	22.00 (24.44)	13.00 (27.08)	9.00 (21.43)	.533
Anaemia	11.00 (12.22)	4.00 (8.33)	7.00 (16.67)	.339
High blood pressure	52.00 (57.78)	31.00 (64.58)	21.00 (50.00)	.125
Liver disease	3.00 (3.33)	2.00 (4.17)	1.00 (2.38)	1.000
Joint problems	15.00 (16.67)	6.00 (12.50)	9.00 (21.43)	.296
Lung problems	6.00 (6.67)	1.00 (2.08)	5.00 (11.90)	.099
Cancer	7.00 (7.78)	4.00 (8.33)	3.00 (7.14)	1.000
Stroke	5.00 (5.56)	1.00 (2.08)	4.00 (9.52)	.188

Variable	All kidney-only	DDKT	LDKT	*p*
Heart problems	15.00 (16.67)	10.00 (20.83)	5.00 (11.62)	.238
Circulatory problems	8.00 (8.89)	5.00 (10.42)	3.00 (7.14)	.717
Memory problems	4.00 (4.44)	2.00 (4.17)	2.00 (4.76)	1.000
Chronic viral infection	3.00 (3.33)	2.00 (4.17)	1.00 (2.38)	1.000
Mental health problems	12.00 (13.33)	7.00 (14.58)	5.00 (11.90)	.680
Other	23.00 (25.26)	10.00 (20.83)	13.00 (30.95)	.331
Transplant pre-dialysis *n (%)*	19.00 (21.35)	7 (15.22)	12.00 (28.57)	.092
Previous failed transplant *n (%)*	20.00 (20.22)	9.00 (18.75)	11.00 (26.19)	.397
Registered as disabled *n (%)*	18.00 (20.00)	11.00 (22.92)	7.00 (16.67)	.460
Registered as visually impaired *n (%)*	2.00 (2.25)	0.00 (0.00)	2.00 (4.76)	.220

Note. M: mean; *SD*: standard deviation; LDKT: living-donor kidney transplant; DDKT: deceased-donor kidney transplant; BMI: body mass index.
*Missing data for four participants. **Missing data for two participants.

PROs after kidney transplantation from recruitment/three-months to 12-months and six/seven-years follow-up. Forty-seven participants were recruited to the original ATTOM study shortly after receiving a kidney transplant and indicated that they still had the working kidney transplant at the current follow-up. This included 27 men and 20 women with an average age of 56 years (*SD* = 12.57); the mean time since transplantation was 82 months (*SD* = 5.34, *range* = 73.00-95.00). The majority were white (94%) and had either basic (45%) or higher-level education (43%). Sixteen (34%) were transplanted prior to having started dialysis and four (8.5%) had a previous failed transplant.

The PROMs data were not normally distributed, so non-parametric Friedman's ANOVAs were carried out to investigate whether PROMs scores changed over the three time points. Due to substantial missing data the sample size varied from 39 to 44 across the PROMs analyses. Table 3.4 presents the results of the ANOVAs. Details of pairwise comparisons, including effect sizes (*r*), are given in the text.

Quality of life. The Friedman's ANOVA indicated that the Generic QoL scores differed significantly across the three time points. Pairwise comparisons indicated that whilst Generic QoL scores improved from three-months to 12-month follow-up, this was not statistically significant when adjusted for multiple testing, $z = -2.04$, $p = .041$ (adjusted $p = .123$), $r = -.23$. Generic QoL scores remained

stable from 12-months to six/seven-years follow-up, z = 1.27, p = .204 (adjusted p = .612), r = .14. Overall, the Generic QoL scores were not significantly different at the six/seven-year follow-up compared to three-months post-transplant, z = -0.77, p = .440 (adjusted p = 1.00), r = -.09.

A Friedman's ANOVA indicated that the Renal-Dependent QoL Overview item scores significantly changed over time. Pairwise comparison tests indicated that scores at three-months post-transplant did not differ significantly from those at 12-month follow-up after adjustment for multiple testing, z = -2.24, p = .025 (adjusted p = .076), r = -.25, or between 12-month and six/seven-years follow-up, z = 0.28, p = .780 (adjusted p = 1.00), r = .03. Overall, the Renal-Dependent QoL Overview item scores were better at six/seven-years follow-up compared to three-months post-transplant, however this was not statistically significant after adjustment for multiple testing, z = -1.96, p = .050 (adjusted p = .151), r = -.22. RDQoL AWI scores significantly improved from three-months to 12-month follow-up with a medium effect, z = -3.23, p = .001 (adjusted p = .004), r = -.37, and then remained stable up to six/seven-years follow-up, z = -1.02, p = .308 (adjusted p = .925), r = -.12. Overall, the RDQoL AWI scores were significantly better at the six/seven-years follow-up than three-months follow-up, indicating that QoL was less negatively impacted by the renal condition with a medium/large effect, z = -4.25, p < .001, r = -.48.

Renal treatment satisfaction. The RTSQs total scores were found to have changed over time. RTSQs scores at 12-month follow-up were better than at three-months but after adjustment for multiple testing the scores were not significantly different, z = -2.26, p = .024 (adjusted p = .071), r = -.25. Similarly, scores were better at six/seven-years follow-up compared to 12-month follow-up, but this was not significant after Dunn-Bonferroni adjustment, z = -2.26, p = 0.024 (adjusted p = 0.071), r = -.25. Overall, RTSQs total scores were significantly better at six/seven-years follow-up compared to three-months post-transplant, z = -4.53, p < .001, r = -.50.

Health status. The EQ-VAS health status scores changed significantly over time. EQ-VAS scores improved from recruitment to 12-month follow-up with a medium/large effect, z = -4.64, p < .001, r = -.49, and remained stable at six/seven-years follow-up when multiple testing was taken into account, z = 2.08, p = .038 (adjusted p =.113), r = .22. Overall, EQ-VAS scores were significantly better at

six/seven-years follow-up compared to recruitment with a small/medium effect, z = -2.56, p = .011 (adjusted p = .032), r = -.27. The EQ-5D-5L health utility scores also improved significantly from recruitment to 12-month follow-up with a medium effect, z = -3.78, p < .001, r = -.40, and then remained stable up to six/seven-years follow-up, z = 0.37, p = .709 (adjusted p = 1.00), r = .04. Overall, the utility scores were significantly better at six/seven-years follow-up compared to recruitment with a medium effect, z = -3.41, p = .001 (adjusted p = .002), r = -.36.

Well-being. There were no significant differences in W-BQ12 overall scores over the three time points, or on the Positive Well-Being, Negative Well-Being and Energy subscales. These results indicate that well-being remained stable over time.

Table 3.4.

Non-parametric Friedman's Repeated Measures ANOVA Comparisons of PROs from Recruitment/three-months to 12-months and six/seven-years Post-Kidney Transplant Follow-up

Measures	**Recruitment/ 3-month follow-up**		**12-month follow-up**		**6/7-year follow-up**				
	Mdn (IQR)	**Range**	***Mdn (IQR)***	**Range**	***Mdn (IQR)***	**Range**	X^2_F	***df***	***p***
Generic QoL (*n* = 41)	1.00 (1.00)	-1.00, 3.00	2.00 (1.00)	-1.00, 3.00	2.00 (1.00)	-1.00, 3.00	7.12	2	**.028**
Renal-Dependent QoL Overview (*n* = 40)	-2.00 (1.75)	-3.00, 1.00	-1.00 (1.00)	-3.00, 1.00	-1.00 (1.75)	-3.00, 1.00	9.14	2	**.010**
RDQoL AWI[a,b] (*n* = 39)	-3.50 (3.12)	-8.07, 0.06	-1.94 (3.53)	-7.12, -0.06	-1.63 (2.78)	-5.41, 0.00	20.17	2	**.000**
RTSQs total[b] (*n* = 41)	68.00 (9.84)	31.00, 77.00	70.00 (10.00)	55.00, 78.00	73.00 (10.00)	49.00, 78.00	22.72	2	**.000**
EQ-VAS[a,b] (*n* = 44)	70.00 (25.00)	30.00, 100.00	85.00 (15.00)	30.00, 100.00	80.00 (20.00)	50.00, 100.00	25.49	2	**.000**
EQ-5D-5L Utility[a,b] (*n* = 44)	0.88 (0.21)	0.08, 1.00	0.92 (0.17)	0.40, 1.00	0.93 (0.18)	0.19, 1.00	20.38	2	**.000**
W-BQ12 (*n* = 44)	25.50 (9.50)	7.00, 36.00	27.50 (8.38)	11.00, 36.00	25.00 (9.50)	13.00, 36.00	2.00	2	.368
Positive W-B (*n* = 45)	9.00 (4.00)	0.00, 12.00	9.00 (3.50)	2.00, 12.00	8.00 (4.00)	0.00, 12.00	0.78	2	.677

	Recruitment/ 3-month follow-up		12-month follow-up		6/7-year follow-up				
Measures	***Mdn (IQR)***	**Range**	***Mdn (IQR)***	**Range**	***Mdn (IQR)***	**Range**	X^2_F	***df***	***p***
Negative W-B (*n* = 44)	1.00 (3.00)	0.00, 8.00	1.00 (2.00)	0.00, 7.00	1.00 (2.00)	0.00, 8.00	1.06	2	.588
Energy (*n* = 44)	6.50 (4.75)	0.00, 12.00	8.00 (3.00)	1.00, 12.00	6.00 (4.75)	0.00, 12.00	3.74	2	.154

Note. M: mean; *SE*: standard error; *Mdn:* median; *IQR:* interquartile range; Energy: Energy subscale of W-BQ12; EQ-5D-5L utility: EuroQoL-5 Dimension-5 Level utility score; EQ-VAS: EuroQol Visual Analogue Scale of perceived health status; Generic QoL: Generic Quality of Life; Negative W-B: Negative Well-Being subscale of W-BQ12; Positive W-B: Positive Well-Being subscale of W-BQ12; RDQoL AWI: Renal Dependent Quality of Life average weighted impact score; Renal-Dependent QoL Overview: overview item of impact of the renal condition on quality of life; RTSQs: Renal Treatment Satisfaction Questionnaire status version; W-BQ12: Well-Being Questionnaire 12-item version.

[a] indicates significant differences between scores at recruitment/three-months and 12-month follow-up after Dunn-Bonferroni corrections, $p < .05$.

[b] indicates significant differences between scores at recruitment/three-months and 6/7-year follow-up after Dunn-Bonferroni corrections, $p < .05$.

Comparisons of PROs from pre- to post-kidney transplantation. Thirty-nine participants received their kidney transplant since recruitment to the original ATTOM study and provided pre-transplant data at recruitment/three-month follow-up and post-transplant data at the current follow-up. This sub-group of patients had their kidney transplants for a mean of 55 months (*SD* = 20.28), ranging from 17 to 92 months. The mean age was 58 years (*SD* = 10.59) and included 23 men and 15 women. Twelve participants had a previous failed transplant and three had received their transplant pre-emptively (see Appendix MM, Table MM5).

Table 3.5 presents the results of the analyses comparing pre- to post-transplant PROs. Due to missing data at the two time points the sample size ranges from 34 to 38 across the PROMs. Significant results were found indicating that the Renal-Dependent QoL Overview item and the RDQoL AWI scores improved from pre- to post-transplantation with a medium effect size, $t(33) = -2.28$, $p = .036$, $r = .37$, and $t(33) = -2.84$, $p = .015$, $r = .44$, respectively. The results indicate that participants' quality of life was less negatively impacted by their renal condition post-transplant compared to pre-transplant. Furthermore, RTSQs total scores improved significantly from pre- to post-transplantation with a large effect, $t(32) = -5.71$, $p < .001$, $r = .71$. There were no significant differences from pre- to post-transplantation on Generic QoL, EQ-VAS health status, EQ-5D-5L utility, overall W-BQ12, Positive Well-Being, Negative Well-Being, and Energy subscale scores. These results suggest that health status and well-being remained stable from pre- to post-transplantation.

Table 3.5.

*Repeated Measures t-test and Bootstrapped t-test Comparisons of PROs from Pre- and Post-Kidney Transplant**

Measures	**Pre-transplant**	**Post-transplant**					
	M (SE)	***M (SE)***	***Mean difference (95% CI)***	***t***	***df***	***p***	***r***
Generic QoL (*n* = 34)	0.74 (0.20)	0.97 (0.17)	-0.24 (-0.68, 0.21)	-1.07	33	.292	.18
RTSQs total (*n* = 33)	55.19 (2.52)	68.95 (1.43)	-13.76 (-18.67, -8.85)	-5.71	32	**<.001**	**.71**
EQ-VAS (*n* = 38)	65.13 (3.11)	70.84 (3.27)	-5.71 (-13.82, 2.39)	-1.43	37	.162	.23
W-BQ12 (*n* = 38)	22.45 (0.99)	22.21 (1.01)	0.24 (-1.76, 2.23)	0.24	37	.811	.04
Negative W-B (*n* = 38)	2.21 (0.40)	2.13 (0.37)	0.08 (-0.72, 0.88)	0.20	37	.843	.03
Energy (*n* = 38)	5.32 (0.40)	5.55 (0.48)	-0.24 (-1.11, 0.89)	-0.48	37	.635	.08
	M (SE)	***M (SE)***	***Mean difference (95% BCa CI)***	***t***	***df***	***p***	***r***
Renal-Dependent QoL Overview (*n* = 34)	-2.21 (0.17)	-1.79 (0.22)	-0.41 (-0.85, -0.06)	-2.28	33	**.036**	**.37**
RDQoL AWI (*n* = 34)	-3.55 (0.39)	-2.60 (0.36)	-0.95 (-1.66, -0.33)	-2.84	33	**.015**	**.44**
EQ-5D-5L Utility (*n* = 36)	0.82 (0.04)	0.78 (0.04)	0.04 (-0.02, 0.10)	1.36	35	.182	.22
Positive W-B (*n* = 38)	7.34 (0.41)	6.79 (0.52)	0.55 (-0.51, 1.64)	0.95	37	.340	.15

Note. M: mean; *SE*: standard error; 95% CI: 95% confidence intervals; BCa 95% CI: Bias-corrected and accelerated 95% confidence intervals; *r*: effect size; Energy: Energy subscale of W-BQ12; EQ-5D-5L utility: EuroQoL-5 Dimension-5 Level utility score; EQ-VAS: EuroQol Visual Analogue Scale of perceived health status; Generic QoL: Generic Quality of Life; Negative W-B: Negative Well-Being subscale of W-BQ12; Positive W-B: Positive Well-Being subscale of W-BQ12; RDQoL AWI: Renal Dependent Quality of Life average weighted impact score; Renal-Dependent QoL Overview: overview item of impact of the renal condition on quality of life; RTSQs: Renal Treatment Satisfaction Questionnaire status version; W-BQ12: Well-Being Questionnaire 12-item version.
*Mean of 55 months post-transplant (*range* = 17-92 months).

Comparisons of LDKT and DDKT recipients' PROs at the current follow-up. Table 3.3 presents the demographic characteristics for LDKT and DDKT recipients (n = 90). When comparing the two groups at follow-up, LDKT recipients were found to be significantly younger (M = 52.90, SD = 12.24) than DDKT recipients (M = 58.92, SD = 11.04), $t(88) = 2.45$, $p = .016$. A Fisher's exact test indicated that significantly more DDKT recipients were from an ethnic minority group (15%) compared to LDKT recipients (all white), $p = .013$. There was no significant difference between the two groups on overall marital status; however, when this variable was converted into a dichotomous variable of those with and without a partner the Chi-squared test indicated that significantly more LDKT recipients had a partner (79%) compared to DDKT recipients (56%), $\chi^2(1) = 5.02$, $p = .025$. A Fisher's exact test indicated that more LDKT recipients were in full-time employment (55%) than DDKT recipients (31%), and more DDKT recipients were retired (44%) than LDKT recipients (24%), $p = .029$. There was a trend indicating that more LDKT recipients had received a pre-emptive transplant compared to DDKT recipients, $\chi^2(1) = 2.84$, $p = .092$, and LDKT recipients had their transplants for longer than DDKT recipients, $t(88) = -1.81$, $p = .081$. No significant differences were found between DDKT and LDKT recipients on gender, educational level, BMI, having a previous failed transplant, being registered as visually impaired, or registered as disabled.

Independent samples t-tests were carried out to compare DDKT and LDKT recipients' PROs at the current follow-up. Table 3.6 shows the results of the t-tests and raw mean scores; there were no significant differences between DDKT and LDKT recipients on any outcomes. There was a non-significant trend towards LDKT recipients reporting less negatively impacted renal-dependent QoL (M = -1.75, SE = 0.27) compared to DDKT recipients (M = -2.46, SE = 0.27), $t(86) = -1.76$, $p = .076$, r = 0.19. The mean difference between DDKT and LDKT recipients' RDQoL AWI scores was -0.70, BCa 95% CI [-1.40, 0.06]. These t-tests do not control for other variables or pre-transplant outcomes.

Table 3.6.

*T-test and Bootstrapped t-test Comparisons of DDKT and LDKT Recipients' PROs at Follow-up**

Measures	**DDKT**	**LDKT**					
	M (SE)	***M (SE)***	**Mean difference (95% CI)**	***t***	***df***	***p***	***r***
Generic QoL (*n* = 89)	1.26 (0.15)	1.43 (0.14)	-0.17 (-0.58, 0.23)	-0.84	87	.401	.09
W-BQ12 (*n* = 88)	23.62 (0.99)	23.73 (0.94)	-1.11 (-2.84, 2.63)	-0.08	86	.938	.01
Positive W-B (*n* = 89)	7.34 (0.47)	7.73 (0.40)	-0.39 (-1.63, 0.85)	-0.62	87	.538	.07
Energy (*n* = 88)	6.16 (0.46)	6.19 (0.42)	-0.03 (-1.28, 1.22)	-0.04	86	.965	.00
	M (SE)	***M (SE)***	**Mean difference (95% BCa CI)**	***t***	***df***	***p***	***r***
Renal-Dependent QoL Overview (*n* = 88)	-1.61 (0.17)	-1.40 (0.21)	-0.20 (-0.76, 0.32)	-0.76	86	.434	.08
RDQoL AWI (*n* = 88)	-2.46 (0.28)	-1.75 (0.27)	-0.70 (-1.40, 0.06)	-1.76	86	.076	.03
RTSQs total (*n* = 88)	69.49 (1.09)	71.05 (1.24)	-1.56 (-4.71, 1.94)	-0.94	86	.354	.10
EQ-VAS (*n* = 87)	73.30 (2.50)	77.46 (2.53)	-4.16 (-11.58, 2.97)	-1.15	85	.247	.12
EQ-5D-5L Utility (*n* = 86)	0.81 (0.03)	0.86 (0.03)	-0.05 (-0.14, 0.04)	-1.10	84	.295	.12
Negative W-B (*n* = 88)	1.83 (0.32)	2.19 (0.36)	-0.36 (-1.25, 0.45)	-0.77	86	.455	.08

Note. M: mean; *SE*: standard error; 95% CI: 95% confidence intervals; BCa 95% CI: Bias-corrected and accelerated 95% confidence intervals; DDKT: deceased-donor kidney transplant; LDKT: living-donor kidney transplant; Energy: Energy subscale of W-BQ12; EQ-5D-5L utility: EuroQoL-5 Dimension-5 Level utility score; EQ-VAS: EuroQol Visual Analogue Scale of perceived health status; Generic QoL: Generic Quality of Life; Negative W-B: Negative Well-Being subscale of W-BQ12; Positive W-B: Positive Well-Being subscale of W-BQ12; RDQoL AWI: Renal Dependent Quality of Life average weighted impact score; Renal-Dependent QoL Overview: overview item of impact of the renal condition on quality of life; RTSQs: Renal Treatment Satisfaction Questionnaire status version; W-BQ12: Well-Being Questionnaire 12-item version.

*Current follow-up was a mean of 64 months (*range* = 14.5-95) and 72 months (*range* = 17-91) post-transplant for DDKT and LDKT recipients respectively.

ANCOVAs were carried out to compare DDKT and LDKT recipients' PROs at the six/seven-year follow-up, controlling for significantly correlated demographic variables (See Appendix MM, Table MM10). Table 3.7 presents the adjusted mean scores and main results of the ANCOVAs. Details of the significance of the covariates are given in the text, along with effect sizes η_p^2.

Quality of life. Months since transplantation, BMI, number of comorbidities, and marital status were used as covariates when assessing DDKT and LDKT recipients' Generic QoL scores. Months since transplantation and BMI did not reach significance, but marital status (having a partner or not) and number of comorbidities were significant, $F(1, 78) = 4.21$, $p = .044$, $\eta_p^2 = .05$, and $F(1, 78) = 13.16$, $p = .001$, $\eta_p^2 = .14$. Those with a partner had significantly better ($M = 1.50$, $SE = 0.11$) Generic QoL scores than those with no partner ($M = 1.07$, $SE = 0.17$) with a mean difference of -0.42, 95% CI [-0.85, -0.01]. For each unit increase in comorbidities Generic QoL scores decreased by 0.20, 95% CI [-0.30, -0.09]. After controlling for these variables, there was still no significant difference between DDKT and LDKT recipients' Generic QoL scores.

For the Renal-Dependent QoL Overview item, a bootstrapped ANCOVA was conducted, controlling for having a previous failed transplant and ethnicity which were significant covariates, $F(1, 84) = 6.39$, $p = .011$, $\eta_p^2 = .07$, and $F(1, 84) = 3.76$, $p = .001$, $\eta_p^2 = .04$. Those with a previous failed transplant reported worse renal-dependent QoL ($M = -2.48$, $SE = 0.24$) than those with no history of a previous failed transplant ($M = -1.73$, $SE = 0.16$) with a mean difference of 0.75, BCa 95% CI [0.08, 1.34]. Members of ethnic minorities scored worse ($M = -2.57$, $SE = 0.20$) than those of white ethnicity ($M = -1.64$, $SE = 0.16$) with a mean difference of 0.93, BCa 95% CI [-0.02, 1.88]. Controlling for these variables, there was still no significant difference between DDKT and LDKT recipients on the Renal-Dependent QoL Overview item.

Ethnicity, self-reported mental health problems, and having a previous failed transplant were included as covariates when assessing the differences between LDKT and DDKT recipients on RDQoL AWI scores. Having a previous failed transplant was not significant but self-reported mental health problems were significant. Those with mental health problems had more negatively impacted QoL ($M = -4.00$, $SE = 0.33$) than those with no reported problems ($M = -2.83$, $SE = 0.53$) with a mean difference of 1.17 BCa 95% CI [0.11, 2.19], $F(1,82) = 4.50$, $p = .025$,

η_p^2 = .05. Ethnicity was also significant, indicating that the QoL of those of an ethnic minority was more negatively impacted by their renal condition (*M* = -4.17, *SE* = 0.58) than those of white ethnicity (*M* = -2.66, *SE* = 0.30) with a mean difference of 1.51 BCa 95% CI [0.11, 2.91], *F*(1, 82) = 4.59, *p* = .003, η_p^2 = .05. Controlling for these variables, there was still no significant difference between DDKT and LDKT recipients' RDQoL AWI scores.

Treatment satisfaction. A bootstrapped ANCOVA controlling for age was conducted to determine the effects of transplant type on RTSQs scores. The effect of age was significant, indicating that for each year increase in age the RTSQs total score increased by 0.16, BCa 95% CI [0.05, 0.30], *F*(1, 85) = 5.48, *p* = .013, η_p^2 = .06. Controlling for age, there was still no significant difference between DDKT and LDKT recipients' RTSQ total scores.

Health status*.* A bootstrapped ANCOVA was carried out to determine differences in LDKT and DDKT recipients on the EQ-VAS, controlling for months since transplantation, BMI, number of comorbidities, marital status, and self-reported mental health problems. The effect of months since transplantation and marital status were not significant. BMI, mental health problems, and the number of comorbidities were significant covariates; *F*(1, 75) = 3.73, *p* = .018, η_p^2 = .05; *F*(1, 75) = 4.12, *p* = .048, η_p^2 = .05; and *F*(1, 75) = 23.66, *p* = .001 η_p^2 = .24, respectively. For every unit increase in BMI there was a decrease in EQ-VAS scores by 0.67 BCa 95% CI [-1.30, 0.00]. Those with mental health problems had worse EQ-VAS scores (*M* = 65.92, *SE* = 1.86) compared to those with no reported problems (*M* = 75.97, *SE* = 4.98), with a mean difference of 10.04, BCa 95% CI [1.73, 17.89]. For each additional comorbid condition reported, the EQ-VAS score decreased by 4.56, BCa 95% CI [-7.55, -2.57]. Controlling for all of these covariates, there was still no significant difference between LDKT and DDKT recipients' EQ-VAS scores.

A bootstrapped ANCOVA controlling for months since transplantation, marital status, and self-reported mental health problems was conducted to determine differences in LDKT and DDKT recipients' utility scores. The number of comorbidities was not included as a covariate in the reported analysis because it was found to violate the assumption of homogeneity of the regression lines. The covariates, months since transplantation and marital status, did not reach significance. Self-reported mental health problems was significantly related to the utility scores, *F*(1, 80) = 16.06, *p* = .009, η_p^2 = .17. Those with mental health

problems had lower utility scores (*M* = 0.58, *SE* = 0.10) than those with no reported problems (*M* = 0.85, *SE* = 0.02) with a mean difference of 0.27, BCa 95% CI [0.09, 0.46]. Controlling for these covariates, there was still no significant difference between LDKT and DDKT recipients' utility scores.

Well-being. For the analysis of the overall W-BQ12 scores, the covariates of marital status, self-reported mental health problems, and number of comorbidities were included. Marital status, mental health problems, and number of comorbidities were all significant, $F(1, 81) = 12.13$, $p = .001$, $\eta_p^2 = .13$; $F(1, 81) = 25.62$, $p < .001$, $\eta_p^2 = .24$; and $F(1, 81) = 6.38$, $p = .014$, $\eta_p^2 = .07$, respectively. Those with a partner scored significantly better (*M* = 21.62, *SE* = 1.15) than those with no partner (*M* = 17.50, *SE* = 0.91) with a mean difference of -4.12, 95% CI [-6.47, -1.77]. Participants with mental health problems scored significantly worse (*M* = 15.31, *SE* = 1.57) than those with no reported problems (*M* = 23.81, *SE* = 0.62) with a mean difference of 8.50, 95% CI [5.16, 11.84]. For each additional comorbid condition reported, the overall W-BQ12 score decreased by 0.88, 95% CI [-1.58, -0.19]. Controlling for the effects of the covariates, there was still no significant difference between LDKT and DDKT recipients' overall W-BQ12 scores.

For Positive Well-Being, months since transplantation, marital status, and mental health problems were included as covariates. Months since transplantation was not significant, $F(1, 83) = 1.57$, $p = .214$, $\eta_p^2 = .02$. Marital status and mental health problems were significant, $F(1, 83) = 8.34$, $p = .005$, $\eta_p^2 = .09$, and $F(1, 83) = 14.53$, $p < .001$, $\eta_p^2 = .15$. Those with a partner scored significantly better on the Positive Well-Being subscale (*M* = 6.86, *SE* = 0.47) compared to those without a partner (*M* = 5.10, *SE* = 0.59) with a mean difference of -1.76, 95% CI [-2.98, -0.55]. Those with mental health problems scored significantly worse (*M* = 4.37, *SE* = 0.80) than those with no reported problems (*M* = 7.59, *SE* = 0.32) with a mean difference of 3.22, 95% CI [1.54, 4.91]. Controlling for these variables, there was still no significant effect of transplant type on Positive Well-Being subscale scores.

In the comparison of LDKT and DDKT recipients on the Negative Well-Being subscale, age, marital status, and mental health problems were controlled for. Although the variable number of comorbidities was identified as a possible covariate, it was removed from the analysis because its inclusion violated the assumption of homogeneity of the regression lines. All three covariates were significant. For each year increase in age, Negative Well-Being scores decreased

by 0.04, BCa 95% CI [-0.07, -0.01], $F(1, 82) = 4.32$, $p = .023$, $\eta_p^2 = .05$. For marital status, those with a partner scored significantly better ($M = 2.56$, $SE = 0.37$) than those with no partner ($M = 3.92$, $SE = 0.48$) with a mean difference of 1.38, BCa 95% CI [0.35, 2.32], $F(1, 82) = 9.28$, $p = .009$, $\eta_p^2 = .10$. For mental health problems, those with reported mental health problems scored significantly worse ($M = 4.56$, $SE = 0.61$) than those with no reported problems ($M = 1.93$, $SE = 0.26$) with a mean difference of -2.63, BCa 95% CI [-3.89, -1.38], $F(1, 82) = 17.60$, $p = .001$, $\eta_p^2 = .18$. Controlling for the covariates, there was still no significant difference between LDKT and DDKT recipients' Negative Well-Being scores.

In the analysis of the Energy subscale scores, mental health problems and number of comorbidities were included as covariates, both of which were significant, $F(1, 82) = 13.14$, $p = .001$, $\eta_p^2 = .14$, and $F(1, 82) = 12.14$, $p = .001$, $\eta_p^2 = .13$, respectively. Those with mental health problems scored significantly lower ($M = 3.47$, $SE = 0.78$) than those with no reported problems ($M = 6.51$ $SE = 0.29$) with a mean difference of 3.32, 95% CI [1.37, 4.70]. For each additional comorbid condition reported, the energy score decreased by 0.61, 95% CI [-0.95, -0.26]. Controlling for these variables, there was still no significant difference between LDKT and DDKT recipients' Energy subscale scores.

Summary of ANCOVA results. Overall, there were no significant differences between LDKT and DDKT recipients across any of the PROMs at the current follow-up; however, some of the included covariate variables were significantly related to the outcomes. Those with a partner reported significantly better Generic QoL, overall W-BQ12, Positive Well-Being, and Negative Well-Being compared to those without a partner. The number of comorbidities was negatively associated with Generic QoL, EQ-VAS health status, overall W-BQ12, and Energy sub-scale scores. Those with a previous failed transplant reported significantly more negatively impacted Renal-Dependent QoL Overview item scores and those from an ethnicity minority reported more negatively impacted Renal-Dependent QoL Overview item and RDQoL AWI scores. Those with self-reported mental health problems reported significantly more negatively impacted RDQoL AWI scores, lower EQ-5D-5L utility scores, and worse overall W-BQ12, Positive Well-Being, Negative Well-Being, and Energy subscale scores. BMI was negatively associated with EQ-VAS health status. Age was positively associated with RTSQs total scores and negatively associated with Negative Well-Being.

Table 3.7.

ANCOVA and Bootstrapped ANCOVA Comparisons of DDKT and LDKT Recipients' PROs at Follow-up, Controlling for Clinical and Demographic Variables.*

Measures	**DDKT**	**LDKT**					
	M (SE)	***M (SE)***	**Mean difference *(95% CI)***	***F***	***df***	***p***	η_p^2
Generic QoL (*n* = 84)	1.27 (0.13)	1.29 (0.15)	-0.02 (-0.41, 0.37)	0.01	1, 78	.907	.00
W-BQ12 (*n* = 86)	19.72 (0.97)	19.41 (1.06)	0.313 (-1.88, 2.50)	0.08	1, 81	.777	.00
Positive W-B (*n* = 88)	6.04 (0.50)	5.93 (0.54)	0.11 (-1.05, 1.27)	0.04	1, 83	.850	.00
Energy (*n* = 86)	4.88 (0.48)	5.10 (0.50)	-0.22 (-1.29, 0.85)	0.17	1, 82	.685	.00
	M (SE)	***M (SE)***	**Mean difference *(BCa 95% CI)***	***F***	***df***	***p***	η_p^2
Renal-Dependent QoL Overview (*n* = 86)	-2.16 (0.12)	-2.05 (0.24)	-0.11 (-0.66, 0.41)	0.19	1, 84	.687	.00
RDQoL AWI (*n* = 87)	-3.69 (0.36)	-3.14 (0.44)	-0.55 (-1.25, 0.18)	2.12	1, 82	.120	.03
RTSQs total (*n* = 88)	69.05 (1.09)	71.52 (1.14)	-2.47 (-5.80, 0.64)	2.28	1, 85	.119	.03
EQ-VAS (*n* = 82)	70.13 (2.74)	71.76 (3.44)	-1.63 (-7.80, 4.25)	0.29	1, 75	.600	.00
EQ-5D-5L Utility (*n* = 85)	0.71 (0.05)	0.72 (0.06)	-0.02 (-0.11, 0.07)	0.15	1, 80	.703	.00
Negative W-B (*n* = 87)	3.02 (0.38)	3.47 (0.44)	-0.45 (-1.33, 0.53)	1.05	1, 82	.336	.01

Note. M: adjusted means; *SE*: standard error; 95% CI: 95% confidence intervals; BCa 95% CI: Bias-corrected and accelerated 95% confidence intervals; η_p^2: partial eta squared effect size; DDKT: deceased-donor kidney transplant; LDKT: living-donor kidney transplant. Energy: Energy subscale of W-BQ12; EQ-5D-5L utility: EuroQoL-5 Dimension-5 Level utility score; EQ-VAS: EuroQol Visual Analogue Scale of perceived health status; Negative W-B: Negative Well-Being subscale of W-BQ12; Positive W-B: Positive Well-Being subscale of W-BQ12; RDQoL AWI: Renal Dependent Quality of Life average weighted impact score; RTSQs: Renal Treatment Satisfaction Questionnaire status; W-BQ12: Well-Being Questionnaire 12-item version.

*Current follow-up was a mean of 64 months (range = 14.5-95) and 72 months (range = 17-91) post-transplant for DDKT and LDKT recipients, respectively.

Comparisons of DDKT and LDKT recipients' PROs, controlling for pre-transplant scores. No significant differences in demographic characteristics were found between DDKT and LDKT recipients with pre-transplant data, although a trend was found for marital status. When marital status was dichotomised to having a partner or not having a partner, the Fisher's exact test indicated that LDKT recipients were significantly more likely to have a partner than DDKT recipients, p = .006 (see Appendix MM, Table MM5).

Independent samples t-tests were conducted to compare DDKT and LDKT recipients' PROMs prior to transplantation (recruitment/three-month follow-up) and at the current follow-up (see Appendix MM, Tables MM11 and MM12). Prior to transplantation there was a significant difference on the Renal-Dependent QoL Overview item suggesting that those who went on to receive an LDKT (M = -2.77, SE = 0.67) were more negatively impacted by their renal condition than those who went on to receive a DDKT (M = -1.91, SE = 0.21), with a mean difference of 0.86, BCa 95% CI [0.34, 1.35], t(32.99) = 3.21, p = .004, r = .49. There was also a non-significant trend indicating that those who went on to receive an LDKT (M = -4.45, SE = 0.56) had worse RDQoL AWI scores prior to transplantation than those who went on to receive a DDKT (M = -2.98, SE = 0.45), with a mean difference of 1.47, BCa 95% CI [0.03, 2.90], t(33) = 2.05, p = .060, r = .34. At six/seven-years follow-up there were no significant differences between the two groups; however, there was a trend for LDKT recipients to be more satisfied with their renal treatment (M = 71.67, SE = 1.92) than DDKT recipients (M = 66.79, SE = 1.65), with a mean difference of -4.88, BCa 95% CI [-9.63, -0.35], t(36) = -1.92, p = .068, r = .30. No other variables were controlled for in these initial t-test comparisons.

ANCOVAs comparing DDKT and LDKT recipients PROMs at the current follow-up were carried out controlling for pre-transplant scores and significantly correlated demographic variables (see Appendix MM, Table 13). Table 3.8 presents the adjusted means and results of the ANCOVAs. The significance of the covariates are given in the text, along with (η_p^2) effect sizes.

Quality of life. A bootstrapped ANCOVA, controlling for pre-transplant Generic QoL scores and number of comorbidities, was carried out to compare DDKT and LDKT recipients' QoL. The number of comorbidities was significant, F(1, 30) = 6.96, p = .006, η_p^2 = .19. For every additional comorbid condition reported, the Generic QoL score decreased by 0.26, BCa 95% CI [-0.43, -0.12].

Controlling for these covariates, there was still no significant effect of transplant type on Generic QoL scores. The bootstrapped ANCOVA controlling for pre-transplant Renal-Dependent QoL Overview scores and age indicated that there was no significant effect of transplant type on Renal-Dependent QoL Overview scores at follow-up. Age was not a significant covariate, $F(1, 30) = 4.42$, $p = .088$, $\eta_p^2 = .13$. When controlling for pre-transplant scores, there was also no significant effect of transplant type on RDQoL AWI scores. Overall, it appears that DDKT and LDKT recipients do not differ significantly on QoL or renal-dependent QoL.

Treatment satisfaction. A bootstrapped ANCOVA was conducted to compare RTSQs total scores, controlling for the pre-transplant scores. There was a trend indicating that LDKT recipients were more satisfied with their renal treatment compared to DDKT recipients.

Health status. An ANCOVA was carried out to compare DDKT and LDKT recipients' EQ-VAS health status scores, controlling for pre-transplant EQ-VAS scores and number of comorbidities. The number of comorbidities was a significant covariate, $F(1, 34) = 14.64$, $p = .003$, $\eta_p^2 = .30$. For each additional comorbid condition a person reported, the EQ-VAS score decreased by 5.64, BCa 95% CI [-9.91, -2.77]. Controlling for the covariates, there was still no significant effect of transplant type on EQ-VAS scores.

EQ-5D-5L utility scores at follow-up were assessed, with pre-transplant EQ-5D-5L utility scores, marital status, and mental health problems as covariates. The number of comorbidities was removed as a covariate from the analysis because its inclusion appeared to violate the assumption of homogeneity of the regression lines. Marital status and mental health problems were not significant, $F(1, 32) = 0.33$, $p = .588$, $\eta_p^2 = .01$, and $F(1, 32) = 1.90$, $p = .238$, $\eta_p^2 = ,06$, respectively. Controlling for the effects of the covariates, there was still no significant difference between DDKT and LDKT recipients' utility scores.

Well-being. An ANCOVA comparing DDKT and LDKT recipients' overall W-BQ12 scores, controlling for pre-transplant W-BQ12 scores, marital status, and mental health problems, was carried out. The number of comorbidities was removed as a covariate from the analysis because it violated the assumption of homogeneity of the regression lines. Marital status and mental health problems were significant covariates, $F(1, 33) = 7.91$, $p = .008$, $\eta_p^2 = .19$, and $F(1, 33) = 11.09$, $p = .002$, $\eta_p^2 =$

.25. Those with a partner scored higher (*M* = 21.62, *SE* = 1.09) than those with no partner (*M* = 16.49, *SE* = 1.71), with a mean difference of -5.13, 95% CI [-8.84, -1.42]. Those with mental health problems scored significantly lower (*M* = 15.54, *SE* =1.97) than those with no problems (*M* = 22.57, *SE* = 0.91) with a mean difference of 7.04 [95% CI 2.74, 11.33]. Controlling for these variables, there was still no effect of the transplant type on W-BQ12 total scores.

Similarly, a bootstrapped ANCOVA was conducted to compare DDKT and LDKT recipients' Positive Well-Being subscale scores, controlling for pre-transplant scores, marital status, and mental health problems. Marital status was a significant covariate, $F(1, 33) = 5.92$, $p = .048$, $\eta_p^2 = .15$; those with a partner scored significantly better (*M* = 6.69, *SE* = 0.73) than those with no partner (*M* = 3.94, *SE* = 1.39) with a mean difference of -2.75, BCa 95% [CI -5.43, -0.51]. Self-reported mental health problems was not a significant covariate, $F(1, 33) = 4.71$, $p = .068$, $\eta_p^2 = .12$. Controlling for these variables, there was no significant effect of transplant type on Positive Well-Being scores.

In the analysis of the Negative Well-Being subscale, pre-transplant scores and mental health problems was controlled for. Marital status was removed from the analysis as its inclusion as a covariate violated the assumption of homogeneity of the regression lines. Mental health problems was not significant, $F(1, 34) = 0.37$, $p = .532$, $\eta_p^2 = .01$. Controlling for these variables, there was no significant effect of transplant type on Negative Well-Being scores.

For the analysis of Energy subscale scores, pre-transplant scores, marital status, mental health problems and number of comorbidities were controlled for. Mental health problems and the number of comorbidities were significant covariates, $F(1, 32) = 14.59$, $p = .001$, $\eta_p^2 = .31$, and $F(1, 32) = 9.30$, $p = .005$, $\eta_p^2 = .23$. Those with mental health problems scored significantly lower (*M* = 2.46, *SE* = 0.84) than those with no reported problems (*M* = 5.94, *SE* = 0.42) with a mean difference of 3.48 [95% CI 1.62, 5.33]. For every additional comorbid condition reported, Energy scores decreased by 0.60 [95% CI -1.01, -0.20]. Marital status was not significant, $F(1, 32) = 3.67$, $p = .064$, $\eta_p^2 = .10$. Controlling for these variables, there was no effect of the transplant type on Energy Subscale scores.

Summary of ANCOVA results. Overall, there does not appear to be a significant difference between DDKT and LDKT recipients on generic QoL, renal-

dependent QoL, health status, or well-being when controlling for pre-transplant scores and other associated variables. LDKT recipients appear to report better renal treatment satisfaction compared to those with a DDKT, but this difference did not reach significance. Some of the included covariates were significant. Those with a partner reported better overall W-BQ12 and Positive Well-Being scores than those without a partner, and those with self-reported mental health problems reported worse W-BQ12 scores and Energy subscale scores than those without mental health problems. The number of comorbidities was negatively associated with Generic QoL, EQ-VAS health status, and Energy sub-scale scores.

Table 3.8.

ANCOVA and Bootstrapped ANCOVA Comparisons of DDKT and LDKT Recipients' PROs at Follow-up, Controlling for Pre-transplant PROs and Demographic variables*

Measures	**DDKT**	**LDKT**					
	M (SE)	***M (SE)***	**Mean difference *(95% CI)***	***F***	***df***	***p***	η_p^2
RDQoL AWI (*n* = 34)	-2.88 (0.36)	-2.15 (0.46)	-0.73 (-1.95, 0.50)	1.47	1, 31	.235	.05
W-BQ12 (*n* = 38)	19.00 (1.10)	19.11 (1.62)	-0.12 (-3.50, 3.27)	0.01	1, 33	.945	.00
Energy (*n* = 38)	4.07 (0.50)	4.32 (0.71)	-0.25 (-1.80, 1.30)	0.11	1, 32	.743	.00
	M (SE)	***M (SE)***	**Mean difference *(BCa 95% CI)***	***F***	***df***	***p***	η_p^2
Generic QoL (*n* = 34)	0.84 (0.23)	1.18 (0.27)	-0.33 (-1.03, 0.41)	1.13	1, 30	.334	.04
Renal-Dependent QoL Overview (*n* = 34)	-1.83 (0.28)	-1.73 (0.34)	-0.10 (-0.89, 0.70)	0.06	1, 30	.838	.00
RTSQs total (*n* = 33)	66.72 (1.73)	72.38 (2.26)	-5.67 (-11.38, -0.23)	4.17	1, 30	**.051**	**.12**
EQ-VAS (*n* = 38)	67.94 (4.25)	75.29 (4.50)	-7.34 (-19.79, 5.45)	1.56	1, 34	.227	.04
EQ-5D-5L Utility (*n* = 37)	0.70 (0.07)	0.76 (0.08)	-0.07 (-0.24, 0.06)	0.92	1, 32	.412	.03
Positive W-B (*n* = 38)	5.55 (0.82)	5.08 (1.29)	0.46 (-1.61, 3.01)	0.20	1, 33	.687	.01
Negative W-B (*n* = 38)	2.68 (0.54)	1.74 (0.53)	0.93 (-0.24, 2.49)	1.87	1, 34	.162	.05

Note. M: adjusted means; *SE*: standard error; 95% CI: 95% confidence intervals; BCa 95% CI: Bias-corrected and accelerated 95% confidence intervals; η_p^2: partial eta squared effect size. Energy: Energy subscale of W-BQ12; EQ-5D-5L utility: EuroQoL-5 Dimension-5 Level utility score; EQ-VAS: EuroQol Visual Analogue Scale of perceived health status; Negative W-B: Negative Well-Being subscale of W-BQ12; Positive W-B: Positive Well-Being subscale of W-BQ12; RDQoL AWI: Renal Dependent Quality of Life average weighted impact score; RTSQs: Renal Treatment Satisfaction Questionnaire status version; W-BQ12: Well-Being Questionnaire 12-item version.
*Mean time since DDKT and LDKT was 52 (range = 17-92) and 60 (range = 17-83.5 months, respectively.

Discussion

The current study followed participants up approximately six years after the original ATTOM detailed PROMs study. No significant changes were found across the PROMs from 12 months to six/seven-years post- kidney or SPK transplant. Significant improvements in PROMs scores from pre- to post-kidney transplant indicated that recipients were more satisfied with their renal treatment and were less negatively impacted by their renal condition. At the current follow-up, no significant differences were found between LDKT and DDKT recipients across the PROMs. Most participants expressed being satisfied/very satisfied with various aspects of the renal service that they had received.

Long-term follow-up of PROs post-transplant. Results show that SPKT recipients' health status significantly improved from recruitment to the original ATTOM study shortly after transplantation to 12-months post-transplantation. Although health status scores had decreased slightly at the current follow-up this was not a significant change. There was also a trend indicating that diabetes treatment satisfaction improved from three-months to 12-months post-SPKT and then remained stable at the highest possible score to the current follow-up. For kidney transplant recipients, significant improvements were found from recruitment/three-months to 12-months post-transplantation in renal-dependent QoL, health status, and utility scores. There was also a trend for renal treatment satisfaction to be better at 12-months compared to three-months post-transplant. Whilst renal-dependent QoL, treatment satisfaction, health status, and utilities were significantly better at the current six/seven-year follow-up compared to recruitment/three-months post-transplant, the scores had remained stable from 12-months follow-up. The results suggest that when the PROMs were completed shortly after transplantation, individuals were likely still recovering from the transplant operation, were adjusting to their new anti-rejection medications, and had not yet experienced the full benefits of the transplant. However, by 12-months post-transplant, participants were feeling healthier, were more satisfied with their treatment, and kidney-recipients were less impacted by having a renal condition, and this remained the case up to approximately six years later. For those who had an SPKT, they no longer needed to follow dietary restrictions, monitor their blood glucose levels, or inject insulin and so diabetes treatment satisfaction reached ceiling levels by 12-months post-SPKT and remained stable. Whilst the

individualised condition-specific QoL scores indicated that transplant recipients were still impacted by having a renal condition (and diabetes), it is encouraging to see that this impact does not appear to have worsened over time. Whilst health status for SPKT recipients was still quite high at six/seven-years follow-up, the trend for a decline since 12-months post-transplant might be due to other health issues or the impact of the anti-rejection medications. There were no significant changes in well-being across any of the post-transplant time points for either SPK or kidney transplant recipients. For the SPKT recipients, there were no significant differences across the three time points in generic QoL, renal-dependent and diabetes-dependent QoL, renal treatment satisfaction, utility scores, and well-being. Similarly, for the kidney-only recipients, although the overall ANOVAs indicated significant differences in Generic QoL and the Renal-Dependent QoL Overview item scores across the three time points, the Dunn-Bonferroni corrected pairwise comparisons were not significant. It is possible that the lack of changes in PROs over time may reflect a type 2 error due to the small sample and lack of power, particularly as fewer than the required 28 SPKT recipients were recruited to achieve adequate power (see GPower calculations presented in Chapter 2).

There is limited other longitudinal PROMs research which has followed kidney-only or SPK transplant recipients over several time points post-transplant, none of which have used individualised measures of condition-specific QoL. For example, improvements were found in effects of kidney disease, burden of kidney disease, work status, cognitive function, sexual function, sleep, and overall health domains of the KDQoL-SF from one month to two years post-kidney transplantation (Costa-Requena, Cantarell, Moreso, Parramon, & Seron, 2017). Whilst the KDQoL-SF is very different to the RDQoL used in the current study, the findings do indicate that functioning and the impact of kidney disease improved from shortly after transplantation to over one-year post-transplant. In other research, Griva et al. (2011) found that physical component scores on the SF-36 worsened over a six-year period post-transplant, but mental health component scores improved. Participants also reported more worry about the graft viability and perceived responsibility to do well on the TxEQ across the two time points (Griva et al., 2011). Another study found a significant improvement in role physical but a decline in vitality on the SF-36 for SPKT recipients, and a decline in general health on the SF-36 and increase in impact on the DQoL for kidney-only recipients with diabetes over a three year follow-up (Sureshkumar et al., 2005). A limitation of the studies by Griva et al. (2011) and Sureshkumar et al. (2005) is that participants appear to have

had their transplants for varying lengths of time when they were recruited to the study, so it is unclear what the findings really mean for individuals at certain time points post-transplant. In a cross-sectional comparison of patients with short (≤one year), mid- (one to eight years), and long-term (over eight to 15 years) kidney transplants, no significant difference was found in perceived health status on the EQ-VAS, although those with longer-term transplants reported more symptoms and comorbidities (Schulz et al., 2013). The current findings do suggest that one-year follow-up is a good indication of post-transplant PROs including QoL, and that these individualised measures remain stable over time. It should also be noted that this sample only included those with a working transplant and not those who experienced graft loss, so results may not be representative of all patients who receive a transplant in the UK.

Change in PROs from pre- to post-transplant. In a sub-sample of kidney recipients, renal treatment satisfaction improved significantly from pre- to post-transplant. Participants were also significantly less negatively impacted by their renal condition post-kidney transplantation. No other significant changes were detected for the more generic measures of generic QoL, well-being, health status or utilities. These findings suggest that the RDQoL is sensitive to change and measures something very different from the EQ-5D-5L utilities and EQ-VAS measures, which are sometimes inaccurately reported to be measures of QoL rather than health utilities or health status. This highlights the importance of including genuine measures of condition-specific QoL when assessing the impact of treatments such as transplantation. Although a very different measure, previous research has found significant improvements in several condition-specific and general domains of the KDQoL-SF from pre- to post-kidney transplantation including improved general health, vitality, effect of kidney disease (Gil et al., 2020; Kostro et al., 2016), burden of kidney disease, and symptoms (Lønning et al., 2018; von der Lippe et al., 2014). It is important to remember that although the KDQoL-SF is often reported as a measure of QoL, a large proportion of it is a generic measure that more accurately assesses different aspects of functioning. It should be noted that due to the small sub-sample in the current research there may not have been enough power to detect significant changes in other variables. Despite this, the findings highlight the importance of including a genuine, individualised measure of QoL. As pre- and post-SPKT data were only available for three individuals, similar analyses to investigate the impact of SPK transplantation were not possible. Further

research that focuses on this subsample of patients would be beneficial, as their experiences may differ from kidney-only transplant recipients.

Comparison of PROs between LDKT and DDKT recipients. At the current six/seven-year follow-up, the overall sample of kidney-only transplant recipients had had their transplants for a mean of 68 months. Comparisons of LDKT and DDKT recipients at the current follow-up found no significant effect of transplant type on any of the PROs. The smaller sub-sample of kidney-only transplant recipients with pre- and post-transplant data had had their transplants for slightly less time overall, a mean 55 months. Within this subsample there was a trend for LDKT recipients to report better renal treatment satisfaction at follow-up compared to DDKT recipients when controlling for pre-transplant scores. Both kidney transplant groups reported high levels of treatment satisfaction, which is an encouraging finding. In the original ATTOM detailed PROMs study, significant differences were found favouring LDKT recipients at 12-months follow-up when controlling for possible confounders. However, when controlling for pre-transplant scores in a sub-sample, LDKT recipients only reported better treatment satisfaction than DDKT recipients (Gibbons et al., 2021). The current findings are in line with previous research which has shown that LDKT and DDKT recipients do not differ across PROMs including the SF-36 and TxEQ, particularly when data were collected several years post-transplant (de Groot et al., 2013; Griva et al., 2011; Griva et al., 2002). Furthermore, one study found that DDKT recipients who were more than 58 months post-transplant reported less anxiety on the HADS and better mental health on the SF-12 compared to LDKT recipients (Zimmermann et al., 2016). However, Gozdowska et al. (2016) found that, compared to DDKT recipients, LDKT recipients reported better mental and environmental scores on the WHOQoL-BREF and a greater sense of happiness on a transplant recipient measure designed for the study. Whilst only patients who had received dialysis prior to transplantation were included in the analyses, no other variables were controlled for in the comparisons (Gozdowska et al., 2016). Overall, the current and previous research largely suggests that LDKT and DDKT recipients report similar PROs several years post-transplant, particularly when possibly confounding variables are controlled. However, it should be noted that because the current and previous research only included patients with working transplants, comparisons between DDKT and LDKT recipients' PROs do not take into account whether or not there were differences in the number of patients who experienced graft loss in the years prior.

Patients and their families need to be provided with sufficient information on the various outcomes associated with DDKTs and LDKTs in order to make informed decisions about which is the right option for them. Although living donation is not believed to have negative health implications, it still involves an invasive procedure and there have often been methodological issues with research such as participant attrition or inappropriate comparisons to general population samples when donors are often healthier than average to begin with (Ommen, Winston, & Murphy, 2006; Reese, Boudville, & Garg, 2015). Furthermore, there is some evidence to suggest that some donors may regret their donation (Holscher et al., 2018; Maple, Chilcot, Weinman, & Mamode, 2017; Wirken et al., 2019). A LDKT may not always be the right option for patients for various reasons and they should be reassured that they can have good medical and patient-reported outcomes with a DDKT.

Renal service satisfaction. Social worker advice and support and psychological advice and support appear to be among the worst rated items on the RSSQ. Although several participants indicated that these items were not applicable to them or that they were neither satisfied nor dissatisfied, some participants indicated dissatisfaction. However, it is unclear whether this reflects a negative experience with these services or difficulties in accessing these services when needed. Furthermore, kidney recipients with self-reported mental health problems reported more negatively impacted renal-dependent QoL and worse health utility and well-being scores than those without mental health problems. These findings suggest it is important that social and psychological advice and support is readily available to individuals with CKD. Mental health problems, such as depression, can be difficult to assess in individuals with CKD because symptoms are common to both conditions (Chilcot, Spencer, Maple, & Mamode, 2014; Chilcot, Wellsted, Da Silva-Gane, & Farrington, 2008). Previous research has indicated that around 20-30% of individuals with kidney failure or a kidney transplant experience depression, although the prevalence varies depending on the definition of depression and the method of assessment (Chilcot et al., 2014; Chilcot et al., 2008). Depression has also been associated with poorer health outcomes in dialysis patients (Chilcot et al., 2008) and kidney recipients (Chilcot et al., 2014) and has even been associated with higher mortality (Palmer et al., 2013). The current study and previous research highlight the need to establish effective ways of screening and treating mental health problems, such as depression, within individuals with CKD (Chilcot & Hudson, 2019).

Study limitations. It was originally intended that participants would be followed up five years post-transplant, as medical outcomes such as graft and patient survival recorded by NHSBT are usually reported one-, two-, five-, and 10-years post-transplant. However, a five-year follow-up was not possible due to logistical delays in commencing data collection. Despite this, the current six/seven-year follow-up provided sufficient time for patients to have adjusted to having a transplant and post-transplant treatment, and the majority of participants transplanted during the ATTOM study would still have a working transplant. Few other studies have followed patients longitudinally to assess long-term PROs over five years post-transplant.

The main limitation of the study is the small sample sizes of the different participant groups. Due to the small sample of individuals on HD, and because these participants were in receipt of various treatments at the three data collection points, statistical analyses were not carried out to assess change in their PROs over time. The sample of HD participants was also too small and heterogeneous to carry out statistical comparisons with transplant recipients as several had one or more failed transplant and only three reported being wait-listed for a transplant at the current follow-up. Previous research has shown that individuals on HD and wait-listed for a kidney transplant are different to those not wait-listed and report better outcomes such as physical functioning, role physical, general health, and social functioning on the SF-36 (Dedić, Milojković, Čukić, & Bokonjić, 2017). As individuals go through a screening process to establish whether they are fit enough for a transplant, individuals who are not wait-listed for a transplant are fundamentally different to those who are wait-listed and to those with a working transplant. Therefore, it was believed that it would be inappropriate to make comparisons with this group. It is also possible that due to a lack of power, changes in PROMs over time may not have been identified, especially in the analyses of data from the SPKT recipients which was a particularly small sample. It is also possible that differences in PROMs between DDKT and LDKT recipients were not detected due to a lack of power; however, other research with a longer post-transplant follow-up have also found few differences on various PROMs.

The study findings may not be generalisable to the whole renal population in the UK. Comparisons of responders and non-responders indicated that more of those who took part in the current follow-up were in full-time employment, were of white ethnicity, and reported better generic QoL at recruitment to the original ATTOM

study compared to those who did not take part. At 12-month follow-up, those who responded to the current follow-up reported better generic QoL, health status, well-being, and less impacted renal-dependent QoL compared to those who did not take part. Furthermore, few participants were from an ethnic minority group, which is not reflective of the renal population. Around 30% of patients on the UK kidney transplant waiting list and 20% of kidney recipients between April 2011 and March 2012, around the time of recruitment to the original ATTOM study, were from an Asian or Black ethnic group (NHSBT, 2012).

Study implications. The current research provides longitudinal findings on the QoL of individuals with CKD using an individualised condition-specific measure of QoL, as well as other measures of treatment satisfaction, health status, utilities, and well-being. The results suggest that outcomes remained stable between the 12-month and six/seven-year follow-up. Scores on the condition-specific measures of QoL indicate that patients are still negatively impacted several years post-transplant by having had CKD and diabetes. It is important that patients awaiting transplantation are aware that it is a treatment and not a cure as they will be likely to continue to experience issues. No significant differences were found between DDKT and LDKT recipients across the PROs, suggesting that after a longer follow-up, outcomes are comparable. This is the first study to have shown this after a longer follow-up period, using a genuine individualised measure of renal-dependent QoL, among other PROMs. The findings have implications for patients' decision making of which type of transplant should be considered the most beneficial. Further longitudinal research of PROs would be useful to help inform patients on the long-term impact of transplantation in SPKT recipients for whom there is limited research. As prospective longitudinal data is particularly challenging to collect, due to the unpredictability of when individuals will receive a transplant and attrition, collection of PROMs data as part of usual care may be especially beneficial.

Conclusions

Other than the original ATTOM detailed PROMs study, this is the only UK-based study to have followed up kidney and SPK transplant recipients longitudinally using a variety of PROMs including measures of individualised condition-specific QoL. The study found some changes in transplant recipients' PROs over time. A significant improvement in the health status of SPKT recipients was found from

shortly after transplantation to 12-months follow-up but otherwise PROs appear to have remained stable up to approximately six/seven-years post-transplant. Of note, SPKT recipients reported being very satisfied with their diabetes treatment as mean scores reached the maximum post-transplant. Significant improvements were found from recruitment/three-months post-kidney transplantation to 12-months follow-up in renal-dependent QoL, health status, and utilities, and remained stable to the current six/seven-year follow-up at which point these outcomes, as well as renal treatment satisfaction, were significantly better than at recruitment/three-month follow-up. For those with pre-transplant data, significant improvements in renal-dependent QoL and renal treatment satisfaction were found from pre- to post-kidney transplantation, indicating that patients were less impacted by their renal condition post-transplant. Lastly, no significant differences were found between DDKT and LDKT recipients on any of the PROMs at the current follow-up, although there was a trend indicating that LDKT recipients reported better renal treatment satisfaction than DDKT recipients when controlling for pre-transplant scores. This information could help patients to make decisions about which type of transplant they would prefer and what they might realistically expect post-transplant.

Chapter 4: Simultaneous Pancreas and Kidney Transplantation: A Longitudinal Study of Patient-Reported Outcomes

Introduction and Aims

Diabetes is one of the leading causes of CKD, resulting in the need for RRT in the form of dialysis or a transplant (Webster et al., 2017). In the UK, individuals with type 1 diabetes (and occasionally those with insulin-treated type 2 diabetes) and comorbid CKD can be given an SPKT from a deceased donor to treat both conditions. The pancreas graft normalises blood glucose levels, which protects the kidney graft from damage due to poorly controlled diabetes (Lindahl, Reinholt, et al., 2014). SPK transplantation is associated with better patient survival compared to wait-listed patients (Ojo et al., 2001; van Dellen et al., 2013), and can help to halt or even improve some diabetes complications (Lindahl, Jenssen, et al., 2014).

As discussed in Chapter 1, PROMs can provide useful information to evaluate treatments. However, measures of functioning or health status have often been referred to in research as measures of QoL or HRQoL and this can result in misleading conclusions (Bradley, 2001). For example, a review of 12 studies which claimed to have investigated QoL after islet cell or pancreas transplantation concluded that, whilst some benefits had been identified, the impact of transplantation on QoL was still unknown because few studies had used actual measures of QoL (Speight, Reaney, Woodcock, Smith, & Shaw, 2010). Mixed results have been found in comparisons of pre-dialysis and dialysis patients, with some studies reporting better outcomes on the KDQoL-36 and EQ-5D-3L for pre-dialysis patients (Al-Mansouri et al., 2021; Krishnan et al., 2020). Other research found no difference on the PHQ-9 and all but one subscale of SF-36 (Abdel-Kader et al., 2009). Generally, SPKT recipients report better outcomes on measures, such as the SF-36, compared to those wait-listed for an SPKT (Nyumura et al., 2017; Pera et al., 2009). Other studies have asked SPKT recipients to complete PROMs retrospectively shortly after transplantation and found significant improvements in SF-36 outcomes when followed-up post-transplant (Scheuermann et al., 2020). Prospective longitudinal PROMs data can be particularly useful for assessing change in PROs from pre- to post-transplantation. For example, Adang et al. (1998) found significant improvements from pre- to 5-, 12-, and 18-months post-SPKT on a 10-point VAS scale of QoL. Martins et al. (2015) collected prospective data from a

sub-sample of 20 participants and found significant pre- to post-SPKT improvements in all five domains of the EQ-5D-5L, EQ-VAS health status, and the GIQLI. In other prospective research, significant pre- to post-SPKT improvements were found in mental and physical component scores of the SF-36 (Gross et al., 2000; G. C. Smith et al., 2010), and in depression (CES-D), well-being (Index of Well-being), satisfaction with diabetes therapy (taken from DQoL), and single item measures of health and life satisfaction (Gross et al., 2000).

The ATTOM detailed PROMs study was the first to use individualised condition-specific measures of QoL to investigate outcomes of SPK transplantation. Controlled cross-sectional comparisons showed that SPKT recipients reported significantly less negative impact of the renal condition on QoL and better generic QoL, renal treatment satisfaction, well-being, and health status compared to those still wait-listed at 12-months follow-up (Gibbons et al., 2020). There were no significant differences between the SPKT recipients and wait-listed participants on diabetes-dependent QoL, diabetes treatment satisfaction, or EQ-5D-5L utilities. Although the study was originally designed to compare SPKT recipients and matched-controls on the waiting list for an SPKT, a subsample of 22 matched controls received an SPKT before their 12-month follow-up and went on to provide post-transplant PROMs data. Results showed that outcomes remained stable for those who were still wait-listed at 12-months follow-up, while SPKT recipients reported significant improvements in generic QoL, renal-dependent QoL, renal treatment satisfaction, health status, and well-being. Health utilities and diabetes-dependent QoL scores remained stable across the two time-points for wait-listed participants and SPKT recipients, although SPKT recipients had significantly better utilities than wait-listed participants (Gibbons et al., 2020). This was the first study to have measured individualised condition-specific QoL both pre- and post-SPKT, and highlights the need for prospective research that uses individualised measures within this patient group.

It has been argued that the way an individual thinks about their health condition and their behavioural response to it can impact on patient outcomes. As previously stated, the CSM of Self-Regulation theorises that individuals hold illness perceptions or representations about the identity, cause, timeline, consequences, and curability/controllability of health conditions and these influence their emotional and behavioural response to the illness (Leventhal et al., 2003; Leventhal et al., 1984). Illness perceptions have been associated with a number of outcomes, such

as psychological well-being, within a variety of health conditions including diabetes and CKD (Chilcot, 2012; Hagger et al., 2017). Research suggests that illness perceptions have a direct and indirect impact on outcomes through coping (Hagger et al., 2017). More negative illness perceptions, such as perceptions of severe illness consequences and lower levels of control and cohesion/understanding, have been associated with depression in CKD when controlling for clinical and demographic variables (Chilcot, 2012). Overall more negative illness perceptions have also been associated with worse anxiety and depression in patients with diabetes (Knowles et al., 2020). A small number of studies have investigated the illness perceptions of kidney transplant recipients (Griva et al., 2012; Griva et al., 2009; Knowles et al., 2016). For example, Griva et al. (2012) found that timeline perceptions became more acute, whilst perceived illness consequences and identity decreased and personal control increased from pre- to post-kidney transplant. Change in perceived illness consequences was found to predict change in mental component scores of the SF-36. However, there is no research specifically investigating illness perceptions of those awaiting or in receipt of an SPKT. Furthermore, the relationships between illness perceptions and the condition-specific PROMs used in the current research are not known. Understanding the associations between illness perceptions and outcomes is important because maladaptive illness perceptions could be targeted in interventions to help improve these outcomes. Interventions targeting illness perceptions have already been trialled for other health conditions, including type 2 diabetes, and found encouraging results at improving some health behaviours and outcomes (Broadbent, Ellis, Thomas, Gamble, & Petrie, 2009; Keogh et al., 2011; Siemonsma et al., 2013).

The main aim of the current study was to collect PROMs data prospectively from individuals on the waiting list for an SPKT and to follow individuals up post-SPKT. To assess the impact of RRT at baseline, PROMs data from those who were pre-dialysis were compared to that of patients receiving dialysis; the PROs of individuals who remained wait-listed were also assessed. A further aim of the study was to investigate participants' illness perceptions. Therefore, the main research question was: What impact does diabetes, CKD, and SPK transplantation have on PROs including QoL, treatment satisfaction, health status, utilities, and well-being? The research also asks: Are patients satisfied with the renal service that they receive pre- and post-SPKT? What are patients' perceptions of their renal condition and diabetes, and do perceptions change after transplantation? Are illness perceptions associated with QoL, treatment satisfaction, and well-being?

Summary of Methods

Design. The study used a prospective longitudinal cohort observation design to collect PROMs data from individuals wait-listed for, and/or in receipt of, an SPKT.

Recruitment and procedure. Recruitment to the study was carried out at three renal transplant units in the UK (Addenbrooke's Hospital in Cambridge; Guys Hospital in London; and the Royal Infirmary of Edinburgh in Scotland) between May 2018 and July 2019. Individuals eligible to take part in the study were adults aged ≥18 years, fluent in English, with the capacity to provide informed consent to participate, had diabetes and CKD, and were on or added to the waiting list for an SPKT during the recruitment period. Study invitation letters were sent to eligible patients by nurses at the three sites along with the study information sheet, consent form, the baseline PROMs, and a form so that participants could provide contact details if they wished to be followed up. Stamped addressed envelopes were provided so that individuals could return the consent form, contact details, and the completed set of PROMs to the researcher (KH) at RHUL. Individuals were provided with details to contact the research team with any questions about the study, or to request telephone completion of questionnaires. Where possible, eligible patients who did not return completed PROMs within approximately one month were contacted by the nurses by phone or by post to remind them about the study. Participants were asked to give consent for the nurses to provide information to the researcher (KH) about any treatment changes including transplantation. Follow-up PROMs were sent to participants six and 12 months after recruitment if they were still on the transplant waiting list, and/or 12-months after receiving an SPKT. Where possible participants were contacted by phone prior to posting follow-up PROMs and approximately one month after sending PROMs if they had not been returned.

Measures. Demographic and medical details including age, gender, marital status, education, employment, current renal treatment, diabetes regimen, comorbidities, and recent and ongoing diabetes complications, were collected by self-report from participants at baseline and updated at each follow-up. The baseline questionnaire pack included primary outcome measures of generic QoL, diabetes-dependent QoL (ADDQoL), and renal-dependent QoL (RDQoL). Further measures of renal and diabetes treatment satisfaction (RTSQs and DTSQs), health status and utilities (EQ-VAS and EQ-5D-5L), well-being (W-BQ16), renal service satisfaction

(RSSQ), and diabetes and renal illness perceptions (Brief IPQ) were also included. Individuals who had not received an SPKT within six months of completing the first set of PROMs were asked to complete a shorter questionnaire pack which included the RDQoL, EQ-5D-5L, EQ-VAS, W-BQ16, and single-item measures of generic QoL, diabetes-dependent QoL, and renal and diabetes treatment satisfaction. This shorter set of PROMs was included in an attempt to capture data within six months of transplantation, but without over-burdening the participants with another full set of PROMs.

At 12-months post-recruitment and 12-months post-SPKT, participants were asked to complete the full set of PROMs as they had done at baseline. In addition, participants were asked to complete the change versions of the RTSQ and DTSQ. These asked participants to compare their satisfaction with their experience of transplantation with their previous treatments of CKD and diabetes, and, for those who remained wait-listed, to compare their current treatment to their treatment 12-months prior when they last completed PROMs. SPKT recipients were asked to complete the RMQ to provide information about their anti-rejection medications including their adherence and the inconvenience/difficulty of taking the medications exactly as recommended. SPKT recipients were not asked to complete the diabetes version of the Brief IPQ because individuals often no longer consider themselves to have diabetes post-SPKT. Further details of these measures can be found in Chapter 2. The collection of follow-up data ended in January 2021.

Participants. Figure 4.1 below shows a flow-diagram of the participants recruited to the study. Thirty-four individuals consented to take part in the study and returned completed baseline PROMs. Follow-up PROMs were sent to participants who were still on the waiting list approximately six months and 12 months after recruitment. Individuals who received an SPKT were sent PROMs 12 months post-transplant. Twenty participants completed follow-up measures 12 months after recruitment to the study or 12 months post-SPKT. Three participants who completed PROMs 12-month post-recruitment received an SPKT shortly afterwards and were followed up 12 months post-SPKT within the study period.

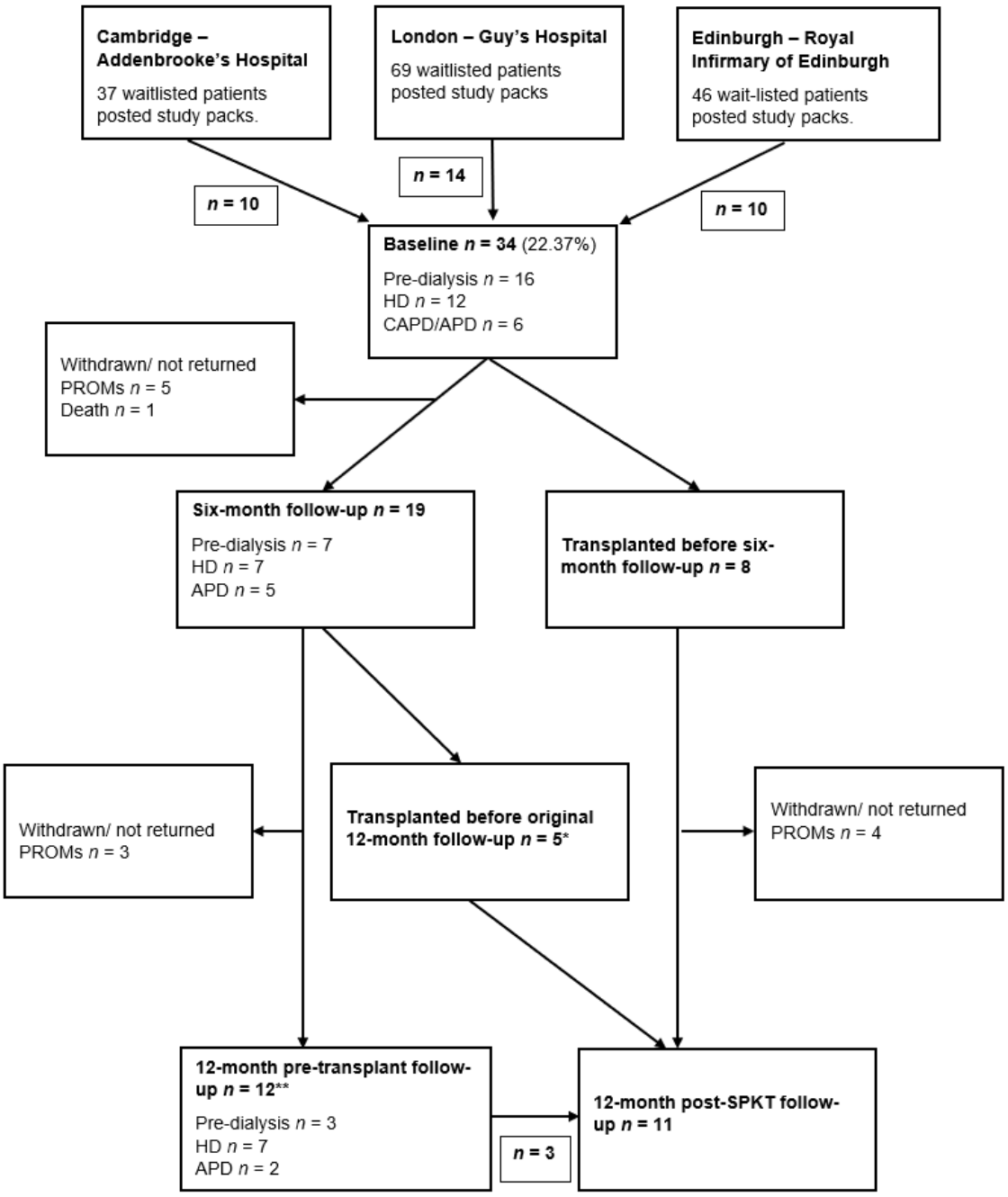

Figure 4.1. Flow diagram of participant recruitment and follow-up for study 2.

Note: *One participant had a transplant after the six-month pre-transplant follow-up but could not be followed up post-SPKT during the study period. **One participant on HD did not provide six-month data but did provide 12-month data.

Analyses. The data were analysed using IBM SPSS Statistics, Version 25.0. Descriptive analyses were carried out; in particular, descriptive results have been reported for the RSSQ and RMQ measures. Mean scores were calculated for each item of the RSSQ and the five highest and lowest rated items are reported based on

this. Missing data were dealt with according to the recommendations for each measure (see Chapter 2). Missing data on the EQ-5D-5L and EQ-VAS were not imputed. Data were checked for normality by assessing the skew and kurtosis. Skew and kurtosis scores divided by their standard errors that were >1.96 were considered to be non-normally distributed (Field, 2013). Histograms and Kolmogorov-Simonov tests were also considered. Where the data were not normally distributed, non-parametric analyses were used. Independent samples t-tests and Mann-Whitney U tests were used to compare different groups on continuous variables, and Chi-square and Fisher's exact tests were used to compare categorical variables. Paired samples t-tests and Wilcoxon Signed Rank tests were carried out to compare within-subjects data. Effect size *r* were calculated for each within-subject comparisons and each between-subject comparisons (Field, 2013).

To assess whether the sample of participants who completed follow-up PROMs were biased, comparisons of baseline demographic and PROMs data were carried out between participants who responded to follow-up (responders) and those who did not (non-responders). Comparisons of baseline data from participants on dialysis and those not yet on dialysis were also carried out. Within-subjects comparisons of baseline and 12-month follow-up PROMs data were carried out for SPKT recipients and participants who remained wait-listed. Where six-month follow-up data were available as the most recent pre-SPKT data (*n* = 4), these scores were substituted for the baseline scores and the analyses of PROMs from pre-to post-SPKT were re-run. Separate analyses were carried out to compare wait-listed participants' and SPKT recipients' PROMs at baseline and follow-up. Lastly, analyses were carried out to determine whether illness perceptions changed from pre- to post-transplant. Pearson's correlation analyses were conducted to assess the relationship between illness perceptions and condition-specific QoL, generic QoL, and treatment satisfaction. Where data were not normally distributed, Kendal's tau correlation analyses were used.

Results

Table 4.1 presents demographic details of the sample. At recruitment, the mean age of the overall sample (*n* = 34) was 39 years (*SD* = 8.81) and included 13 men and 21 women. Participants included those already on the transplant waiting list and those newly added to the transplant waiting list. The mean number of months on the waiting list was 6.54 months (*SD* = 8.14). The majority of the sample were of white ethnicity (88%). Around half of the sample were employed at recruitment with eight in full-time

and eight in part-time employment. At recruitment 16 participants had not yet started on any type of dialysis (47%), 11 were on hospital-based HD (32%), one was on home-based HD (3%), one was on CAPD (3%), and five were on APD (15%). One participant reported having insulin-treated type 2 diabetes whilst all others had type 1 diabetes. Half of the participants reported being on a flexible dose, flexible meal-time diabetes regimen and six (18%) used an insulin pump. The majority of participants (85%) reported having a comorbid health condition such as high blood pressure (68%). Several also reported diabetes complications such as eye problems (82%). One participant reported having a previous failed kidney transplant. Participants reported worrying about their blood sugar levels being too high: always (*n* = 8), often (*n* = 14), sometimes (*n* = 8), or rarely (*n* = 4). All but one participant reported restricting their diet (avoid sugary food and drinks), either always (*n* = 11), often (*n* = 12), sometimes (*n* = 8), or rarely (*n* = 2).

Comparisons between follow-up responders and non-responders. Twenty participants provided follow-up data, nine provided data whilst still on the transplant waiting list approximately 12 months after recruitment and 11 provided data approximately 12 months after receiving an SPKT. Fourteen participants recruited to the study did not provide 12-month follow-up data. One participant recruited to the study died before they could be followed-up and another participant who was due to complete 12-month follow-up questionnaires received a transplant and could not be followed-up 12 months post-SPKT within the study period. These two participants were excluded from baseline comparisons of responders and non-responders to follow-up because they did not have the opportunity to complete follow-up measures. No significant differences were found between responders and non-responders on demographic variables or PROMs at baseline (see Appendix NN, Tables NN1 and NN2).

Comparisons of pre-dialysis and dialysis participants at baseline. Table 4.1 presents the baseline demographic details and comparisons between participants who were pre-dialysis or on dialysis at recruitment. Table 4.2 presents comparisons of baseline PROMs between the two groups. No significant differences were found between patients who had or had not started dialysis on any of the demographic variables or PROMs at baseline.

Renal service satisfaction. At baseline, the RSSQ items with the highest mean scores (indicating greatest satisfaction) amongst individuals not yet on dialysis were: ‘continuity of care’ (*M* = 1.69, *SD* = 0.60); ‘discussing with staff any problems

you may have' (*M* = 1.63, *SD* = 0.81); 'information given to you by the staff regarding your results' (*M* = 1.56, *SD* = 0.63); 'cleanliness of the clinic and other treatment areas in the hospital' (*M* = 1.56, *SD* = 0.63); and 'care taken by staff over hygiene' (*M* = 1.56, *SD* = 0.63). The lowest rated items were: 'availability of refreshments' (*M* = 0.31, *SD* = 1.18); 'social worker advice and support' (*M* = 0.63, *SD* = 0.92); 'surgical procedures' (*M* = 0.67, *SD* = 1.63); 'psychological advice and support' (*M* = 0.73, *SD* = 1.27); and 'ease with which staff are able to access hospital notes and recent results' (*M* = 0.94, *SD* = 0.99). However, it should be noted that several participants indicated that these items were not applicable. For example, one of 16 participants indicated being slightly dissatisfied but eight indicated that 'social worker advice and support' was not applicable. For participants on dialysis, the highest rated items were: 'care taken by staff over hygiene' (*M* = 1.39, *SD* = 1.33); 'how you are treated as a person by the staff' (*M* = 1.33, *SD* = 1.19); 'the value to you in talking to staff' (*M* = 1.28, *SD* = 1.18); 'the extent to which computers are used to improve the quality of care you receive' (*M* = 1.25, *SD* = 1.13); and 'cleanliness of the clinic and other treatment areas in the hospital' (*M* = 1.24, *SD* = 1. 35). The lowest rated items were: 'social worker advice and support' (*M* = -0.14, *SD* = 1.29); 'psychological advice and support' (*M* = 0.21, *SD* = 1.37); 'ease of getting to the hospital/unit' (*M* = 0.31, *SD* = 1.35); 'availability of refreshments' (*M* = 0.38, *SD* = 1.20); and 'comfort of the waiting areas' (*M* = 0.41, *SD* = 1.46). Again, some participants indicated these items were not applicable. For example, 43% and 29% of 14 patients indicated they were slightly dissatisfied/dissatisfied with social worker and psychological advice and support respectively. (See Appendix NN, Tables NN3 and NN4 for further details of highest and lowest rated RSSQ items.)

Table 4.1.

Baseline Participant Demographic Characteristics and Comparisons between Pre-dialysis and Dialysis Participants

Variable	All participants (*n* = 34)	Pre-dialysis (*n* = 16)	Dialysis (*n* = 18)	*p*
Age *Mdn (IQR)*	36.50 (11.25)	36.50 (10.50)	37.50 (17.00)	.878
BMI *M (SD)*	24.10 (3.58)	24.73 (3.62)	23.42 (3.53)	.302
Sex: male *n (%)*	13.00 (38.24)	5.00 (31.25)	8.00 (44.44)	.429
Diabetes duration in years *M (SD)*	26.74 (9.87)	26.10 (9.92)	26.08 (10.27)	.996
Months on waiting list *Mdn (IQR)*	3.00 (13.25)	3.50 (9.88)	2.75 (12.00)	.551
Ethnicity *n (%)*				.257
White British/European	30.00 (88.24)	13.00 (81.25)	17.00 (94.44)	
African	1.00 (2.94)	1.00 (6.25)	0.00	
Indian	1.00 (2.94)	0.00	1.00 (5.56)	
Pakistani	1.00 (2.94)	1.00 (6.25)	0.00	
White and Asian	1.00 (2.94)	1.00 (6.25)	0.00	
Marital status *n (%)*				.370
Married/civil partnership/ living with a partner	21.00 (61.76)	11.00 (68.75)	10.00 (55.56)	
Divorced/separated	1.00 (2.94)	1.00 (6.25)	0.00	
Single	12.00 (35.29)	4.00 (25.00)	8.00 (44.44)	
Education *n (%)*				.487
No formal qualification	1.00 (2.94)	1.00 (6.25)	0.00	
Basic qualification	20.00 (58.82)	8.00 (50.00)	12.00 (66.67)	
Higher qualification	13.00 (38.24)	7.00 (43.75)	6.00 (33.33)	
Employment *n (%)*				.367
Unemployed	16.00 (47.06)	6.00 (37.50)	10.00 (55.56)	
Part-time	8.00 (23.53)	5.00 (31.25)	3.00 (16.67)	
Full-time	8.00 (23.53)	5.00 (31.25)	3.00 (16.67)	
Retired	2.00 (5.88)	0.00	2.00 (11.11)	
Renal treatment *n (%)*				n/a
Pre-dialysis	16.00 (47.06)	16.00 (100.00)	n/a	
Hospital-based HD	11.00 (32.35)	n/a	11.00 (61.11)	
Home-based HD	1.00 (2.94)	n/a	1.00 (5.56)	
APD	5.00 (14.71)	n/a	5.00 (27.78)	
CAPD	1.00 (2.94)	n/a	1.00 (5.56)	
Diabetes treatment *n (%)*				.418
Two injections mixed insulin	2.00 (5.88)	0.00	2.00 (11.11)	
Basal/bolus, fixed doses, fixed mealtimes	2.00 (5.88)	2.00 (12.50)	0.00	
Basal/bolus, flexible doses, fixed mealtimes	4.00 (11.76)	1.00 (6.25)	3.00 (16.67)	
Basal/bolus, flexible doses, flexible mealtimes	17.00 (50.00)	7.00 (43.75)	10.00 (55.56)	
Insulin pump	6.00 (17.65)	4.00 (25.0)	2.00 (11.11)	

Variable	All participants	Pre-dialysis	Dialysis	*p*
Other diabetes treatment**	2.00 (5.88)	1.00 (6.25)	1.00 (5.56)	
Previous other transplant *n (%)*	1.00 (2.94)	0.00	1.00 (5.56)	1.000
Number of comorbidities *M (SD)*	1.82 (1.24)	1.69 (1.01)	1.8 (1.29)	.720
Comorbidities *n (%)*	29.00 (85.29)	14 (87.50)	15.00 (83.33)	1.00
Anaemia	16.00 (47.06)	8.00 (50.00)	8.00 (44.44)	.746
High blood pressure	23.00 (67.65)	11.00 (68.75)	12.00 (66.67)	.897
Liver disease	1.00 (2.94)	1.00 (6.25)	0.00	.471
Joint problems	3.00 (8.82)	1.00 (6.25)	2.00 (11.11)	1.00
Lung problems	2.00 (5.88)	0.00	2.00 (11.11)	.487
Cancer	0.00	0.00	0.00	-
Stroke	2.00 (5.88)	1.00 (6.25)	1.00 (5.56)	1.00
Heart problems	3.00 (8.82)	0.00	3.00 (16.67)	.230
Circulatory problems	3.00 (8.82)	1.00 (6.25)	2.00 (11.11)	1.00
Chronic viral infection	0.00	0.00	0.00	-
Memory problems	0.00	0.00	0.00	-
Mental health problems	5.00 (14.71)	3.00 (18.75)	2.00 (11.11)	.648
Other	3 (8.82)	2 (12.5)	1 (5.56)	.591
Number of diabetes complications *M (SD)*	2.24 (1.44)	1.81 (1.45)	2.67 (1.50)	.085
Diabetes complications *n (%)*				
Eye problems	28.00 (82.35)	12.00 (75.00)	16.00 (88.89)	.387
Nerve problems	18.00 (52.94)	8.00 (50.00)	10.00 (55.56)	.746
Foot problems	5.00 (14.71)	1.00 (6.25)	4.00 (22.22)	.340
Amputation	0.00	0.00	0.00	-
Ketoacidosis	11.00 (32.35)	3.00 (18.75)	8.00 (44.44)	.152
Severe hypoglycaemia	9.00 (26.47)	2.00 (12.50)	7.00 (38.89)	.125
Other	5.00 (14.71)	2.00 (12.50)	3.00 (16.67)	1.00
Visual impairment *n (%)*				.236
Visually impaired	2.00 (5.88)	2.00 (12.50)	0.00	
Severely visually impaired*	2.00 (5.88)	0.00	2.00 (11.11)	
Registered disabled* *n (%)*	11.00 (32.35)	4.00 (25.0)	7.00 (38.89)	.712

Note. Mdn: median; *IQR*: interquartile range; *M*: mean; *SD*: standard deviation.
*Missing data for one participant.
** Other: DAFNE; 5x insulin injections per day before meals/snacks; Basal/Bolus but flexibility unclear.

Table 4.2.

T-test and Mann-Whitney U test Comparisons of Baseline PROs between Pre-dialysis and Dialysis Participants

Measures	**Pre-dialysis**	**Dialysis**					
	M (SE)	***M (SE)***	***Mean difference (95% CI)***	***t***	***df***	***p***	***r***
Generic QoL (*n* = 34)	0.06 (0.43)	-0.78 (0.28)	0.84 (-0.21, 1.89)	1.63	32	.113	.28
ADDQoL AWI (*n* = 34)	-4.12 (0.49)	-4.69 (0.44)	0.57 (-0.78, 1.91)	0.86	32	.395	.15
RDQoL AWI (*n* = 34)	-4.36 (0.63)	-5.55 (0.43)	1.19 (-0.34, 2.72)	1.58	32	.123	.27
RTSQs (*n* = 34)	55.55 (3.41)	47.57 (3.70)	7.98 (-2.35, 18.31)	1.57	32	.125	.27
DTSQs-item 2 (*n* = 33)	2.63 (0.36)	3.35 (0.44)	-0.73 (-1.89, 0.44)	-1.27	31	.213	.22
EQ-VAS (*n* = 32)	49.33 (5.77)	50.88 (5.57)	-1.55 (-18.36, 15.27)	-0.19	30	.852	.03
W-BQ16 (*n* = 33)	21.56 (2.81)	21.56 (2.12)	0.00 (-7.12, 7.12)	0.00	31	.999	.00
W-BQ12 (*n* = 34)	16.13 (1.96)	15.44 (1.35)	0.68 (-4.08, 5.44)	0.29	32	.773	.05
Negative W-B (*n* = 34)	4.81 (0.92)	4.33 (0.51)	0.48 (-1.60, 2.56)	0.46	23.73	.653	.09

Measures	Pre-dialysis	Dialysis					
	M (SE)	***M (SE)***	***Mean difference (95% CI)***	***t***	***df***	***p***	***r***
Positive W-B (*n* = 34)	5.50 (0.82)	4.89 (0.72)	0.61 (-1.61, 2.83)	0.56	32	.579	.10
Energy (*n* = 34)	3.06 (0.67)	2.64 (0.55)	0.42 (-1.33, 2.18)	0.49	32	.627	.09
Stress (*n* = 33)	6.19 (0.86)	6.18 (0.93)	0.01 (-2.57, 2.60)	0.01	31	.993	.00
	Mdn (IQR)	***Mdn (IQR)***		***U***		***p***	***r***
Renal-Dependent QoL Overview (*n* = 34)	-2.00 (1.00)	-3.00 (1.00)		116.00		.347	-.18
DTSQs (*n* = 33)	30.00 (7.50)	25.00 (12.80)		86.00		.074	-.31
DTSQs-item 3 (*n* = 33)	2.00 (1.75)	2.00 (1.50)		162.00		.363	.17
EQ-5D-5L utility (*n* = 32)	0.84 (0.38)	0.75 (0.34)		123.00		.882	-.03

Note. M: mean; *SE*: standard error; *Mdn*: median; *IQR*: interquartile range; *r*: effect size; ADDQoL AWI: Audit of Diabetes Dependent Quality of Life average weighted impact score (-9-3, indicates maximum negative impact/importance to maximum positive impact/importance); DTSQs: Diabetes Treatment Satisfaction Questionnaire status version (0-36, higher scores indicate better satisfaction); DTSQs-item 2: perceived frequency of unacceptably high blood sugars (0-6, none of the time to most of the time); DTSQs-item 3: perceived frequency of unacceptably low blood sugars (0-6, none of the time to most of the time); Energy: Energy subscale of W-BQ16 (0-12, higher scores indicate better energy); EQ-5D-5L utility: EuroQoL-5 Dimension-5 Level utility score (-0.28- +1, state worse than death to optimal health state); EQ-VAS: EuroQol Visual Analogue Scale of perceived health status (0-100, higher scores indicate better perceived health); Generic QoL: Generic Quality of Life (-3- +3, indicates extremely bad to excellent quality of life); Negative W-B: Negative Well-Being subscale of W-BQ16 (0-12, higher scores indicate worse negative well-being); Positive W-B: Positive Well-Being subscale of W-BQ16 (0-12, higher scores indicate better positive well-being); RDQoL AWI: Renal Dependent Quality of Life average weighted impact score (-9-3, indicates maximum negative impact/importance to maximum positive impact/importance); Renal-Dependent QoL Overview: overview item of impact of the renal condition on quality of life (-3- +1, indicates maximum negative impact to positive impact); RTSQs: Renal Treatment Satisfaction Questionnaire status version (0-78, higher scores indicate better satisfaction); Stress: Stress subscale of W-BQ16 (0-12, higher scores indicate worse stress); W-BQ12: Well-Being Questionnaire 12-item version (0-36, higher scores indicate better general well-being); W-BQ16: Well-Being Questionnaire 16-item version (0-48, higher scores indicate better general well-being).

Comparisons of PROs from baseline to approximately 12-months follow-up. Table 4.3 presents the baseline demographics for the nine participants who remained wait-listed at follow-up and the 11 SPKT recipients who provided follow-up data approximately 12 months post-transplant (*M* = 12.90 months, *SD* = 2.28). Six participants received pre-emptive SPKTs, whilst two had been on HD and three had been on APD. Participants received their transplant after a mean of 19 months on the waiting list (*SD* = 8.15; range = 1.00-29.00). The median age of SPKT recipients at baseline was 34 years and the sample included five men and six women. Even after a successful SPKT, several recipients reported that they often (*n* = 1) or sometimes (*n* = 4) worried about their blood sugar levels being too high, and often (*n* = 3) or sometimes (*n* = 5) restricted their diet/ avoided sugary foods or drink. Six SPKT recipients reported monitoring their blood glucose levels since their transplant. It is important to note that eight of the 11 SPKT recipients (73%) completed their post-transplant PROMs after 23rd March 2020, when restrictions due to the COVID-19 pandemic were first announced.

Medications. All 11 of the SPKT recipients reported taking a form of Mycophenolic acid, 10 reported also taking Tacrolimus, and six were also on the steroid medication Prednisolone. Adherence, whether participants took each medication exactly as recommended, was assessed on a scale of 0 (none of the time) to 6 (all of the time). Participants often reported high levels of adherence, defined as scores of 6 or 5: Mycophenolic acid (91% scored 6); Tacrolimus (90% scored 6 with 1 missing); Prednisolone (83% scored 6, 17% scored 5). On the same scale of 0 to 6, participants indicated that the medications were generally not inconvenient/difficult to take as prescribed, defined as scores of 0 or 1: Mycophenolic acid (72% scored 0, 18% scored 1); Tacrolimus (60% scored 0, 20% scored 1); Prednisolone (83% scored 0, 17% scored 1).

Table 4.3.

Baseline Demographic Characteristics and Comparisons between Wait-listed Participants and SPKT Recipients

Variable	**Wait-listed** (*n* = 9)	**SPKT** (*n* = 11)	***p***
Age *Mdn (IQR)*	41.00 (14.50)	34.00 (6.00)	.261
BMI *M (SD)*	24.61 (1.36)	23.43 (0.75)	.434
Diabetes duration in years *M (SD)*	29.28 (11.23)	23.80 (5.37)	.209
Months on waiting list *M (SD)*	1.72 (2.18)	12.95 (8.34)	**.001**
Sex: male *n (%)*	2.00 (22.22)	5.00 (45.45)	.374
Ethnicity *n (%)*			.711
White British/European	8.00 (88.89)	10.00 (90.91)	
Indian	1.00 (11.11)	0.00	
White and Asian	0.00	1.00 (9.09)	
Marital status *n (%)*			1.00
Married/civil partnership/living with a partner	6.00 (66.67)	7.00 (63.64)	
Single	3.00 (33.33)	4.00 (36.36)	
Education *n (%)*			.175
No formal qualification	0.00	1.00 (9.09)	
Basic qualification	3.00 (33.33)	7.00 (63.64)	
Higher qualification	6.00 (66.67)	3.00 (27.27)	
Employment *n (%)*			.156
Unemployed	4.00 (44.44)	7.00 (63.64)	
Part-time	2.00 (22.22)	4.00 (36.36)	
Full-time	3.00 (33.33)	0.00	
Renal treatment (when wait-listed) *n (%)*			.850
Pre-dialysis	4.00 (44.44)	6.00 (54.55)	
Hospital HD	3.00 (33.33)	2.00 (18.18)	
APD	2.00 (22.22)	3.00 (27.27)	
Diabetes treatment (when wait-listed) *n (%)*			1.00
Two injections mixed insulin	1.00 (11.11)	1.00 (9.09)	
Basal/bolus, fixed doses, fixed meals	0.00	1.00 (9.09)	
Basal/bolus, flexible doses, fixed meals	1.00 (11.11)	1.00 (9.09)	
Basal/bolus, flexible doses, flexible meals	5.00 (55.56)	5.00 (45.45)	
Insulin pump	2.00 (22.22)	3.00 (27.27)	

Variable	Wait-listed	SPKT	*p*
Previous other transplant *n (%)*	1.00 (11.11)	0.00	.450
Number of comorbidities *M (SD)*	2.32 (1.22)	1.91 (1.45)	.494
Number of complications *M (SD)*	2.78 (2.22)	2.46 (1.03)	.588
Visual impairment *n (%)*			.230
Visually impaired	0.00	2.00 (18.18)	
Severely visually impaired	0.00	2.00 (18.18)	
Registered disabled* *n (%)*	3.00 (33.33)	5.00 (45.45)	.670

Note. M: mean; *SD*: standard deviation; *Mdn*: Median; *IQR*: interquartile range; BMI: body mass index; SPKT: simultaneous pancreas and kidney transplant.
* Missing data for one participant.

PROs from pre- to post-SPKT. Table 4.4 presents results from the paired-samples t-test and Wilcoxon Signed Rank test comparisons of PROMs data from pre- to post-SPKT. Generic QoL significantly improved from baseline to post-SPKT with a large effect size; $t(10) = -5.19$, $p < .001$, $r = .85$. ADDQoL AWI scores also improved significantly with a medium effect size, indicating that participants' QoL was less negatively impacted by their diabetes after transplantation; $T = 56.00$, $p = .041$, $r = .44$. However, Renal-Dependent QoL Overview item scores and RDQoL AWI scores did not change significantly from pre- to post-SPKT.

Both diabetes and renal treatment satisfaction improved significantly from pre- to post-SPKT with large effect sizes; $t(10) = -4.09$, $p = .002$, $r = .79$, and $t(10) = -5.60$, $p < .001$, $r = .87$, respectively. Item 2 and item 3 of the DTSQs significantly improved indicating that SPKT recipients experienced unacceptably high or low blood sugar levels less frequently after their transplant; $t(10) = 5.83$, $p < .001$, $r = .88$, and $T = 3.00$, $p = .007$, $r = -.58$, respectively. EQ-VAS health status scores significantly improved with a medium effect size; $T = 39.00$, $p = .047$, $r = .44$. However, the EQ-5D-5L utility scores did not change significantly. Overall, the W-BQ16 scores significantly improved with a medium effect size; $T = 48.50$, $p = .032$, $r = .48$. The Energy and Positive Well-Being subscales improved significantly with large effect sizes; $t(10) = -2.99$, $p = .014$, $r = .69$, and $t(10) = -3.73$, $p = .004$, $r = .73$, respectively. However, Negative Well-Being and Stress sub-scale scores did not change significantly from pre- to post-SPKT.

Four SPKT recipients completed the shorter set of PROMs six months after completing baseline PROMs whilst still on the transplant waiting list. The remaining seven SPKT recipients all received their transplants within around six months of

completing the baseline measures so did not complete the second batch of pre-transplant measures. T-tests and Wilcoxon Signed Rank tests were carried out to compare pre- and post-SPKT PROMs using the most recent pre-transplant data by including the four participants' six-month data at baseline. Results of the analyses were similar to those presented in Table 4.4 and indicated significant pre- to post-SPKT improvements in Generic QoL, overall Well-Being, Energy subscale scores, and EQ-VAS health status (see Appendix NN, Table NN5). However, pre- (M = 5.18, SE = 0.88) to post-SPKT (M = 6.55, SE = 0.79) improvements in Positive Well-Being subscale scores were no longer significant, $t(10) = -2.19$, $p = .053$, $r = .57$. Furthermore, the decrease in Stress subscale scores from pre- (M = 7.36, SE = 0.82) to post-SPKT (M = 5.27, SE = 0.95) became significant, $t(10) = 2.81$, $p = .018$, $r = .66$.

Table 4.4.

T-test and Wilcoxon Signed Rank test Repeated Measures Comparisons of PROs from Pre- to 12-months Post-SPKT

Measures	**Baseline**		**12-months post-SPKT**					
	M (SE)	***Range***	***M (SE)***	***Range***	***t***	***df***	***p***	***r***
Generic QoL (*n* = 11)	0.00 (0.36)	-1.00, 2.00	1.73 (0.19)	1.00, 3.00	-5.19	10	**<.001**	**.85**
RDQoL AWI (*n* = 11)	-5.08 (0.60)	-7.76, -2.24	-3.59 (0.73)	-7.81, 0.00	-1.72	10	.116	.48
DTSQs (*n* = 11)	27.25 (1.77)	15.00, 34.80	35.27 (0.51)	31.00, 36.00	-4.09	10	**.002**	**.79**
DTSQs-item 2 (*n* = 11)	3.18 (0.50)	1.00, 6.00	0.09 (0.09)	0.00, 1.00	5.83	10	**<.001**	**.88**
RTSQs (*n* = 11)	52.50 (3.19)	36.00, 72.00	70.59 (1.94)	59.00, 78.00	-5.60	10	**.000**	**.87**
EQ-5D-5L utility (*n* = 10)	0.71 (0.07)	0.31, 1.00	0.73 (0.06)	0.48, 1.00	-0.40	9	.702	.13
Negative W-B (*n* = 11)	4.64 (0.81)	1.00, 8.00	3.36 (0.73)	0.00, 7.00	1.24	10	.244	.36
Positive W-B (*n* = 11)	4.36 (0.94)	0.00, 10.00	6.55 (0.79)	3.00, 12.00	-3.73	10	**.004**	**.76**
Energy (*n* = 11)	2.09 (0.68)	0.00, 7.00	5.82 (0.91)	0.00, 9.00	-2.99	10	**.014**	**.69**
Stress (*n* = 10)	6.60 (0.95)	1.00, 12.00	5.40 (1.05)	0.00, 10.00	1.43	9	.182	.43

Measures	Baseline		12-months post-SPKT				
	Mdn (IQR)	***Range***	***Mdn (IQR)***	***Range***	***T***	***p***	***r***
Renal-Dependent QoL Overview (*n* = 11)	-3.00 (1.00)	-3.00, 0.00	-3.00 (3.00)	-3.00, 0.00	12.00	.221	.26
ADDQoL AWI (*n* = 11)	-5.53 (2.78)	-7.11, -2.50	-3.74 (3.52)	-6.42, -0.21	56.00	.**041**	**.44**
DTSQs-item 3 (*n* = 11)	3.00 (2.00)	1.00, 5.00	0.00 (0.00)	0.00, 3.00	3.00	**.007**	**-.58**
EQ-VAS (*n* = 11)	47.50 (32.50)	30.00, 80.00	70.00 (20.00)	40.00, 90.00	39.00	**.047**	**.44**
W-BQ12 (*n* = 11)	12.00 (14.00)	6.00, 22.00	21.00(10.00)	12.00, 32.00	61.00	**.013**	**.53**
W-BQ16 (*n* = 10)	20.00 (13.75)	6.00, 33.00	28.75 (15.63)	14.00, 44.00	48.50	**.032**	**.48**

Note: M. mean; *SE*: standard error; *Mdn*: median; *IQR*: interquartile range; *r*: effect size; SPKT: simultaneous pancreas and kidney transplant; ADDQoL AWI: Audit of Diabetes Dependent Quality of Life average weighted impact score; DTSQs: Diabetes Treatment Satisfaction Questionnaire status version; DTSQs-item 2: assesses perceived frequency of unacceptably high blood sugars; DTSQs-item 3: perceived frequency of unacceptably low blood sugars; Energy: Energy subscale of W-BQ16; EQ-5D-5L utility: EuroQoL-5 Dimension-5 Level utility score; EQ-VAS: EuroQol Visual Analogue Scale of perceived health status; Generic QoL: Generic Quality of Life; Negative W-B: Negative Well-Being subscale of W-BQ16; Positive W-B: Positive Well-Being subscale of W-BQ16; RDQoL AWI: Renal Dependent Quality of Life average weighted impact score; Renal-Dependent QoL Overview: overview item of impact of the renal condition on quality of life; RTSQs: Renal Treatment Satisfaction Questionnaire status version; Stress: Stress subscale of W-BQ16; W-BQ12: Well-Being Questionnaire 12-item version; W-BQ16: Well-Being Questionnaire 16-item version.

Wait-listed participants' PROs. Baseline demographic characteristics for the nine participants who remained wait-listed at follow-up are presented in Table 4.3. At baseline, the median age of the participants who remained wait-listed was 41 years and the sample included two men and seven women. Of the nine participants who remained wait-listed, three had remained on HD, and one had remained on APD at 12-month follow-up. One participant had changed from APD to HD. Of the four participants who were not on dialysis at recruitment, one had begun APD, and one had begun HD by 12-month follow-up. Three of the nine participants (33%) completed their follow-up PROMs after 23rd March 2020, when restrictions for the COVID-19 pandemic were first announced; however, one of these participants completed their PROMs only a few days after 23rd March 2020.

Table 4.5 presents the repeated measures comparisons of wait-listed participants' baseline and follow-up PROMs data. No significant differences were found between baseline and 12-month follow-up, only a non-significant trend indicated that renal treatment satisfaction scores worsened over time; $t(8) = 2.23$, $p = .056$, $r = .62$.

Table 4.5.

T-test and Wilcoxon Signed Rank test Repeated Measures Comparisons of Wait-listed Participants' Baseline and 12-month Follow-up PROs

Measures	**Baseline**		**12-month follow-up**					
	M (SE)	***Range***	***M (SE)***	***Range***	***t***	***df***	***p***	***r***
Generic QoL (*n* = 9)	-0.22 (0.62)	-3.00, 3.00	0.44 (0.60)	-1.00, 3.00	-2.00	8	.081	.58
ADDQoL AWI (*n* = 9)	-3.41 (0.67)	-6.29, -0.42	-2.91 (0.60)	-5.83, -0.37	-0.82	8	.436	.28
Renal-Dependent QoL Overview (*n* = 9)	-2.22 (0.22)	-3.00, -1.00	-2.00 (0.29)	-3.00, -1.00	-1.00	8	.347	.33
DTSQs (*n* = 8)	27.35 (2.50)	15.00, 35.00	27.50 (3.42)	9.00, 36.00	-0.09	7	.932	.03
RTSQs (*n* = 9)	57.67 (3.96)	36.00, 75.00	49.00 (6.16)	19.00, 77.00	2.23	8	**.056**	**.62**
EQ-VAS (*n* = 9)	55.00 (8.78)	20.00, 90.00	57.56 (9.60)	10.00, 98.00	-0.38	8	.715	.13
EQ-5D-5L utility (*n* = 9)	0.73 (0.08)	0.29, 0.94	0.62 (0.12)	-0.05, 1.00	1.22	8	.256	.40
W-BQ16 (*n* = 9)	24.33 (3.54)	8.00, 40.00	24.56 (4.56)	3.00, 42.00	-0.11	8	.919	.04
W-BQ12 (*n* = 9)	17.56 (2.54)	7.00, 30.00	18.22 (3.48)	3.00, 33.00	-0.42	8	.679	.15
Negative W-B (*n* = 9)	4.33 (0.78)	2.00, 9.00	4.56 (1.17)	0.00, 11.00	-0.30	8	.772	.11
Positive W-B (*n* = 9)	5.89 (1.05)	2.00, 11.00	5.89 (1.33)	1.00, 11.00	0.00	8	1.00	.00
Stress (*n* = 9)	5.22 (1.18)	1.00, 11.00	5.67 (1.26)	0.00, 12.00	-0.52	8	.616	.18

Measures	Baseline		12-month follow-up				
	Mdn (IQR)	***Range***	***Mdn (IQR)***	***Range***	***T***	***p***	***r***
RDQoL AWI (*n* = 9)	-5.44 (3.71)	-6.24, -0.53	-4.35 (3.68)	-6.47, -0.41	30.00	.374	.21
Energy (*n* = 9)	4.00 (4.50)	0.00, 9.00	4.00 (7.00)	0.00-11.00	8.50	.196	.30

Note. M: mean; *SE*: standard error; *Mdn*: median; *IQR*: interquartile range; *r*: effect size; SPKT: simultaneous pancreas and kidney transplant; ADDQoL AWI: Audit of Diabetes Dependent Quality of Life average weighted impact score; DTSQs: Diabetes Treatment Satisfaction Questionnaire status version; Energy: Energy subscale of W-BQ16; EQ-5D-5L utility: EuroQoL-5 Dimension-5 Level utility score; EQ-VAS: EuroQol Visual Analogue Scale of perceived health status; Generic QoL: Generic Quality of Life; Negative W-B: Negative Well-Being subscale of W-BQ16; Positive W-B: Positive Well-Being subscale of W-BQ16; RDQoL AWI: Renal Dependent Quality of Life average weighted impact score; Renal-Dependent QoL Overview: overview item of impact of the renal condition on quality of life; RTSQs: Renal Treatment Satisfaction Questionnaire status version; Stress: Stress subscale of W-BQ16; W-BQ12: Well-Being Questionnaire 12-item version; W-BQ16: Well-Being Questionnaire 16-item version.

Comparisons of wait-listed participants and SPKT recipients.

Comparisons of wait-listed participants' and SPKT recipients' baseline demographic characteristics are presented in Table 4.3. At baseline, participants who received an SPKT had been on the transplant waiting list for significantly longer (M = 12.95 months, SD = 8.34) than those who remained on the waiting list (M = 1.72 months, SD = 2.18), $t(11.64) = -4.29$, $p = .001$. There were no other significant differences in baseline demographics between the two groups.

No significant differences were found between wait-listed participants and SPKT recipients' baseline PROMs data (see Appendix NN, Table NN6). Results of the independent t-tests and Mann Whitney U test comparisons of wait-listed participants' and SPKT recipients' follow-up PROMs data are presented in Table 4.6 below. At follow-up, SPKT recipients reported significantly better DTSQs and RTSQs scores compared to those still on the waiting list, with large effect sizes; $U = 83.00$, $p = .010$, $r = .62$, and $t(9.59) = -3.34$, $p = .008$, $r = .73$, respectively. As expected, SPKT recipients reported significantly lower scores on items 2 and 3 of the DTSQs with large effect sizes, indicating that they experienced unacceptably high or low blood sugars less frequently than wait-listed participants, $U = 0.50$, $p < .001$, $r = -.89$, and $U = 17.50$, $p < .012$, $r = -.60$, respectively. Significant differences at follow-up were also found between wait-listed participants' and SPKT recipients' scores on the change versions of the DTSQ and RTSQ; $U = 83.50$, $p = .007$, $r = .59$, and $U = 95.00$, $p < .001$, $r = .78$, respectively. These findings suggest that SPKT recipients were more satisfied with their renal and diabetes treatment than those who remained wait-listed. There were no other significant differences between the two groups at follow-up.

Renal service satisfaction. Among wait-listed participants, the items on the RSSQ with the highest mean scores were: 'how you are treated as a person by the staff'; 'the extent to which staff are caring and supportive'; 'cleanliness of the clinic and other treatment areas in the hospital'; 'care taken by staff over hygiene' (all M = 1.78, SD = 0.44); and 'arrangement of giving blood samples for routine measures of renal control' (M = 1.67, SD = 0.50). The items with the lowest mean scores were: 'availability of refreshments', and 'social worker advice and support' (both M = 0.00, SD = 1.26), although these two items were reported as non-applicable by three of the nine participants. Satisfaction scores were also low for: 'psychological advice and support' (M = 0.33, SD = 1.22); 'comfort of the waiting areas' (M = 0.78, SD = 1.30); and 'opportunities to talk with other patients who have

renal failure' (*M* = 0.88, *SD* = 1.36). For example, two participants indicated being slightly dissatisfied with 'opportunities to talk to other patients' and one was dissatisfied with social worker and psychological advice and support. Among SPKT recipients, the RSSQ items with the highest mean scores were: 'the value to you in talking to staff'; 'discussing with staff any problems you may have'; 'surgical procedures'; 'privacy' (all *M* = 1.82, *SD* = 0.40); and 'the extent to which you feel understood by the staff' (*M* = 1.77, *SD* = 0.41). The item with the lowest mean score was 'social worker advice and support' (*M* = 0.43, *SD* = 0.98), with one participant indicating they were slightly dissatisfied, although four participants indicated that this item was not applicable. Other lowest rated items included: 'opportunities to talk with other patients who have renal failure' (*M* = 0.55, *SD* = 1.13); 'psychological advice and support' (*M* = 0.56, *SD* = 1.13); 'ease of getting to the hospital/unit' (*M* = 0.73, *SD* = 1.01); and 'availability of refreshments' (*M* = 0.73, *SD* = 1.27). Two participants reported being slightly dissatisfied with 'opportunities to talk with other patients' and 'psychological advice and support'. (See Appendix NN, Tables NN7 and NN8 for further details of the five highest and lowest rated RSSQ items.)

Table 4.6.

T-test and Mann Whitney U test Comparisons Between Wait-listed Participants' and SPKT Recipients' PROs at 12-month Follow-up

Measures	**Wait-listed** (*n* = 9)	**SPKT** (*n* = 11)					
	M (SE)	***M (SE)***	***Mean difference (95% CI)***	***t***	***df***	***p***	***r***
ADDQoL AWI	-2.91 (0.60)	-3.47 (0.63)	0.56 (-1.29, 2.41)	0.64	18	.530	.15
RDQoL AWI	-3.73 (0.71)	-3.59 (0.73)	-0.14 (-2.31, 2.03)	-0.14	18	.894	.03
RTSQs	49.00 (6.16)	70.59 (1.94)	-21.59 (-36.08, -7.11)	-3.34	9.59	**.008**	**.73**
EQ-VAS	57.56 (9.60)	70.91 (4.31)	-13.35 (36.47, 9.77)	-1.27	11.18	.230	.35
EQ-5D-5L utility	0.62 (0.12)	0.73 (0.05)	-0.11 (-0.40, 0.18)	-0.84	11.21	.417	.24
W-BQ12	18.22 (3.48)	21.00 (1.93)	-2.78 (-10.73, 5.18)	-0.73	18	.473	.17
W-BQ16	24.56 (4.56)	27.72 (2.78)	-3.17 (-13.96, 7.62)	-0.62	18	.545	.14
Negative W-B	4.56 (1.17)	3.36 (0.73)	1.19 (-1.59, 3.98)	0.90	18	.381	.21
Positive W-B	5.89 (1.33)	6.55 (0.79)	-0.66 (-3.77, 2.46)	-0.44	18	.663	.10

Measures	**Wait-listed** (*n* = 9)	**SPKT** (*n* = 11)					
	M (SE)	***M (SE)***	***Mean difference (95% CI)***	***t***	***df***	***p***	***r***
Energy	4.89 (1.29)	5.82 (0.91)	-0.93 (-4.15, 2.30)	-0.61	18	.553	.14
Stress	5.67 (1.26)	5.27 (0.95)	0.39 (-2.86, 3.65)	0.25	18	.802	.06
	Mdn (IQR)	***Mdn (IQR)***		***U***		***p***	***r***
Generic QoL	-1.00 (3.50)	2.00 (1.00)		69.00		.152	.34
Diabetes-Dependent QoL Overview	-2.00 (3.00)	-3.00 (1.00)		38.50		.412	-.21
Renal-Dependent QoL Overview	-2.00 (2.00)	-3.00 (3.00)		45.00		.766	-.08
DTSQs	27.00 (13.50)	36.00 (0.00)		83.00		**.010**	**.62**
DTSQs-item 2	3.00 (2.00)	0.00 (0.00)		0.50		**<.001**	**-.89**
DTSQs-item 3	2.00 (3.00)	0.00 (0.00)		17.50		**.012**	**-.60**
DTSQc	5.00 (13.50)	18.00 (4.00)		83.50		**.007**	**.59**
RTSQc	2.00 (21.50)	38.00 (9.00)		95.00		**.000**	**.78**

Note. M: mean; *SE*: standard error; *Mdn*: median; IQR: interquartile range; SPKT: simultaneous pancreas and kidney transplant; ADDQoL AWI: Audit of Diabetes Dependent Quality of Life average weighted impact score; Diabetes-dependent QoL Overview: overview item of impact of diabetes on quality of life; DTSQs: Diabetes Treatment Satisfaction Questionnaire status version; DTSQs-item 2: perceived frequency of unacceptably high blood sugars; DTSQs-item 3: perceived frequency of unacceptably low blood sugars; Energy: Energy subscale of W-BQ16; EQ-5D-5L utility: EuroQoL-5 Dimension-5 Level utility score; EQ-VAS: EuroQol Visual Analogue Scale of perceived health status; Generic QoL: Generic Quality of Life; Negative W-B: Negative Well-Being subscale of W-BQ16; Positive W-B: Positive Well-Being subscale of W-BQ16; RDQoL AWI: Renal Dependent Quality of Life average weighted impact score; Renal-Dependent QoL Overview: overview item of impact of the renal condition on quality of life; RTSQs: Renal Treatment Satisfaction Questionnaire status version; Stress: Stress subscale of W-BQ16; W-BQ12: Well-Being Questionnaire 12-item version; W-BQ16: Well-Being Questionnaire 16-item version.

Illness perceptions.

Perceived causes of diabetes and CKD. Using the Brief IPQ, participants were asked at baseline to indicate what they believed were the three most important factors that caused their diabetes in rank order. Seven participants did not give any answers to this question and three indicated that they did not know. The most frequently reported most important cause of diabetes was genetics or family history of diabetes (*n* = 9). Participants were also asked to indicate in rank order what they believed were the three most important factors that caused their renal condition. One participant did not indicate any possible causes. Twenty-eight participants indicated that the first most important cause of their renal condition was 'diabetes', four other participants specifically indicated that poor diabetes control had caused their renal condition, one of whom specifically indicated that it was their poor diabetes control when they were younger which caused their renal condition (see Appendix NN, Tables NN9 and NN10 for other reported causes of diabetes and CKD).

Comparisons of pre-dialysis and dialysis patients' illness perceptions. No significant differences in baseline renal condition Brief IPQ scores were found between participants on dialysis and those who were pre-dialysis (see Appendix NN, Table NN11). Scores on the renal condition Brief IPQ were high (*Mdn* ≥ 7.00) indicating that participants perceived the condition to be chronic and that they attributed a lot of symptoms to it. High scores also indicated that participants felt that the renal condition had a high level of consequences and that it was concerning and affected them emotionally. Participants who were on dialysis and those who were pre-dialysis felt that their treatment controlled their renal condition (*Mdn* = 8.00) and they perceived themselves to have a moderate level of personal control (*Mdn* ≤ 5.50).

Correlations between illness perceptions and PROMs at baseline. Table 4.7 presents correlation analyses between renal condition Brief IPQ scores and Generic QoL, RDQoL AWI, RTSQs, and W-BQ16 scores. Significant negative correlations indicated that worse perceptions of renal condition consequences were associated with more negative impact of the renal condition on QoL, and poorer generic QoL, well-being, and energy. Significant correlations also indicated that a worse renal identity (symptoms) was associated with poorer well-being and energy and more stress, whilst renal treatment identity was associated with more negatively impacted renal-dependent QoL and poorer generic QoL. Perceptions of greater

renal treatment control were associated with better well-being on the subscales. Better understanding of the renal condition was associated with better renal treatment satisfaction but higher levels of negative well-being. Lastly, stronger emotional representations of the renal condition were associated with poorer well-being. Table 4.8 presents correlations between the diabetes Brief IPQ scores and Generic QoL, ADDQoL AWI, DTSQs, and W-BQ16 scores. Significant negative correlations indicated that perceptions of worse diabetes consequences were associated with more negative impact of diabetes on QoL and poorer well-being and energy. Greater perceived diabetes consequences were also associated with higher stress levels, and more chronic timeline perceptions were associated with more energy. Significant positive correlations indicated that participants' understanding of diabetes and their perceived personal and treatment control over diabetes was associated with better diabetes treatment satisfaction. Perceptions of personal control were also negatively associated with negative well-being. Poorer emotional representations of diabetes were associated with poorer well-being. Other correlations were not significant.

Table 4.7.

Pearson's r and Kendal's tau (τ) Correlations Between Baseline Renal Illness Perceptions with Renal-Dependent QoL, Generic QoL, Renal Treatment Satisfaction, and Well-Being (n = 34)

Brief IPQ (renal condition)	RDQoL AWI	Generic QoL	RTSQs	W-BQ16	Positive W-B	Negative W-B	Energy τ	Stress
Consequences τ	-.41**	-.32*	-.13	-.29*	-.13	.28*	-.29*	.27
Timeline τ	-.09	-.06	-.10	-.02	-.01	.02	.11	.09
Personal control	-.01	.07	.18	.24	.27	-.21	.15	-.04
Treatment control	.13	.13	.27	.23	.35*	-.40*	.17	.06
Renal treatment identity	-.40*	-.48**	-.26	-.33	-.22	.17	.17	.24
Renal identity τ	-.16	-.22	-.17	-.35**	-.21	.18	-.38**	.30*
Concern τ	-.18	-.05	-.08	-.16	-.05	.17	-.01	.18
Understanding τ	-.01	.26	.26*	.26	.26	.34*	.21	-.16
Emotional representation τ	-.21	-.16	-.12	-.31*	-.17	.44**	-.09	.25

Note. Pearson's *r* unless stated otherwise. Brief IPQ: Brief Illness Perceptions Questionnaire; Energy: Energy subscale of W-BQ16; Generic QoL: Generic Quality of Life; Negative W-B: Negative Well-Being subscale of W-BQ16; Positive W-B: Positive Well-Being subscale of W-BQ16; RDQoL AWI: Renal Dependent Quality of Life Average Weighted Impact scores; RTSQs: Renal Treatment Satisfaction Questionnaire status version; Stress: Stress subscale of W-BQ16; W-BQ16: Well-Being Questionnaire 16-item version.
*$p < .05$; **$p < .01$

Table 4.8.

Pearson's r and Kendal's tau (τ) Correlations Between Baseline Diabetes Illness Perceptions with Diabetes-Dependent QoL, Generic QoL, Diabetes Treatment Satisfaction, and Well-Being (n = 34)

Brief IPQ (diabetes)	ADDQoL AWI	Generic QoL	DTSQs	W-BQ16	Positive W-B	Negative W-B	Energy τ	Stress
Consequences τ	-.43**	-.18	-.23	-.37**	-.30*	.21	.-36**	.36**
Timeline τ	-.01	.11	-.17	.03	.08	.05	.31*	.20
Personal control	.24	.33	.58**	.33	.23	-.40*	.22	-.17
Treatment control τ	.22	.13	.41**	.12	.11	-.23	.05	-.05
Diabetes treatment identity τ	-.18	-.01	-.06	-.08	-.03	-.10	-.02	.20
Diabetes identity τ	-.04	-.14	.02	-.19	-.12	.20	.05	.26
Concern τ	-.23	.03	.00	-.07	-.01	-.06	-.08	.16
Understanding τ	.06	.22	.50**	.16	.15	-.20	.23	-.07
Emotional representation τ	-.15	-.07	-.13	-.30*	-.10	.33*	-.22	.26

Note. Pearson's *r* unless stated otherwise. ADDQoL AWI: Audit of Diabetes Dependent Quality of Life average weighted impact scores; Brief IPQ: Brief Illness Perceptions Questionnaire; DTSQs: Diabetes Treatment Satisfaction Questionnaire status version; Energy: Energy subscale of W-BQ16; Generic QoL: Generic Quality of Life; Negative W-B: Negative Well-Being subscale of W-BQ16; Positive W-B: Positive Well-Being subscale of W-BQ16; Stress: Stress subscale of W-BQ16; W-BQ16: Well-Being Questionnaire 16-item version.
Missing data for one participant on the DTSQs, W-BQ16, and Stress subscale, and missing data for three participants on the Brief IPQ timeline item.
*$p < .05$; **$p < .01$

Change in illness perceptions overtime. T-tests and Wilcoxon Signed Rank tests indicated that there were no significant changes in wait-listed participants' diabetes and renal condition Brief IPQ scores from baseline to 12-month follow-up (see Appendix NN, Table NN12 and NN13). Table 4.9 presents results from analyses of the pre- to post-SPKT renal condition Brief IPQ scores. SPKT recipients' perceptions of the consequences of the renal condition and their concern about their renal condition significantly decreased from pre- to post-transplant; $t(10) = 4.28$, $p = .002$, $r = .80$; and $t(10) = 2.29$, $p = .045$, $r = .59$ respectively. Recipients reported significantly fewer symptoms (identity) from the renal condition and its treatment post-SPKT with large effect sizes; $t(10) = 9.28$, $p < .001$, $r = .95$; and $t(10) = 2.34$, $p = .041$, $r = .59$, respectively. Perceptions of personal control and treatment control over the renal condition significantly increased with large effect sizes; $t(10) = -4.23$, $p = .002$, $r = .80$, and $t(10) = -2.73$, $p = .020$, $r = .65$, respectively. Participants' level of understanding, emotional representations, and timeline perceptions of the renal condition remained stable from pre- to post-SPKT. Brief IPQ scores indicated that SPKT recipients perceived the renal condition to be chronic, with low/moderate consequences and few symptoms (identity). Concern and emotional representations of the renal condition were generally moderate. SPKT recipients reported a high level of understanding and perceived a high level of personal and treatment control over their renal condition on average.

Table 4.9.

T-test and Wilcoxon Signed Rank test Repeated Measures Comparisons of Renal Condition Brief Illness Perception Questionnaire Scores from Pre- to 12-months Post-SPKT (n = 11)

Brief-IPQ	**Baseline**		**12 months post-SPKT**					
(renal condition)	***M (SE)***	***Range***	***M (SE)***	***Range***	***t***	***df***	***p***	***r***
Consequences	8.27 (0.30)	7.00, 10.00	3.91 (0.89)	0.00, 9.00	4.28	10	**.002**	**.80**
Timeline	7.00 (0.88)	2.00, 10.00	8.45 (0.97)	0.00, 10.00	-1.22	10	.251	.36
Personal control	5.18 (0.77)	2.00, 9.00	7.27 (0.60)	4.00, 10.00	-4.23	10	**.002**	**.80**
Treatment control	7.45 (0.74)	3.00, 10.00	9.73 (0.19)	8.00, 10.00	-2.73	10	**.020**	**.65**
Renal treatment identity	6.09 (0.87)	0.00, 9.00	3.27 (0.89)	0.00, 8.00	2.34	10	**.041**	**.59**
Renal identity	6.91 (0.55)	2.00, 9.00	1.09 (0.94)	0.00, 3.00	9.28	10	**.000**	**.95**
Concern	8.45 (0.74)	2.00, 10.00	5.09 (1.00)	1.00, 10.00	2.29	10	**.045**	**.59**
Emotional representation	6.82 (0.99)	0.00, 10.00	5.36 (1.12)	0.00, 10.00	1.93	10	.083	.52
	Mdn (IQR)	***Range***	***Mdn (IQR)***	***Range***	***T***		***p***	***r***
Understanding	9.00 (1.00)	6.00, 10.00	9.00 (1.00)	7.00, 10.00	22.00		.161	.30

Note. *M*: mean; *SE*: standard error; *Mdn*: median; *IQR*: interquartile range; *r*: effect size.
Brief IPQ: Brief Illness Perception Questionnaire for renal condition (each item scored 0 to 10, higher scores indicate stronger perception).

Correlations between illness perceptions and PROMs post-SPKT. Table 4.10 presents correlations between the renal condition Brief IPQ, Generic QoL, RDQoL AWI, RTSQs, and W-BQ16 scores at follow-up. Significant negative correlations indicated that greater perceived consequences of the renal condition were associated with worse generic QoL and well-being. There was a significant positive correlation between timeline perceptions and generic QoL, suggesting that chronic timeline perceptions were associated with better QoL. Perceptions of greater treatment control were associated with less impact of the renal condition on QoL and less negative well-being. Higher levels of understanding were associated with worse generic QoL and positive well-being. A significant negative correlation indicated that higher levels of perceived renal identity (more symptoms) were associated with worse renal treatment satisfaction, and, lastly, worse emotional representations of the renal condition were associated with poorer well-being and greater stress.

Table 4.10.

Pearson's r and Kendal's tau (τ) Correlations between Post-SPKT Renal Condition Illness Perceptions with Renal-dependent QoL, Generic QoL, Renal Treatment Satisfaction, and Well-Being (n = 11)

Brief IPQ (renal condition)	RDQoL AWI	Generic QoL	RTSQs	W-BQ16	Positive W-B	Negative W-B	Energy	Stress
Consequences	-.55	-.64*	-.15	-.62*	-.51	.65*	-.41	.51
Timeline τ	.49	.69*	.05	.18	.39	-.19	.03	.11
Personal control	-.16	-.25	-.43	.25	-.36	-.11	.59	-.38
Treatment control τ	.53*	.55	-.13	.46	.30	-.58*	.29	-.45
Renal treatment identity τ	.00	-.07	-.40	-.12	-.23	.37	.10	.06
Renal identity	-.47	-.45	-.61*	-.14	-.51	.12	.02	-.08
Concern τ	.30	.40	.12	.08	.12	.10	-.02	-.06
Understanding	-.40	-.64*	-.05	-.35	-.72*	.39	.06	.19
Emotional representation	-.30	-.29	-.42	-.62*	-.45	.50	-.45	.62*

Note. Pearson's *r* unless stated otherwise. Brief IPQ: Brief Illness Perceptions Questionnaire; Energy: Energy subscale of W-BQ16; Generic QoL: Generic Quality of Life; Negative W-B: Negative Well-Being subscale of W-BQ16; Positive W-B: Positive Well-Being subscale of W-BQ16; RDQoL AWI: Renal Dependent Quality of Life Average Weighted Impact scores; RTSQs: Renal Treatment Satisfaction Questionnaire status version; Stress: Stress subscale of W-BQ16; W-BQ16: Well-Being Questionnaire 16-item version.
*$p < .05$; **$p < .01$

Discussion

The current study used a prospective longitudinal cohort observation design to assess PROMs of individuals awaiting SPK transplantation. No significant differences were found on any of the baseline PROMs between those who were on dialysis and those who had not yet started dialysis. The main finding was that SPKT recipients experienced significant improvements across several of the PROMs from pre- to post-transplant, including improved generic QoL, well-being, and renal and diabetes treatment satisfaction. SPKT recipients were also less impacted by diabetes post-transplant and perceived that their renal condition was less concerning and had fewer symptoms and consequences. Perceptions of personal and treatment control over the renal condition also improved. However, wait-listed participants' PROMs scores remained stable from recruitment to 12-months follow-up. SPKT recipients were only found to report better treatment satisfaction than those who remained wait-listed. Most participants reported being satisfied/very satisfied with various aspects of the renal service that they had received.

Comparisons of pre-dialysis and dialysis patients. Previous research has found mixed results when comparing individuals who have not yet started dialysis to those who have. For example, individuals who had not yet started dialysis experienced fewer symptoms, and less treatment burden, burden of kidney disease, and effect of kidney disease, and better physical and mental component scores on the KDQoL-SF compared to patients on HD (Al-Mansouri et al., 2021). Krishnan et al. (2020) also found that pre-dialysis patients had significantly better EQ-5D-3L utility scores than patients on dialysis. However, Abdel-Kader et al. (2009) found that individuals on dialysis and individuals who had not yet started dialysis were comparable on measures of symptoms and depression, and on physical and mental component scores of the SF-36. It is possible that whilst some individuals in the current research did not need dialysis yet, they were still quite unwell. This may have impacted their well-being and QoL to a similar extent as those on dialysis, some of whom might have experienced improvements due to treatment.

Impact of SPK transplantation. The finding that several outcomes improved from pre- to post-transplant is encouraging and in line with results for the subsample of 22 participants with pre- and post-SPKT PROMs data in the original ATTOM detailed PROMs study (Gibbons et al., 2020). The current findings are also

in-line with previous studies which reported significant improvements from pre-to post-SPKT on a QoL VAS (Adang et al., 1998) and improved psychological status (Martins et al., 2015) and mental component scores (G. C. Smith et al., 2010). One main difference is that whilst the current study found diabetes-dependent QoL (ADDQoL AWI) significantly improved from pre- to post-SPKT and renal-dependent QoL (RDQoL AWI) did not, Gibbons et al. (2020) found significant improvements in renal-dependent QoL and not in diabetes-dependent QoL. Results of both studies suggest that patients are still negatively impacted by having CKD and diabetes post-transplant.

There may be several reasons for the current findings. SPKT recipients may be significantly less impacted by diabetes post-transplant because they no longer needed to follow a diabetes management regimen, and certain complications such as hypoglycaemia had improved. This may have been sufficient to improve QoL and treatment satisfaction. Similarly, other research has shown that recipients benefit from having a pancreas transplant and have reported improved satisfaction on the DQoL from pre- to post-SPKT (Gross et al., 2000). SPKT recipients have also reported better satisfaction and impact scores on the DQoL compared to wait-listed patients (Sureshkumar et al., 2005) and less diabetes distress on the PAID compared to kidney-only recipients with diabetes (Nyumura et al., 2017). Participants may still experience symptoms from their CKD or from complications of the transplant operation itself post-SPKT, which could continue to impact QoL. After transplantation, individuals are recommended to take anti-rejection medications, some of which may cause side-effects that have a negative impact (Pera et al., 2012; Rosenberger et al., 2010). Furthermore, six of the SPKT recipients in the current study had received a pre-emptive transplant and therefore may not have experienced too much change in their lifestyle due to CKD prior to transplantation or afterwards once they had recovered from the operation. Some individuals who did experience changes in their lifestyle due to becoming unwell with CKD or due to dialysis treatment prior to transplantation, may not yet have been able to return to these activities by the 12-month follow-up. This may be especially true for those who received their transplant shortly before the COVID-19 pandemic, when various social and lifestyle restrictions were put in place in the UK. Individuals with CKD, diabetes, or those with an organ transplant were considered to be clinically extremely vulnerable to the COVID-19 virus and in the UK, from 23rd March 2020, they were recommended to shield themselves from others by staying at home as much as possible. Eight of the 11 SPKT recipients completed their post-transplant

PROMs after March 23rd 2020, and it is possible that their responses were negatively impacted by the restrictions at the time. In a large sample of the UK general population, the prevalence of distress significantly increased from 2019 to April 2020 but returned to pre-pandemic levels by September 2020 (Daly & Robinson, 2021). Pre-existing physical and mental health issues have been found to be a risk factor for distress during the pandemic in the UK (Pierce et al., 2021). A mixed methods study found that lupus patients in the UK who were shielding did not differ to those who were not shielding on a measure of well-being, but qualitative findings indicated that patients had widely varying experiences during the COVID-19 pandemic (Sloan et al., 2021). It is possible that individuals in the current study may have been impacted by the COVID-19 pandemic in various ways.

The lack of any significant change in EQ-5D-5L utility scores in the current study and in the original ATTOM detailed PROMs study (Gibbons et al., 2020) suggests that this measure should not be relied on alone in the assessment of SPK transplantation, as it does not appear to capture the benefit gained from receiving an SPKT. EQ-5D utility score calculations are based on general population valuation assessments of different health states rather than the views of the patients themselves (Devlin et al., 2016). Although the EQ-5D has been used extensively, researchers have argued that it lacks content validity and may not be fit for purpose within certain health conditions such as type 2 diabetes (Matza et al., 2015), asthma (Whalley et al., 2018), and complex mental health problems (Brazier, 2010). In particular, patients with diabetes have reported that the EQ-5D does not capture the impact of dietary restrictions (Matza et al., 2015), a domain that is included in the ADDQoL and has been found to be important to patients' QoL (DAFNE Study Group, 2002; Wee et al., 2006). The main reason for the inclusion of the EQ-5D in the current study was due to its inclusion in the original ATTOM study, which included it for health economic research and because the EQ-5D is recommended by NICE to evaluate treatments. However, the EQ-VAS, which often does not receive as much attention in research as the EQ-5D-3L or 5L, does appear to capture the improvement in health status experienced by SPKT recipients. This finding is supported by Martins et al. (2015) who found improvements in the EQ-VAS, as well as each domain of the EQ-5D-5L. It is important to note that Martins et al. (2015) did not calculate utility scores. The current findings suggest that assessment of SPK transplantation through the use of different measures of generic QoL, condition-specific QoL, treatment satisfaction, and health status (using just the

EQ-VAS or similar single-item measure of self-reported health) may be more useful than relying on one measure such as the EQ-5D.

PROs of wait-listed patients and comparisons with SPKT recipients. It is encouraging that outcomes did not worsen over time for those who remained wait-listed and only a trend was found for worse renal treatment satisfaction at 12-month follow-up. This is in line with results from the original ATTOM study (Gibbons et al., 2020). Generally, patients are added to the transplant waiting list when it is expected that they will need to start dialysis within the next six months. However, as several participants were still pre-dialysis at the 12-month follow-up or had received a pre-emptive SPKT, this suggests that patients may have been added to the waiting list before they had become very unwell and had not deteriorated in their health to require dialysis after 12 months on the waiting list. At the same time, some of those who had started dialysis during the 12 months may have found that this helped them to feel better. The trend for a decline in renal treatment satisfaction may be due to some patients finding that their pre-transplant treatment was no longer as effective, or patients starting on dialysis and experiencing the increased demands of treatment.

Contrary to the findings of the original ATTOM detailed PROMs study (Gibbons et al., 2020), cross-sectional analyses indicated that SPKT recipients did not score significantly better than wait-listed participants on measures of perceived health status, well-being, generic QoL, and renal-dependent and diabetes-dependent QoL. In the current study, SPKT recipients reported significantly better renal and diabetes treatment satisfaction on both the status and change measures and less frequent hypoglycaemia and hyperglycaemia compared to wait-listed participants. Whilst Gibbons et al. (2020) did not find a significant difference between wait-listed participants and SPKT recipients on the status version of the DTSQ, this may have been due to a ceiling effect as participants had rated their satisfaction with their diabetes treatment highly. However, Gibbons et al. (2020) did find that SPKT recipients reported significantly greater improvements in diabetes treatment satisfaction on the change version of the DTSQ compared to wait-listed participants. The non-significant findings of the current study should be interpreted with caution as it is possible that the study was underpowered to detect significant differences between the various groups of participants due to the small sample sizes. Furthermore, whilst eight SPKT recipients (74%) completed follow-up PROMs during the COVID-19 pandemic (after 23rd March 2020), only three of the wait-listed

participants (33%) completed their follow-up PROMs during this time. Therefore, SPKT recipients' PROMs scores may have been disproportionately impacted by the COVID-19 pandemic compared to the wait-listed participants.

Change in illness perceptions. The current study also investigated the illness perceptions of wait-listed participants and SPKT recipients. A majority of participants believed that their diabetes, and specifically poor control of their diabetes, had been a main cause of their CKD. Renal condition-related illness perceptions at baseline did not differ between participants who were pre-dialysis or on dialysis. This contrasts with previous research which found that individuals on PD or HD had stronger perceptions of renal condition consequences and that their treatment could control their CKD compared to individuals who were pre-dialysis (Jansen et al., 2013). In the current study, significant pre- to post-SPKT changes in renal illness perceptions were identified, indicating a decrease in renal condition identity (fewer symptoms), consequences, and concerns. Perceptions of personal and treatment control over the renal condition increased from pre- to post-SPKT. This suggests that participants may have felt that the SPKT and anti-rejection medications kept their CKD under control. They may have also felt that they had more personal control over their conditions and their management. The findings suggest that participants reappraised aspects of their renal condition after receiving an SPKT and these illness perceptions became more positive. Prior to transplantation participants believed that their renal condition was chronic, and this remained stable post-SPKT. Participants also reported having a high level of understanding of their renal condition and a moderate emotional reaction to the condition, which remained stable post-SPKT. Similarly, Griva et al. (2012) found perceptions of personal control, identity (symptoms), and consequences attributed to the renal condition improved from pre- to post-kidney transplantation. However, unlike the current study, timeline perceptions became more acute, which the authors argued may be because the kidney transplant recipients felt physically better and saw the transplant as a curative treatment (Griva et al., 2012). It is possible that the SPKT recipients in the current study continued to see their condition as chronic because they understood that the transplant is a treatment rather than a cure.

The improvements in perceived consequences and control may be additional benefits of transplantation that could also influence other outcomes or behaviours such as adherence to medications or the pursuit of a healthy lifestyle. Griva et al.

(2012) found that positive improvements in pre- to post-transplant perceptions of illness identity, consequences, and control were associated with improvements in mental and physical component scores on the SF-36. In regression analyses improvements in perceived consequences was predictive of better mental component scores (Griva et al., 2012). Other studies have also reported improvements in perceived control from pre- to post-kidney transplantation (de Vries et al., 2017; Schulz et al., 2017); however, these studies used a measure which assesses general perceptions of control (mastery). Improvements in mastery were associated with less distress post-transplant (de Vries et al., 2017; Schulz et al., 2017).

Associations between illness perceptions and PROs. Correlation analyses in the current study were in line with previous research which suggests that more negative illness perceptions are associated with poorer outcomes (Chilcot, 2012; Hagger & Orbell, 2003). For example, greater perceived consequences of the renal condition was associated with poorer QoL and well-being both pre- and post-SPKT. Worse emotional representations were also associated with poorer well-being. For wait-listed participants, renal treatment identity was negatively associated renal-dependent and generic QoL, and renal condition identity was negatively associated with well-being and energy and positively associated with stress. Post-transplant, stronger identity perceptions were associated with worse treatment satisfaction. Perceived control over diabetes was associated with better treatment satisfaction and less negative well-being, whilst greater perceived renal treatment control was associated with less negative well-being both pre- and post-SPKT and positively associated with renal-dependent QoL post-transplant. This suggests that those who trusted that their treatment had control over their renal condition experienced less negative impact of the renal condition on their QoL post-SPKT. Perceptions of control may be particularly important for patient outcomes and is a concept that appears in some form in several other theories/models. For example, perceived control is similar to the concept of self-efficacy, which is a person's beliefs about their ability to carry out behaviours to achieve a particular goal (Bandura, 1977). Similarly, perceived behavioural control is also an important part of the Theory of Planned Behaviour (Ajzen, 1985), and perceptions on the locus of control, whether control is internal or external to the person (Rotter, 1966), has also received substantial attention. Therefore, there is a strong theoretical basis to suggest that interventions might usefully target maladaptive perceptions of control to improve health behaviours and patient

outcomes. The CSM of Self-Regulation and illness perceptions are particularly useful because it distinguishes between personal and treatment control, which provides additional information on more specific perceptions that could be targeted by interventions.

Participants' perceived level of understanding (coherence) of their health conditions was positively associated with better treatment satisfaction in wait-listed participants, but unexpectedly negatively associated with positive well-being and generic QoL post-transplant. Another unexpected finding was that more chronic timeline perceptions were positively associated with generic QoL post-transplant. Previous research has generally indicated that chronic timeline perceptions are negatively associated with well-being outcomes (Hagger & Orbell, 2003). It is possible that in the current research, participants who accepted the chronic nature of their health conditions experienced better QoL. Alternatively, participants may have also held the belief that their transplant would last a long time, which might understandably be associated with better QoL. Using path analysis to test the direct and indirect impact of illness perceptions on outcomes, Hagger et al. (2017) found that timeline perceptions were positively indirectly associated with functioning and well-being through problem-focused coping. The current study did not include a measure of coping, so the indirect relationships between illness perceptions and outcomes through coping could not be assessed. Furthermore, due to the small sample, multivariate analyses to assess whether illness perceptions predicted outcomes whilst controlling for clinical variables could not be reliably carried out, and causality cannot be inferred from cross-sectional analyses.

Whilst SPKT recipients reported very high levels of adherence to medications, other health behaviours and pre-transplant adherence to treatment were not assessed. It has been suggested that illness perceptions could be targeted by cognitive behavioural therapies to improve health behaviours and patient outcomes (Petrie & Weinman, 2006) and some success for such interventions has been reported for other health conditions such as myocardial infarction (Broadbent et al., 2009; Petrie, Cameron, Ellis, Buick, & Weinman, 2002) and type 2 diabetes (Keogh et al., 2011). One intervention guided by the CSM was designed to reduce distress experienced by patients on dialysis, but was not feasible, many patients refused to be screened for distress and did not have the necessary computer skills to complete the online intervention (Hudson et al., 2017; Hudson et al., 2016).

Further research is needed to establish which illness perceptions are the most influential in this patient sample, and whether interventions that aim to change maladaptive illness perceptions can help to improve QoL.

Study limitations. As previously mentioned, a main limitation of the current study was the small sample which resulted from a low initial response rate and attrition from baseline to follow-up. It is therefore possible that the resulting sample may be biased as there may have been certain differences between individuals who decided to take part in the study and those who did not. Despite this, analyses comparing the demographics and baseline PROs of individuals who completed follow-up PROMs and those who did not found no significant differences. Due to the small number of participants more complex analyses comparing wait-listed participants and SPKT recipients could not be conducted reliably. As the study is underpowered, it should also be noted that the effect sizes reported for significant findings, which were mostly moderate to large, may be over-estimates of the true population effect sizes. This is because 'a true effect is only significant in an underpowered study when the effect obtained in the study is larger than the effect at the population level' (Brysbaert, 2019, p1). Whilst it is unclear why participants did not participate in the study and recruitment was already complete before the COVID-19 pandemic; it is possible that the restrictions imposed during the pandemic and concerns about contracting the virus may have deterred some participants from returning completed follow-up PROMs.

Study implications. Few previous studies have used a prospective longitudinal design to investigate PROs before and after SPK transplantation, and studies that have done so also tend to have small sample sizes of around 22-37 SPKT recipients at follow-up (Adang et al., 1998; Gross et al., 2000; G. C. Smith et al., 2010). The current research suggests that SPKTs are beneficial, although patients often continued to be negatively impacted by having had diabetes and CKD. Patients need to be well informed on what to expect from transplantation to avoid disappointment. Most participants were very satisfied/satisfied with various aspects of the renal service that they had received. However, a few participants did indicate dissatisfaction with aspects such as social worker and psychological advice and support, suggesting that some patients may require more support. Further prospective research with larger samples would be useful to investigate predictors of outcomes. Comparisons of prospective longitudinal data between SPKT recipients and individuals with type 1 diabetes who opt to have a kidney-only

transplant would also be useful to confirm the added benefit of the pancreas transplant to QoL. Despite this, the current study highlights the importance of prospectively measuring individualised QoL and other PROs.

The difficulties with recruitment and retainment of participants to the current study highlights a need for routine assessment of PROMs as part of patients' care, which could then be used to evaluate treatment. In particular, use of electronic PROMs (ePROMs) would provide a convenient option for patients to complete measures, rather than requiring completion of traditional paper versions which often need to be returned by post. Use of ePROMs could also save healthcare professionals and/or researchers time and manpower, and there would be less risk of data entry errors compared to traditional pen and paper PROMs (Coons et al., 2009). Furthermore, PROMs could be used to help improve patient care on an individual level by highlighting particular issues. Patients could be asked to complete ePROMs at home or whilst waiting for their appointment at a renal clinic and responses could be available to the healthcare professionals to discuss with patients in their appointment. A recent qualitative study found that individuals with CKD and clinicians felt that the use of ePROMs could help to improve communication between patients and clinicians and could help to identify patients who were experiencing worsening effects of their CKD (Aiyegbusi et al., 2019).

Conclusions

SPK transplantation can lead to improvements in generic and diabetes-dependent QoL, treatment satisfaction, well-being, and perceived health status at approximately 12 months post-transplant. The current findings suggest that whilst SPKT recipients were still impacted by having had diabetes and CKD, they were less impacted by their diabetes post-transplant. Furthermore, SPKT recipients appear to reappraise their renal condition, as illness perceptions of the identity, consequences, and controllability of the renal condition became more positive post-transplant. Overall, these findings highlight the benefit of SPK transplantation to patients' lives and how they feel and think about their health condition. In contrast, wait-listed participants' outcomes remained stable 12-month post-recruitment. This finding is encouraging as even though some patients may have experienced a decline in their condition, outcomes remained stable. The findings may also reflect early listing to the SPKT waiting list as some patients were still pre-dialysis at 12-

month follow-up (and several participants received a pre-emptive SPKT). SPKT recipients reported better diabetes and renal treatment satisfaction than those who remained wait-listed; however, other outcomes were not significantly different between the two groups at follow-up. Unfortunately, several SPKT recipients completed post-transplant PROMs during restrictions due to the COVID-19 pandemic in 2020 and this may have influenced outcomes. However, due to the small sample sizes it is likely that the study was underpowered to detect differences between groups. Despite this, the current study is one of only a few to have collected PROMs data both pre- and post-SPKT. Other than the original ATTOM detailed PROMs study, this is the only study to have used genuine individualised measures of condition-specific QoL with patients awaiting and in receipt of an SPKT. Overall, the results suggest that SPK transplantation is beneficial for patients with insulin-treated diabetes and CKD.

Chapter 5: Experiences of Patients Awaiting Simultaneous Pancreas and Kidney Transplantation: Qualitative Findings

Introduction and Aims

The management of diabetes and CKD is complex. Individuals with insulin-treated diabetes need to carry out a variety of self-management behaviours, such as blood glucose monitoring, counting carbohydrates, and administering insulin, to keep their blood glucose levels controlled. Individuals with kidney failure also need to manage their condition by taking certain medications and following some dietary recommendations and fluid restriction. In addition, patients with kidney failure may eventually need dialysis, either through HD at a hospital or renal unit three times a week, or by carrying out daily PD. Whilst PROMs used in Chapters 3 and 4 identify whether QoL is impacted or changed over time, it is important to consider how and why these two conditions can impact QoL. Qualitative research is an ideal method to address this as it allows for further insight to be gained into patients' experiences, leading to a richer understanding of the lived experience of the conditions under investigation and the antecedents of any impact they have on QoL.

Several studies have reported on the experiences of patients with diabetes or CKD, however there is limited research which has focused specifically on the impact of both conditions on patients. Yu and Tsai (2013) identified five stages of the illness trajectory experienced by patients with diabetes and CKD from (1) the onset of diabetes, to (2) a stable stage of trying to control diabetes, to (3) experiencing the burden of symptoms and treatment, (4) a stage of shock and fear of the need to start dialysis, and (5) ongoing coping with dialysis. Individuals with diabetes and CKD have reported difficulties in following complicated medication and self-care regimens (Clemens et al., 2019; Notaras & Conti, 2018; Shirazian et al., 2016; Williams & Manias, 2014). Patients often experience tiredness and disability, which can impact on self-management and various other aspects of life (Lo et al., 2016). However, this previous research often mainly included patients with type 2 diabetes or a mix of patients with type 2 or type 1 diabetes, despite there often being differences in the treatment of the two conditions, particularly in relation to administering insulin. These studies also mostly focused on patients' experiences of self-management of the two conditions rather than their QoL.

The transactional model of stress and coping proposed by Lazarus and Folkman (1984) suggests that when an individual is faced with a source of stress, such as a chronic health condition, they will make an appraisal of the situation and use certain cognitive and behavioural strategies to cope with it. Individuals are also thought to appraise how successful their coping strategies have been and may adjust them depending on this appraisal. In this way, coping is seen as a process and is often discussed in terms of emotion-focused coping, involving attempts to reduce emotional distress, and problem-focused coping, involving attempts to change or improve the stressful situation (Lazarus & Folkman, 1984). Although research has quantitatively assessed coping in CKD (Knowles, Swan, Salzberg, Castle, & Langham, 2014; Tu, Shao, Wu, Chen, & Chuang, 2014) and diabetes (Knowles et al., 2020; Luyckx, Vanhalst, Seiffge-Krenke, & Weets, 2010), cross-sectional measures of coping tend to reduce behaviour down to a simple trait-like variable (Leventhal, Halm, Horowitz, Leventhal, & Ozakinci, 2004). As coping is part of the experience of living with a chronic condition, qualitative research is well-placed to explore strategies patients use. Two previous UK-based qualitative studies have explored the experiences of individuals with diabetes and CKD and how they coped and adjusted (N. King et al., 2002; K. Reid et al., 2012). Diabetes and CKD was found to impact diet, work, and family and social life (N. King et al., 2002). Individuals expressed negative feelings about their experience with dialysis or fear of needing dialysis in future. Participants in both studies reported uncertainty for the future and expected an inevitable decline in health (N. King et al., 2002; K. Reid et al., 2012). N. King and colleagues (2002) argued that 'stoicism', involving carrying on, making as little fuss as possible, and looking on the bright side, was the main method of coping for the majority of their participants. K. Reid and colleagues (2012) found that it took time for individuals to come to understand their condition, as they did not initially consider their health problems to be serious and struggled to accept them. Participants adjusted to their health problems by using cognitive strategies, such as trying not to think about it, and by asserting control over their treatment and gaining support from others (K. Reid et al., 2012).

Aside from the management of the conditions, waiting for a transplant can be a stressful experience and can pose additional challenges. Tests undertaken when added to the transplant waiting list can be demanding on patients' time and some may feel guilt at the prospect of awaiting someone's death so that they can receive a kidney (Burns et al., 2017; Tong, Jesudason, Craig, & Winkelmayer, 2015). Those wait-listed for a DDKT have reported living with uncertainty as to how long they

would have to wait (Nielsen, Clemensen, Bistrup, & Agerskov, 2019; Yngman-Uhlin et al., 2015) and may fear dying whilst still waiting for their transplant (Burns et al., 2017; Burns et al., 2015; Tong, Hanson, et al., 2015). However, patients have also reported being hopeful that they would receive a transplant that would allow them to return to a more 'normal' way of life, free from dialysis (Burns et al., 2017; Burns et al., 2015; Nielsen et al., 2019; Tong, Hanson, et al., 2015; Yngman-Uhlin et al., 2015). Similar feelings regarding the wait for an SPKT have also been reported in one study with recipients in Spain (Pera et al., 2012). SPKT recipients also reported that, prior to receiving their transplant, they had felt guilty because of the connection between poor diabetes control and the development of CKD (Pera et al., 2012). A limitation of much of the previous research is that samples often included both those who were wait-listed and those who were not (Burns et al., 2015), despite this having very different implications for patients' futures. Previous research has also often focused on patients already on dialysis rather than those who are pre-dialysis, and only Pera et al. (2012) provide insight into experiences prior to SPK transplantation.

Previous research provides some useful insight into the experiences of individuals with diabetes and CKD. However, there is limited research with patients awaiting SPK transplantation specifically. It is unclear whether participants in the two UK-based studies that explicitly investigated the experiences of individuals with both diabetes and CKD were wait-listed for an SPKT (or kidney-only transplant). In particular, the study by N. King et al. (2002) was conducted at a time when few SPKTs were carried out (UK Transplant, 2003). It is possible that those awaiting an SPKT may have different experiences and perspectives on the impact of their conditions on QoL and how they cope. Patients awaiting an SPKT may also have different expectations, hopes, and concerns as the SPKT provides the opportunity to treat both CKD and diabetes. Furthermore, several years have passed since some of these studies were conducted and it is possible that treatments may have changed, and patients' experiences may be different. SPK transplantation is still a relatively new treatment for diabetes and CKD. In order to understand the impact of SPK transplantation, pre-transplant as well as post-transplant experiences need to be understood. The aim of the current study was to supplement the quantitative research, and used responses to the individualised condition-specific QoL measures used in Chapter 4 to gain a better understanding of how QoL is impacted by diabetes and CKD when waiting for an SPKT. The current study aimed to answer

the research questions: (a) How does diabetes, CKD, and wait-listing for an SPKT impact QoL? (b) Secondly, how do patients cope with their health conditions?

Summary of Methods

Design. The study used semi-structured qualitative telephone interviews to investigate the impact of diabetes, CKD, and wait-listing for an SPKT on patients' QoL.

Recruitment and procedure. Participants who returned 12-month follow-up questionnaire packs for study 2, outlined in Chapter 4, were contacted by telephone by the researcher. Participants were thanked for completing the questionnaire pack and invited to take part in a telephone interview. The researcher explained the aim of the interview study and participants were reminded that the interview would be audio-recorded and transcribed for analysis. Participants were reassured that identifiable information, such as names of people or places, would be removed from the transcripts so that they could not be identified from quotes used in reports or articles. Thirteen individuals who returned 12-month questionnaire packs were contacted and invited to take part in a telephone interview. One individual on the SPKT waiting list declined to take part because they felt that they might become upset when speaking about their health problems and experiences. Three other potential interviewees could not be contacted. Six individuals with diabetes and CKD who had been on the SPKT waiting list for at least 12 months, and six SPKT recipients who had been living with their transplant for at least 12 months were interviewed. The interviews were conducted between June 2019 and August 2020. Some participants were interviewed during the COVID-19 pandemic; this was possible because the study design involved telephone interviews. All interviews were carried out by KH, a female PhD researcher with previous experience of conducting telephone interviews and in-person focus groups. No other researchers were present during the interviews.

The telephone interviews followed a semi-structured interview guide. Throughout the interview broad, open-ended questions were asked in order to elicit a description of the participants' experiences. Further questions or prompts were used when needed to gain further information. The interviews with those still on the waiting list started by asking the participant to describe their experience of living with diabetes. Next participants were asked about their experience of having a

kidney condition, such as how they discovered that they were having kidney problems, how the condition progressed, and what treatment they were on, if any. Participants were asked about when they were added to the transplant waiting list and how they felt about being on the waiting list. Using responses to the ADDQoL and RDQoL, participants were asked about how diabetes and CKD impacted certain aspects of their QoL. The aspects of life discussed were selected based on those that the participants had indicated in the questionnaires as being most impacted and most important. If not spontaneously mentioned, participants were asked about their satisfaction with their treatment. Participants were asked about how they coped and adjusted to living with diabetes and CKD and, lastly, if they had any expectations about how life would be after they received an SPKT. At the end of each interview, participants were thanked for their time and asked if there was anything else that they wanted to add about their experiences.

Interviews with those who had already received an SPKT followed a similar interview guide. SPKT recipients were asked about their experience of living with diabetes and CKD, about when they were added to the transplant waiting list and how their QoL was impacted by diabetes and by CKD before they received their SPKT. Participants were also asked about their experiences post-transplant; however, only references to pre-transplant experiences were analysed for the current study and post-transplant details were analysed separately (see Chapter 6). At the end of the interviews, participants were given another opportunity to ask questions about the study and were reminded that they could contact the researcher if they wished to ask something in future. Finally, the interviewer requested permission to contact the participant in future for clarification if necessary. The interviews lasted an average of one hour (ranging from 35 to 86 minutes). With the participants' consent, the interviews were audio-recorded and transcribed verbatim by the researcher (KH). Whilst brief notes were taken during the interviews these were used to aid the discussion and were not included in the analysis. A selection of the interview transcripts were reviewed by supervisor AG to ensure accuracy.

Analysis. The data were analysed using reflexive thematic analysis, as described by Braun and Clarke (Braun & Clarke, 2006, 2019a; Clarke & Braun, 2015). First, familiarisation involved transcribing and checking the interviews with the audio recordings, transcripts were then read again before initial codes were generated. The software NVivo 11 was used to organise the analysis of the interviews. Initial coding was carried out by labelling meaningful sections of the text

in relation to answering the research question. Familiarisation and initial coding were carried out for each interview shortly after the interview was conducted and transcribed. The transcripts were re-visited as other interviews were conducted, transcribed, and added to the analysis. The analysis was carried out inductively by producing codes and developing themes from the data that were specific to these participants' experiences. For example, initial coding often used words taken directly from what had been said by the participant. No pre-defined coding manual or theoretical model was specifically applied in the analysis. However, the interpretation of the data was influenced by awareness of previous research on living with and coping with chronic illness. Once several transcripts had been coded, associated codes were grouped together, and initial themes were generated. The use of NVivo 11 aided coding and the development of themes as all text labelled under the same code could be easily accessed, reviewed, and clustered to form themes. The themes and interpretations of what participants said about their experiences were reviewed in discussions with supervisor AG throughout the analysis process. Lastly, the themes were named to reflect their content. A contextualist epistemological approach was taken to the thematic analysis (Madill et al., 2000).

Findings

Table 5.1 presents demographic details of the interviewees. The sample included four men and eight women ranging in age from 32 to 49 years. All participants had type 1 diabetes. Of the six participants still on the waiting list, three were still pre-dialysis at 12-month follow-up and three were on HD. Of those who had received a transplant, five had a pre-emptive SPKT and one had had a short period of PD prior to transplantation.

Table 5.1.

Characteristics of Interview Participants – Pre-SPKT Experiences

Variable	**Sample** (*n* = 12)
Age *M* (range)	39.83 (32.00, 49.00)
Sex: male *n* (%)	4.00 (33.33)
Ethnicity *n* (%)	
White British/ European	11.00 (91.67)
Mixed white and Asian	1.00 (8.33)
Education *n* (%)	
No qualifications	1.00 (8.33)
Basic qualification	4.00 (33.33)
Higher qualifications	7.00 (58.33)
Employment *n* (%)	
Part-time	6.00 (50.00)
Full-time	4.00 (33.33)
Unemployed/unable to work	2.00 (16.67)
Married/living with partner *n* (%)	7.00 (58.33)
Insulin regimen* *n* (%)	
Two injections of mixed insulin	1.00 (8.33)
Basal/bolus, fixed doses, fixed mealtimes	1.00 (8.33)
Basal/bolus, flexible doses, fixed mealtimes	2.00 (16.67)
Basal/bolus, flexible doses, flexible mealtimes	4.00 (33.33)
Insulin pump	4.00 (33.33)
Current renal treatment *n* (%)	
Pre-dialysis	3.00 (25.00)
HD	3.00 (25.00)
SPKT pre-dialysis	5.00 (42.67)
SPKT after PD	1.00 (8.33)
Previous other transplant *n* (%)	0.00

Note. *M:* mean; SPKT: simultaneous pancreas and kidney transplant; PD: peritoneal dialysis; HD: haemodialysis.
*Insulin regimen at the time of the interview or prior to SPKT.

Participants often described when they were first diagnosed with diabetes and gave some details on how the condition and its treatment had progressed since, before describing their experiences with CKD. The analysis produced four themes relating to how QoL was impacted by diabetes and CKD. Participants' experience with diabetes management was often described as being a struggle and, secondly, diabetes and its management was invasive as it was frequently on participants'

minds. The combination of CKD and diabetes often restricted participants' lives in various ways and, lastly, participants felt uncertain for the future. Three themes relating to coping were identified. Participants tried to accept their health problems and did what they could. Participants sought out information and tried to follow diabetes and CKD self-care recommendations. Support from family, peers, and healthcare professionals was important in helping some participants to cope with their conditions. Figure 5.1 below presents a visual representation of the themes.

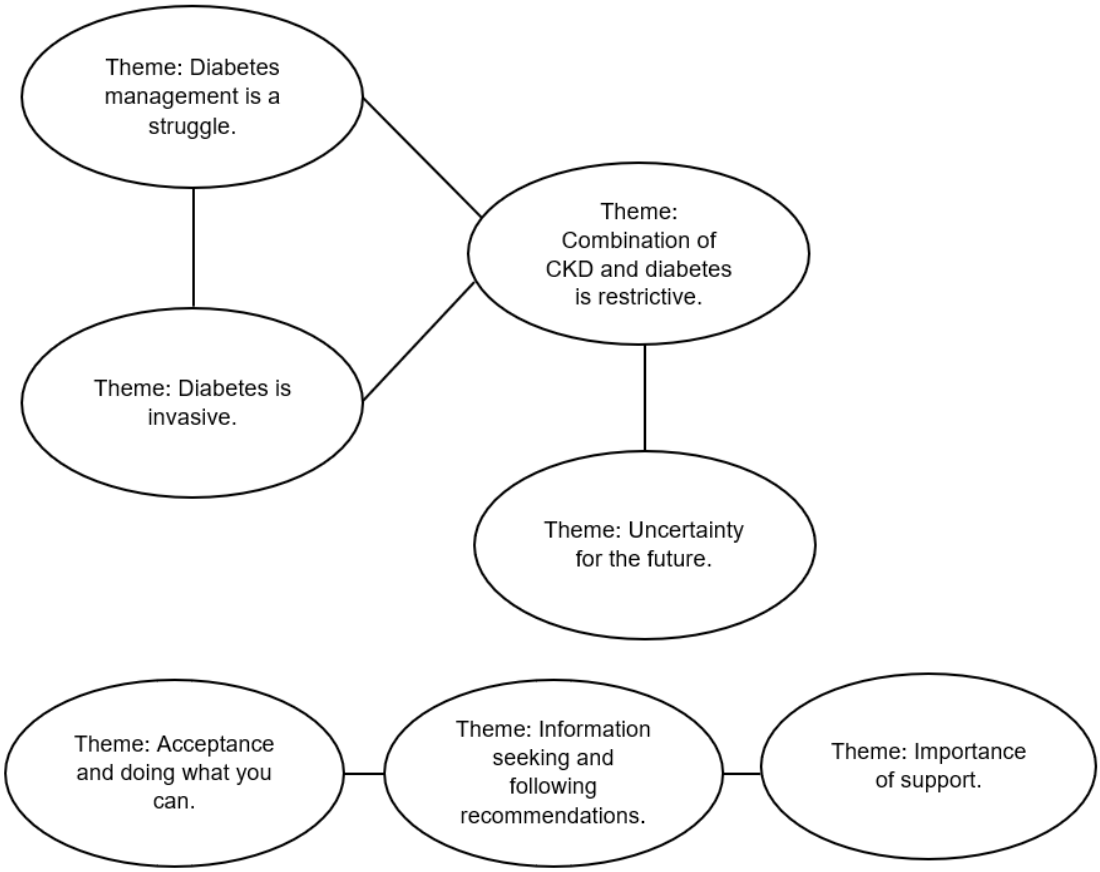

Figure 5.1. Thematic map showing how QoL is impacted by diabetes and CKD and how patients cope whilst wait-listed for an SPKT.

Diabetes management is a struggle. Most of the participants were diagnosed with diabetes at a young age and some spoke about having sometimes neglected their diabetes management in adolescence and/or young adulthood when they were trying to establish more independent management. Those diagnosed in adolescence indicated that this had been a difficult time to receive a diagnosis. Some participants had tried to ignore their diabetes, and would miss insulin injections and/or eat unhealthy foods. From this, they might suffer short-term

consequences, such as feeling nauseous. One participant revealed they had omitted insulin injections in order to control their weight as a teenager. For most, this neglect of diabetes management was attributed to the feeling that diabetes was inconvenient. Participants wanted to live like their peers, they did not want to be different, and felt that living life was more important at the time:

> I found it frustrating quite often because obviously my friends were, like, eating tonnes of chocolate and stuff and sometimes, erm, I would ignore the fact that I was diabetic and do the same because you want to fit in. (PID2, woman on HD.)

A few participants felt that they lacked some understanding of diabetes management when they were younger. One participant indicated they were aware of potential diabetes complications when they were younger but had felt that they were not causing damage at the time because they were not experiencing immediate issues:

> …at that sort of age you think you know everything, but you don't, you're very young and naïve... when you get told, oh, your HbA1c's a bit high but everything else comes back and they say, oh, this looks really good, your eyes are good, no problems there. You think you're getting away with it. What you don't realise is that you're damaging stuff that you can't see that will have, like, knock-on effects years down the line. And I think you, you know the risks but I think I always just assumed that they would happen instantly if you abused your body… (PID8, woman one-year post-SPKT.)

Several participants believed that their poor control of diabetes in their younger years had contributed to the damage to their kidneys that they experienced as adults and their subsequent need for an SPKT:

> …when I reached 16 and that's when I then, kind of, forgot about my diabetes, erm, lived life how I wanted to live life which then caused all my kidney disease in the first place. 'Cause I obviously wasn't looking after myself as a teenager. (PID7, woman one-year post-SPKT.)

Whilst most participants indicated that they made a conscious effort to manage their diabetes in adulthood, several indicated that this was a struggle and they found it difficult to keep their blood glucose levels within the desired range. A few participants had continued to try to ignore their diabetes and the seriousness of their condition as an adult. Some participants described their diabetes as 'brittle' and reported that their blood glucose levels were unpredictable. For example, hormones, stress, or comorbid conditions could cause blood glucose levels to fluctuate, which was often frustrating:

> Also, getting really stressed and, you know, realising that the more stressed I got, like before an operation, my sugar levels would be off the scale high. But that was obviously me releasing things into my system, erm, I would think adrenaline or something like that, which was affecting how my sugar levels were. (PID8, woman one-year post-SPKT.)

Some felt that they had a good grasp on their diabetes management and would experience warning signs if their blood glucose levels were high or dropping low. However, others were no longer able to detect changes and had lost their awareness of symptoms of hypoglycaemia, which sometimes resulted in difficult and/or dangerous situations. Sometimes participants preferred to keep their glucose levels high to prevent hypoglycaemia. Some participants indicated that their diabetes became more problematic as their CKD progressed and mixed reports were given regarding the impact of dialysis on diabetes management. One participant indicated that their blood glucose levels had been easier to control since starting HD whilst another felt it was completely unpredictable. For some, this struggle with diabetes management was quite frustrating and distressing at times:

> …obviously I'm on dialysis now and like some days I can be perfect and then other days I'm, one minute I'm high 20s and the next minute I'm low…Even to this day I'm severely struggling. (PID4, man on HD.)

Participants described their diabetes treatment as having improved "in leaps and bounds" (PID1, man pre-dialysis) since they were first diagnosed. Several participants reported using CGMs and/or insulin pumps, which helped them to improve their control over their blood glucose levels and simplified their diabetes management. Whilst these new technologies were beneficial and caused less discomfort compared to frequent finger prick blood tests, some participants still found that they would experience hypoglycaemia. A considerable amount of effort was still needed to manage the condition, such as carb-counting and feeding information into the devices:

> It's surprising how much freedom that [insulin pump] gives you. And my blood sugars were more, I still had crazy amounts of lows, but they weren't so high, apart from night-time, they were more stable throughout the day. So it was loads better. (PID12, woman 18-months post-SPKT.)

Diabetes is invasive. Participants depicted their treatment and diabetes symptoms or complications, such as experiencing hypoglycaemia, as quite invasive. Participants described needing to frequently think about what they ate and carb-count, as well as checking their blood glucose levels throughout the day and injecting insulin. Due to the need to manage diabetes constantly, it was always on some participants' minds, even those who indicated that they were not bothered by having diabetes:

> I've been living with diabetes all the time, all the time thinking about something, how many carbs I ate, how many insulin units I still have active in my body, should I do this, should I do that, how I'm feeling now, am I going low or high. (PID5, woman pre-dialysis.)

Some participants found this constant need to think about and manage their diabetes quite stressful. For example, one individual who reported putting a lot of effort into improving their diabetes control so that they could be added to the SPKT waiting list said:

> …my diabetes wasn't very well controlled, so I had the pressure of trying to get it under control really quickly, so I could then get on the transplant list. So I had that pressure of that, blood checking every 2 hours, writing down everything I was eating, carb counting, every little thing... (PID7, woman one-year post-SPKT.)

Several participants reported worrying about experiencing hypoglycaemia whilst out or when exercising. For example, participants described always needing to be prepared and not being able to leave the house without taking their insulin injections and snacks or a sugary drink:

> …if say for instance I want to go and play football or whatever like that, I have to make sure my sugars are alright, or I've got something there. It's just, there's always that worry that somethings going to happen, I can't just go and do something and not stress about it. (PID4, man on HD.)

Diabetes and its complications sometimes intruded on participants' lives when it became visible to others, which made some feel self-conscious. For example, some participants described stressful situations when they had needed assistance when they experienced hypoglycaemia whilst out or at work. At times participants found it embarrassing when they experienced hypoglycaemia in public because afterwards they were aware that they had behaved strangely or even rudely towards others.

Participants also reported that at times others had not understood what was wrong and, for example, assumed that they were drunk:

> …if I'm in the house it's fine but if I'm out anywhere, for whatever reason, and I'm away from, erm, a med kit or, you know, there's no-one with me I would tend to get a bit worried then, erm, because I would get confused and people would-. People have thought I've been drunk in the past when I'm going low. So, it is quite difficult, erm, I just have to be organised. (PD1, man pre-dialysis.)

Participants were sometimes concerned about how they were perceived by others due to their diabetes. One participant spoke about being perceived as a drug addict due to aspects of his appearance related to the diabetes and the need to carry around his medications and insulin:

> I had my pills on me and I had my injection on me and I had my ID to say I was diabetic, [but] I wouldn't get in [to bars]. Honestly. I was like… I don't run a shooting gallery, I'm not, that's not what I do. So, what, what can I do? [And the bouncer said] "Well, you look like a junkie." (PID10, man one-year post-transplant.)

Several participants spoke about experiencing diabetes complications, such as diabetic retinopathy, for which they had had to undergo quite invasive and unpleasant treatments. Other complications included neuropathy, ketoacidosis, hearing loss, and necrobiosis lipoidica, a skin condition associated with diabetes which can cause a lot of discomfort (S. D. Reid, Ladizinski, Lee, Baibergenova, & Alavi, 2013). Most participants indicated that they could carry on with life as they wanted and did not let diabetes stop them from doing the things that they wanted to do. Despite this, a few found that it restricted how active or independent they could be. Specifically, some participants reported not being able to drive either temporarily or permanently due to diabetic retinopathy and/or frequent hypoglycaemia. This meant that individuals sometimes had to rely on family and/or friends or take public transport to get around or go to appointments: "Well, er, because of my eyes I am unable to drive, so my licence was taken away, erm, [several] years ago. So, I'm reliant on friends and family to drive me around…" (PID2, woman on HD.)

Combination of diabetes and CKD is restrictive. Whilst some indicated that their kidney function was monitored and slowly declined over several years, participants often described shock at being told they would need to start thinking about dialysis and/or transplantation. A few who received dialysis treatment were

also shocked and upset when they had suddenly needed to start dialysis. Some found that as their kidney function declined their diabetes symptoms/complications, such as hypoglycaemia, worsened. It was often difficult to separate the impact of the two conditions. The combination of both diabetes and CKD was often described as more restrictive than diabetes alone due to the associated symptoms, such as reduced energy levels, and, for some, time spent unwell in hospital or on dialysis. Participants also often had frequent appointments, especially when being added to the transplant waiting list. Even those who were still pre-dialysis often found that their reduced energy levels made it more difficult to do the activities that they wanted to do and they spent more time resting:

> …since the kidney problems have manifested my energy levels have fallen. Erm. I have more muscle aches and pains than I ever did and so it's sort of effecting my mobility quite a lot. And it's funny because it's a whole package, everything comes together, it just kind of weighs on top of you. (PID1, man pre-dialysis.)

Aspects of life such as socialising, leisure activities, and holidays were often restricted by poor health, dialysis, and the need to remain local and ready to go to the hospital if they were called in suddenly for their transplant. Some also reported difficulty exercising and taking part in physical activities due to their symptoms and concern of experiencing hypoglycaemia. Those on dialysis sometimes found it difficult to make plans because they did not know how they would feel on the day. On the other hand, some participants felt unable to be spontaneous due to their dialysis treatment, and this particularly impacted their social life:

> Because of having to fit dialysis in and having to plan everything… you can't be spontaneous. So, if someone phones up on the Friday and says, "you wanna come out?" it's like, well, no 'cause I got to go to dialysis and then I'm gonna be knackered. (PID3, woman on HD.)

Whilst some managed to continue working, they had generally been allowed by their employer to work reduced or flexible hours and/or would work from home or even whilst they were on the HD machine at the hospital. Some participants had to reduce their working hours or gave up work entirely due to their poor health and reduced energy levels: "I've just gone back to work and I do 2 days a week now. But that's, that's pushing it, I mean, I'm just about managing that…" (PID4, man on HD.)

Some participants indicated that they no longer felt 'normal' due to their health problems and the impact this was having on their life. A few participants felt that

their poor health and the restrictions that this imposed on them was upsetting, demotivating, and sometimes negatively impacted their confidence:

> …when you're lacking in energy and motivation it's quite easy to fall into a, fall into procrastination, thinking I've got all the time to do that I'll do it tomorrow, I'll do it tomorrow or that doesn't need to be doing. So, yeh, it was quite difficult. (PID9, man one-year post-SPKT.)

Furthermore, some indicated that their health issues had impacted their relationships. For example, some partner relationships were impacted due to sexual dysfunction and/or the partner needing to take on more of a caring role. Others avoided romantic relationships due to lowered confidence and/or not wanting to be a burden:

> I'm single at the moment. Again, I think it comes down to the confidence thing, I'm not as confident to meet someone or have someone. I think, with everything that's wrong with me I can't see what somebody would, could see in me… (PID2, woman on HD.)

Furthermore, some women spoke about not feeling able to independently care for or entertain their children as well as they would have liked. Reasons for this included low energy levels and/or the possibility of having severe hypoglycaemia. Participants in this situation expressed feelings of frustration and even guilt that they felt unable to fulfil their parenting role as well as they wanted:

> it was just silly things like having enough energy to tidy up after the kids had been at home all day and doing stuff for the children, I was always so tired that, and they had to spend a lot of time just amusing themselves. (PID12, woman one-year post-SPKT.)

Participants on dialysis found fluid restrictions difficult, and several participants found the combined diabetes and CKD dietary requirements more restrictive and difficult to follow. The fluid and dietary restrictions were particularly frustrating for some as they impacted on other aspects of life such as socialising and having meals with friends. It was sometimes felt that the dietary recommendations for the two conditions were contradictory and a few participants reported struggling to acquire dietary advice from healthcare professionals that catered for both the diabetes and CKD:

> I went to see the diabetic specialist about the diet and stuff, erm, and they gave me, sort of, lots of ideas and stuff and as soon as I said, well, actually I'm on

> dialysis, they were like, oh, no, hang on, we need to research that. And you know, that was about a year ago and I still haven't heard anything. (PID6, woman on HD.)

Another participant said: "Ironically, the diet they want to give you on a kidney, with your kidney damage is the complete opposite to what you would eat if you're a type 1 diabetic." (PID8, woman one-year post-SPKT.)

Uncertainty for the future. Participants on the transplant waiting list were wary about having too many expectations of transplantation. Despite this, they were hopeful that they would receive a transplant which would treat their CKD and diabetes. Those who still felt quite well, hoped that the transplant would enable them to carry on enjoying life and doing what they wanted. Others who were less well hoped that after receiving an SPKT they would have more energy, independence, and freedom from their diabetes regimen and/or dialysis:

> Yeh, I just think it is that freedom, isn't it? It's that quality of life, do you know what, I fancy going down the pub, or I fancy going out with friends or to a restaurant or whatever and not having to take a bag full of, you know, drugs. (PID6, woman on HD.)

However, overall participants reported feelings of uncertainty as to whether they would get a transplant, how long they would need to wait, what would happen in the meantime, and how successful the transplant would be. Participants who had received a transplant also indicated that they had felt hopeful but uncertain when on the waiting list. In particular, those who had been told that they had high levels of antibodies or that they would be difficult to match, were quite uncertain about their future and discussed considering alternative options (e.g. a LDKT):

> And then the blood test revealed that I have [a high level of] antibodies. So, the chances of me finding a match are quite slim. Yeh, the team have told me that, you know, it's highly unlikely that I will find a match. 'Cause I'm obviously going for the kidney pancreas, so they're saying that, you know, potentially just a kidney would do. Erm. They, they did say that my best chance is to go for a, erm, family donor. (PID2, woman on HD.)

One participant reported initially being excited about being added to the transplant waiting list but then became more wary as he learnt that the SPKT would not last indefinitely and that it would still require a certain amount of care: "So, I thought you

have a transplant and then you're a normal person again, but it's not as, er, simple as that." (PID4, man on HD.)

Participants felt aware of the possible risks of transplantation and that they might experience side-effects from the anti-rejection medications required after the transplant. One SPKT recipient reported that prior to transplantation they had been very concerned about the increased risk of skin cancer and the need to stay out of the sun post-transplant. Some participants who were still feeling quite well and/or had not yet started on dialysis at the time of their interview reported having concerns that their health would decline or that further diabetes complications would develop before they received a transplant. Participants who felt quite well still were also concerned that the transplant and medications would leave them in a worse state than they were currently in:

> …it's a bit of a fear of the unknown, even though they tell you everything about it. But I think for me, particularly, I would, I'm more nervous about afterwards, like, will I still be as fit and healthy and doing all the same things. Will I still, sort of, look the same… (PID5, woman pre-dialysis.)

Acceptance and doing what you can. Participants were asked about how they coped or adjusted to their health problems. Whilst not always recognised as coping strategies, participants indicated that they "just get on with it". Participants indicated that they accepted they had health problems and tried to not let it take over their life. Participants also tried to keep a positive attitude and not worry about things they could not change:

> I just like to think about the situation, analyse it, you know, find a solution. What can I change? What can I not change? If I can change something, change it, if I cannot change it accept it and life goes on. (PID5, woman pre-dialysis.)

Another participant said:

> I'm definitely a, sort of, glass-half-full person. I always see the good, even though stuff around isn't always going great. Erm. I've always had that, sort of, attitude really. So, I wouldn't say cope, I just get on with it and life is what it is, I can't change it… (PID3, woman pre-dialysis.)

Participants indicated that they tried to continue to do things as best they could or adjusted what they did. For example, some participants adjusted their work patterns, reduced their hours, or purposefully found a job with flexible working hours so that they could continue working. This relied on the individual having a supportive employer who allowed them to adjust how they worked. The ability to continue

working was important to most participants, as one participant pointed out, working allowed them to maintain an element of normality:

> So, it's had an impact, erm, in terms of I can't be in the office so much, but we've now worked a way around it, so actually I'm still doing my work, erm, so, yeh, it's not, it's not as bad…Cause at work hardly anybody knows. Only my, sort of, manager and my team know. So, that's why I like still working because that's where I can be still normal. (PID2, woman on HD.)

A few participants also indicated that humour helped them to get through difficult times. However, some participants, especially those who were particularly unwell, found it difficult to cope and indicated that their poor health and the restrictions it imposed on them impacted on their mental health. One participant felt that his life was "over but it's not over" (PID4, man on HD) and another described struggling with the impact that their health problems had on their life:

> I think everything effects my mental health, which then has a big impact on, kind of, life, and how I view life. And, so, it's all a kind of, it's a horrible web of, kind of, trying to work out what's what… (PID1, man pre-dialysis.)

Information seeking and following recommendations. Participants often mentioned attending information sessions run by their hospitals to inform them about treatments for CKD, including transplantation. At these sessions, participants were usually able to speak to transplant recipients about their experiences. Some participants had searched for information about kidney disease and the treatments available, and had tried to ask staff lots of questions so that they were well informed and prepared: "…when, erm, I started going [to the renal unit/dialysis] and stuff, er, I asked questions, I kept constantly asking questions." (PID4, man on HD.)
Another participant said:

> I want to know as much as possible so that I can adapt myself and prepare myself in advance. What if? "Yeh, but that might not happen." Yeh, ok, that won't happen, but what if? I just want to know. (PID5, woman pre-dialysis.)

Although diabetes was a struggle to control for some participants, most had tried to gain better control. Participants also tried to follow recommendations such as fluid restrictions, dietary requirements, and taking medications although this was sometimes quite difficult:

> …the sort of strategies I've taken is, I would follow the diabetic guidelines first and then rule out anything that the kidneys, erm, stop from there. So, there's a lot

> of, kind of, erm, online, kind of tools you can use for that… (PID1, man pre-dialysis.)

Importance of support. Participants spoke about receiving practical and emotional support from family and friends. Family support included attending appointments together, driving them when they were unable to, taking on more responsibilities around the home, and helping with organisation, such as ensuring that they had snacks and their insulin when they went out together:

> So, I surrendered my driving licence, so obviously I became quite reliant on my fiancé. Erm. 'Cause she was driving me everywhere and that's another reason why we moved home really, so that there were other people, sort of, around to help me with things as I, sort of, worsened… (PID9, man one-year post-SPKT.)

Some participants indicated that family had helped them when they had experienced hypoglycaemia, which was stressful. Participants also received emotional support from their close family and could speak about things that might be troubling them. Sometimes participants found others would fuss over them and a few participants wished to protect certain family members from potentially stressful information about their condition. Some participants benefited from speaking to other patients who were in a similar situation as them, for example, during HD. Others appreciated hearing from patients who had already received a transplant and could tell them about their experiences. One participant explained that they liked being able to speak to other patients because they felt that they had a better understanding of what they were going through than those without CKD: "Yeh. I mean, we chat through, like, our sessions, 'cause obviously they're going through the same things, so, erm, I think you become more like friends, you know? You've got a bit more connection." (PID4, man on HD.)

Some participants acknowledged that they could access psychological support such as counselling, however it appears that few accessed this support as they were either not interested in therapy or felt that it was difficult to access from where they lived. One participant reported having heard from another patient that counselling was available but he had not been offered it directly. Another participant who had accessed psychological support to help with their feelings around diabetes and its management reported that this had been useful. Some participants felt their diabetes care had not been sufficient and, for example, reported other issues such as delays in being told about the decline in their kidney function. However, on the

whole individuals did appear to appreciate the support and information provided by their renal teams:

> I see my nephrologist every 2 months and I can speak with her, I could ask [about] whatever occur[ed] in those 2 months, if anything. If there is any development. And then I have [a] coordinator, she's really engaged and open to any kind of talk, like, what kind of pyjamas should I pack when I'm called. You know, anything. (PID5, woman pre-dialysis.)

Discussion

This is the first UK-based qualitative study to investigate how QoL is impacted by insulin-treated diabetes, CKD, and wait-listing for an SPKT. Findings from the semi-structured interviews revealed that several participants had struggled with diabetes management and indicated that it was invasive. The combination of diabetes and CKD symptoms and time spent on treatments often restricted participants' lives. Participants felt uncertain for their future as they did not know when they would receive a transplant or whether they would experience further complications. Participants often coped by accepting their situation and trying to continue to do as much as they could whilst following recommendations. Practical and emotional support from family, friends and healthcare professionals was beneficial whilst coping with diabetes and CKD.

Impact of diabetes management. Some participants felt that problems with their diabetes management started during adolescence and/or young adulthood and this had contributed to the damage to their kidneys, resulting in their subsequent need for a transplant. This expands on responses given on the Brief IPQ used in study 2, described in Chapter 4, which showed that most participants felt that diabetes was an important main cause of their CKD. Participants who indicated that they had suboptimal diabetes control during adolescence and young adulthood often felt that this was because diabetes management was inconvenient, or they had not wanted to be different from their peers without diabetes. This has been noted as an issue in previous research with adolescents with type 1 diabetes (Borus & Laffel, 2010; Tuohy et al., 2019). Adolescents have been found to believe that they are at greater risk of short-term rather than long-term complications and they believe others with diabetes are at greater risk of complications than themselves (Patino, Sanchez, Eidson, & Delamater, 2005). A qualitative study in the US found

that adolescents with type 1 diabetes had limited knowledge of long-term diabetes complications, such as kidney disease, and believed that because clinicians had not spoken to them in-depth about complications they were not personally at risk (Katz et al., 2021). The current and past research suggests that adolescents with diabetes need to be well educated on the possible long-term consequences of poorly controlled diabetes and made aware that damage caused by high or fluctuating blood glucose levels may not be noticeable for many years. However, care needs to be taken to not scare patients as perceptions of very severe consequences of health conditions have been associated with poorer well-being (Hagger & Orbell, 2003).

Most participants had tried to improve control of their diabetes management in adulthood, and some did not find having diabetes stressful. A few indicated that they did not acknowledge the seriousness of their condition and/or continued to ignore their diabetes to an extent until they became unwell with CKD and needed to improve control. As participants were aware that their diabetes contributed to their CKD, this may have led some to re-evaluate the seriousness of their condition and heightened their desire to control their blood glucose levels to slow the progression of CKD if possible. Young adults with type 1 diabetes have previously reported that with age they had become increasingly concerned for their future health and the development of complications due to past poor control (Balfe et al., 2013). The development of microvascular complications, such as retinopathy and nephropathy, can act as a 'wake-up call' for some patients and may motivate improved diabetes care (Ritholz, MacNeil, & Weinger, 2017). K. Reid et al. (2012) also reported that individuals with diabetes and CKD suddenly found that they could no longer ignore their health problems as they became more unwell, and their condition began to have more of an impact on them. The authors argue that this fits within the shifting perspectives model of chronic illness, which suggests that those living with a chronic illness shift between having illness or wellness at the foreground of their perspective (Paterson, 2001).

Whilst participants in the current study often indicated that they had successfully improved control of their diabetes, and new technologies such as CGMs and insulin pumps had helped with diabetes management, a few reported still struggling and having brittle diabetes. Brittle diabetes refers to diabetes with large unexplained fluctuations in blood glucose levels that can severely disrupt the person's life. Comorbid conditions, complications, and mental health problems can disrupt blood

glucose levels and contribute to brittle diabetes and treatment of these comorbidities can sometimes help (Hirsch & Gaudiani, 2020). However, it is possible that this struggle with diabetes management may have impacted some participants' perceptions of personal and treatment control over diabetes and, similarly, their self-efficacy beliefs in their ability to carry out self-management behaviours (Bandura, 1977, 1982). Outcome expectations, which are beliefs about the likelihood that certain behaviours will result in a particular outcome, can also influence behaviour (Bandura, 1977). Participants' outcome expectations about whether following self-care recommendations would lead to controlled blood glucose levels may have also been disrupted due to the unpredictable nature of brittle diabetes, leading some to feel that even if they followed recommendations, they might still not experience positive outcomes. Furthermore, participants' self-efficacy may have also been impacted by the added need to follow CKD self-care recommendations. Research suggests that self-efficacy and perceptions of control are associated with self-care behaviours and glycaemic control in patients with diabetes and could be targeted to improve diabetes management (Breland, Wong, & McAndrew, 2020; Iannotti et al., 2006; Mc Sharry, Moss-Morris, & Kendrick, 2011; Nouwen, Urquhart Law, Hussain, McGovern, & Napier, 2009), which could help prevent or slow the progression of complications such as CKD. The current research indicates that patients with brittle diabetes need additional help to identify factors that contribute to the unpredictable fluctuations in blood glucose so that these can be addressed.

Several participants indicated that their struggle with diabetes management and the invasiveness of the condition was stressful at times, and some were often concerned about experiencing hypoglycaemia, which they tried to avoid. Hypoglycaemia can be a particular cause of distress for individuals with type 1 diabetes, as well as worry about the risk of other diabetes complications (Balfe et al., 2013; Gonder-Frederick, 2013; Martyn-Nemeth, Duffecy, Fritschi, & Quinn, 2019; Martyn-Nemeth, Farabi, Mihailescu, Nemeth, & Quinn, 2016). The higher prevalence of depression in those with diabetes compared to general population samples has been well documented (Chireh, Li, & D'Arcy, 2019; Hasan, Mamun, Clavarino, & Kairuz, 2015; Rotella & Mannucci, 2013). However, some measures of depression include somatic symptoms which may be affected by the health condition rather than the presence of depression (Bradley, 1994b). This could mean that the prevalence of depression is over-estimated in people with diabetes. Research has also investigated the presence of 'diabetes distress', which is specifically distress caused by diabetes and its management and is distinct from

clinical depression (Fisher, Hessler, Polonsky, & Mullan, 2012; Polonsky et al., 2005). Seven aspects of diabetes distress have been identified, these include: powerlessness; negative social perceptions; physician distress; friend/family distress; hypoglycaemia distress; management distress; and eating distress (Fisher et al., 2015). Around 20-30% of patients are estimated to have experienced elevated diabetes distress and the risk is higher among women (Sturt, Dennick, Due-Christensen, & McCarthy, 2015). It is possible that some of the participants in the current study had experienced diabetes distress, suggesting that more may need to be done to help detect and alleviate distress in patients with both diabetes and CKD.

Impact of diabetes and CKD on QoL. An important theme in the current study was that the combination of diabetes and CKD was often restrictive. This mirrors the quantitative results reported in Chapter 4 that showed that participants' QoL was negatively impacted by both diabetes and CKD. When asked in the interviews about the individual impact of the two conditions on QoL, some participants found it difficult to separate them or identify which condition caused which issues. A few participants who were pre-dialysis and still felt quite well indicated that the impact on their QoL was minor. Individuals with type 1 diabetes often try not to let diabetes define them or limit what they do, despite the challenges of diabetes management (Freeborn, Dyches, & Roper, 2017). Whilst a few participants indicated that diabetes specifically placed restrictions on them, for example diabetic retinopathy meant that some participants were unable to drive. Most indicated that it was when they became unwell with CKD that their life was most impacted. In particular hypoglycaemia, low energy levels, and dialysis restricted participants' ability to carry out and/or enjoy various activities. Participants tried to carry on with their lives but often could not do as much of the things that they wanted to. Similar findings on lifestyle restrictions have been reported in research with individuals on dialysis and awaiting a DDKT (Burns et al., 2015; Roberti et al., 2018). In particular, fatigue is a common symptom of advanced CKD and is associated with poorer clinical and patient-reported outcomes (Artom, Moss-Morris, Caskey, & Chilcot, 2014; Bossola, Vulpio, & Tazza, 2011). However, living with both insulin-treated diabetes and CKD can be particularly challenging as patients must manage both conditions' symptoms and treatments and may contend with added restrictions as a result of having both conditions. For example, patients with diabetes and CKD may struggle to follow the combined dietary recommendations (Clemens et al., 2019; Notaras & Conti, 2018), which some

participants in the current study felt were contradictory. Patients need to be provided with sufficient advice on how to produce meals that are enjoyable but still cater to both diabetes and CKD recommendations, as dietary freedom is often an important aspect of life that is negatively impacted and could possibly be improved with appropriate provision of information. Furthermore, as evidence suggests that hypoglycaemia is more common in patients with CKD (Moen et al., 2009), individuals with both conditions may need additional support to cope with this also.

The theme of uncertainty for the future was prevalent for participants and is a common theme among patients with chronic health conditions. Whilst uncertainty itself is often considered a neutral cognitive state, it can result in distress if it is appraised negatively (McCormick, 2002). However, participants were often also hopeful that they would receive a transplant. This uncertainty and hope for a transplant has been noted in research with patients awaiting kidney-only (Burns et al., 2015; Nielsen et al., 2019; Tong, Hanson, et al., 2015) and SPK transplantation (Pera et al., 2012). In addition, participants in the current study often indicated that the pancreas transplant was a bonus as it would relieve them of their diabetes and its management and help protect the kidney graft. Participants who were quite unwell hoped that after receiving an SPKT they would be able to do more, enjoy life, and be more like their usual self. Participants mostly felt well informed and aware of their treatment options and that there were risks involved with having an SPKT. Some participants who reported still feeling quite well, were apprehensive about whether the transplant and anti-rejection medications would have a negative impact on their health, ability to be active, and their appearance. These concerns regarding transplantation suggest that participants understood that transplantation is a treatment rather than a cure. Previous research suggests that individuals may have unrealistic expectations (Hart et al., 2019; Schmid-Mohler et al., 2014) or over-estimate rather than under-estimate the benefits of kidney transplantation (Schulz et al., 2014; D. Smith et al., 2008). Whilst Schulz et al. (2014) reported that over-estimation of outcomes post-transplant was not associated with distress, Gibbons and colleagues found that some kidney and SPK transplant recipients experienced disappointment due to unexpected outcomes such as having a large scar and issues with stamina (Gibbons et al., 2021; Gibbons et al., 2020). Patients' expectations need to be well managed to help avoid disappointment. Furthermore, it is thought that people generally want to avoid feelings of regret and make decisions based on which option they anticipate will least likely lead to regret (Tymstra, 1989, 2007). Patients may accept a transplant even when they are still pre-dialysis and

feeling quite well, because they anticipate that they would regret not doing it more, for example, if they became very unwell and could not find a suitable transplant match. Therefore it is important that patients are provided with enough information so that they can make properly informed decisions and only treatments that are likely to benefit patients are offered as individuals may find it difficult to turn down an offered treatment (Tymstra, 1989, 2007).

Coping with diabetes and CKD. Both emotion-focused and problem-focused coping strategies (Lazarus & Folkman, 1984) were used by participants, in line with previous research with CKD patients (Subramanian et al., 2017). It has been argued that individuals often use both types of coping strategies, but are more likely to use emotion-focused coping in situations where they perceive themselves to have limited control and problem-focused coping when they perceive that they do have control (Lazarus, 1998). Some participants found their health conditions difficult to accept, particularly if they felt that their diabetes was unpredictable or they were experiencing complications and symptoms from the two conditions. Participants indicated that they tried to accept their situation and described 'getting on with it' by attempting to continue to live their life by focusing on what they could still do. Some participants tried to have a positive attitude or used humour. Acceptance is thought to be a key first step to coping with chronic illnesses such as CKD, although acceptance alone will likely not be sufficient for positive outcomes (R. Chan, 2013). The current findings also appear to be similar to the 'stoic' coping described by N. King et al. (2002, p338) whereby individuals reported 'carrying on', trying to cause as 'little fuss' as possible, looking on the 'bright side' and acceptance with 'quiet resignation'. N. King et al. (2002) argued that how a person presents themselves to others is important to coping and individuals with chronic conditions may use stoic coping mechanisms because they are concerned about how others would perceive them if they frequently expressed negative emotions, as this could alienate themselves from healthy individuals. However, several participants in the current study also sought information, either by questioning healthcare professionals or through online searches/forums, to gain knowledge about CKD and its treatments. Participants tried to follow recommendations such as diet and fluid restrictions, and tried to control their blood glucose levels, which they hoped would help to slow down the progression of their CKD. These behaviours could be seen as ways in which participants were trying to take some control over their condition or reduce their feelings of uncertainty, which has also been noted in previous research (N. King et al., 2002; K. Reid et al., 2012).

As chronic illnesses like diabetes and CKD can be unpredictable and there are no certainties about transplantation, interventions incorporating mindfulness, such as Mindfulness-Based Stress Reduction (Kabat-Zinn, 1982), Mindfulness-Based Cognitive Behavioural Therapy (Segal, Williams, & Teasdale, 2002), and Acceptance and Commitment Therapy (Hayes, 2004), could be useful to help individuals who struggle to cope with uncertainty and limited control. These mindfulness-based interventions focus on acknowledging and accepting negative thoughts without judgement and living in the present moment. The aim of treatment is to help individuals to reduce the impact of unhelpful thoughts and maladaptive behaviour and work towards valued goals. Encouraging results have been found showing mindfulness-based interventions can improve feelings of stress (Ellis et al., 2019), diabetes distress, depression, and anxiety in individuals with diabetes (Van Son et al., 2013; Whitebird, Kreitzer, Vazquez-Benitez, & Enstad, 2018). Two small-scale mindfulness-based intervention studies have reported improvements in anxiety and depression for individuals on HD (Haghshenas, Assarian, Omidi, Razaghof, & Rahimi, 2019; Sohn et al., 2018). In another small trial, individuals wait-listed for a kidney or SPK transplant who received a mindfulness-based stress-reduction intervention adapted for implementation over the telephone reported significantly improved mental-health component scores on the SF-12 compared to those receiving a support-group intervention (Gross et al., 2017). However, there were no significant improvements on other measures of anxiety, sleep, or fatigue. Further research is needed to verify whether mindfulness-based interventions could help to improve the QoL of patients awaiting SPK transplantation and whether patients could be usefully advised to use mindfulness strategies.

Support. Practical and emotional support from family and healthcare professionals was found to be beneficial for participants and has been noted as important in previous research (Burns et al., 2015; Hill, Ward, & Gleadle, 2019; K. Reid et al., 2012; Roberti et al., 2018; Yngman-Uhlin et al., 2015). Although some issues were highlighted by participants, especially in relation to suboptimal diabetes care, they were generally positive about the support and care they had received regarding their renal treatment and provision of information on transplantation. Whilst one participant specifically reported that counselling had been useful, others had not been offered psychological support or declined because they were not interested or it was not convenient. Support from other patients in a similar situation was valuable to some as they could provide information or were felt to have a better

understanding due to their shared experience. Formal and informal peer support can benefit patients, especially at times of transition such as when starting dialysis, and can help to normalise patients' experiences (Hughes, Wood, & Smith, 2009; F. Taylor, Gutteridge, & Willis, 2016). It is thought that practical and emotional support can directly and/or indirectly benefit individuals through a buffering effect on stress (Baek, Tanenbaum, & Gonzalez, 2014; S. Cohen & Wills, 1985). For example, there is evidence to suggest that social support is beneficial to self-management of chronic health conditions such as diabetes and CKD (Chen et al., 2018; Mollaoglu, 2006; Song, Nam, Park, Shin, & Ku, 2017) and for the mental health of patients (S. D. Cohen, 2013; S. D. Cohen et al., 2007; Joensen et al., 2013). Patients may benefit from being signposted to and encouraged to use sources of support available to them, including peer support.

A small number of participants in the current study indicated that their health problems had impacted their personal relationships. Some participants did not want to burden others, and at least one participant implied that they did not feel they were desirable to potential romantic partners due to their health problems. Maintaining and developing new relationships can be difficult for young adults with CKD because the condition can be restrictive and patients may not want a partner to also have to cope with the illness (E. Coyne et al., 2019). It is possible that some patients may experience illness-related shame and this may impact their self-confidence and/or relationships. Archer (2014) argues that shame in relation to diabetes management is common, especially when individuals struggle to follow diabetes recommendations. Individuals may experience shame in the form of embarrassment or self-consciousness, for example, when experiencing severe hypoglycaemia in public (Archer, 2014). In a study of chronically ill students, illness-related shame was negatively associated with quality of social relationships and psychological health domains of the WHOQoL-BREF (Trindade, Duarte, Ferreira, Coutinho, & Pinto-Gouveia, 2018). In further analyses Trindade et al. (2018) found that the association between illness-related shame and social relationships was mediated by fear of receiving compassion measured with the Acceptance and Action Questionnaire-II (AAQ-II; Bond et al., 2011). The authors argue that individuals with chronic illness-related shame might withdraw or try to conceal their shame by decreasing engagement in social interactions, which in turn can impact on their relationships.

Study limitations. The current sample only included four individuals who had experienced dialysis as three were still pre-dialysis at 12-month follow-up and five of the six with an SPKT had received a pre-emptive transplant. This enabled the exploration of experiences of those who were wait-listed for a transplant despite not yet needing to start dialysis treatment, which may be increasingly common. This contrasts to previous qualitative research with patients awaiting kidney transplantation which has often focused on patients already on dialysis (Burns et al., 2015; Tong, Hanson, et al., 2015). Whilst some of the interviews were conducted during the COVID-19 pandemic these were mostly with individuals who had received a transplant around 12 months prior and therefore their pre-transplant experiences were not impacted by the pandemic. It is acknowledged that individuals interviewed post-transplant may have started to forget or had biased memories of their pre-transplant experiences; however, the experiences described were similar to those who were still awaiting transplantation at the time of their interview. Whilst participants were asked about their use of support, unmet support needs were not explored in depth. Future research could explore unmet needs of patients awaiting SPK transplantation to identify ways in which patients' experiences might be improved.

Study implications. The current research highlights the importance of informing adolescents with diabetes about the possible long-term complications, as some participants believed that suboptimal diabetes management in their younger years had damaged their kidneys. Some patients may benefit from further guidance and advice on managing diabetes and coping with hypoglycaemia. Patients with diabetes and CKD may need more support to cope with uncertainty and restrictions of having both conditions, such as following dietary recommendations. In particular, support needs to be offered to those who may not have sufficient support and/or those who might have concerns about the impact that their health is having on their relationships. Individuals need to be made aware of the sources of support available to them and how they can access this support.

Conclusions

The study found that the QoL of individuals awaiting an SPKT was impacted by the struggle with and the invasiveness of their diabetes management, which was stressful for several participants. Diabetes was found to have placed some restrictions on individuals; however, the combination of CKD and diabetes was more

restrictive, and participants sometimes found it difficult to separate out the impact of the two conditions. Individuals awaiting SPK transplantation live with uncertainty as to how long they will wait, whether their health will deteriorate prior to transplantation, and whether they will experience complications or medication side-effects post-transplantation. Although not necessarily seen as coping mechanisms, participants discussed using a variety of strategies such as acceptance and doing what they could, information seeking, following recommendations, and accepting support from others. Support provided to patients needs to acknowledge the challenge of managing these two health conditions. The management of expectations is also important to prepare patients for transplantation and to support individuals who struggle with uncertainty. Importantly, patients need to be made aware of additional sources of support and how they can access these if and when needed.

Chapter 6: Quality of Life after Kidney and Simultaneous Pancreas and Kidney Transplantation: Qualitative Findings

Introduction and Aims

Findings from the individualised condition-specific measures of QoL (ADDQoL and RDQoL) reported in Chapters 3 and 4 indicate that whilst QoL may be less impacted post-transplant, recipients are often still negatively impacted by having had CKD and diabetes. Specifically, in Chapter 3, results from the ATTOM detailed PROMs follow-up study indicated that renal-dependent QoL improved significantly from pre- to post-kidney transplantation, but scores remained stable between 12-months post-transplant and six/seven years follow-up for kidney-only and SPK transplant recipients. In Chapter 4, SPKT recipients reported significantly improved QoL and less impact from their diabetes on their QoL post-transplant, however improvements in renal-dependent QoL did not reach significance. Although suggestions can be provided to try to explain these quantitative results, qualitative research allows for in-depth exploration of patients' experiences, so that these quantitative findings can be clarified and corroborated and a deeper understanding of the impact of transplantation can be gained.

Previous qualitative research suggests that kidney and SPK transplantation results in improved health, energy and the ability to do more (Bogue Kerr et al., 2018; Dahl & Moen, 2018; de Brito et al., 2015; Dos Santos et al., 2016; Pera et al., 2012; Pinter et al., 2016). Transplant recipients have reported having more freedom and independence, especially if they were receiving dialysis prior to transplantation (de Brito et al., 2015; Dos Santos et al., 2016). Individuals have recounted returning to "normal" life post-transplant, whilst others describe a "new normal", characterised by both improvements and continued health-related problems (Boaz & Morgan, 2014; Bogue Kerr et al., 2018; Dos Santos et al., 2016). Negative aspects of transplantation have also been explored with kidney and SPK transplant recipients and include frequent appointments, fear of graft loss, and the impact of side-effects from the immunosuppressant medications that patients are expected to take after the transplant (Dahl & Moen, 2018; de Brito et al., 2015; Jamieson et al., 2016; J. Jones et al., 2020; Luk, 2004; Pera et al., 2012; Pinter et al., 2016). Kidney transplant recipients' experiences have been described as paradoxical; individuals are unwell whilst also healthy, and they feel that they have changed due to the

transplant yet are still the same person (Amerena & Wallace, 2009; Bogue Kerr et al., 2018). Although previous research provides insight into the experiences of transplant recipients there is limited research with a focus on SPKT recipients (e.g. Dahl & Moen, 2018; Pera et al., 2012). SPK transplantation is still a relatively new treatment. As transplantation techniques and post-transplant treatment improves it is important to continue to evaluate patients' outcomes and experiences in their own words, to identify issues where further improvements could be made.

It is well-established that the management of CKD can be demanding and may be perceived as stressful or distressing by patients (Jamieson et al., 2016; Roberti et al., 2018). Whilst transplantation is often beneficial, post-transplant issues and continued management of the condition can pose its own challenges. Patients need to learn how to cope with these as part of the post-transplant experience (Gill, 2012; J. K. Low et al., 2017; Schmid-Mohler et al., 2014). As previously discussed, individuals are thought to appraise situations and use two main types of coping: emotion-focused coping and problem-focused coping (Lazarus & Folkman, 1984). Studies have used quantitative measures to assess types of coping strategies used by kidney recipients and their association with PROs (Knowles et al., 2016; Nilsson, Forsberg, Lennerling, & Persson, 2013; C. White & Gallagher, 2010). However, as previously stated, cross-sectional quantitative measures of coping tend to assume trait-like coping styles and often don't provide information on when and how patients actually use coping strategies (Leventhal et al., 2004). Alternatively, qualitative research can be used to investigate the coping techniques that individuals usually use. For example, Gill (2012) found LDKT recipients tried to make the most of life post-transplant and used avoidance and denial to cope with fears of graft failure. J. K. Low et al. (2017) found kidney recipients coped with their medication regimen because they were motivated to prevent the need for dialysis and keep themselves alive. Other patients, family, and healthcare professionals also helped recipients to cope. Strategies including acceptance, knowledge acquisition, goal setting, living in the moment, positive thinking, attempts to retain control, and being open and honest with family and friends have also been reported by kidney recipients (Schmid-Mohler et al., 2014). To gain a deeper insight into the QoL of individuals with a kidney or SPK transplant it is important to know about the coping strategies that patients use as this could help to inform recommendations and interventions to reduce the negative impact of the conditions on QoL and other outcomes.

The current study aimed to add to the existing literature and supplement the quantitative research findings in Chapters 3 and 4 by using participants' questionnaire responses to guide interviews about how their QoL has changed and ways in which it continues to be impacted by having CKD (and diabetes). The current study aimed to explore patients' post-transplant experiences to help explain the findings from the quantitative research by asking: (a) How is QoL positively and negatively impacted after SPK and kidney-only transplantation? (b) How have patients coped with health-related issues since transplantation? Whilst the current study includes both SPKT and kidney-only transplant recipients, care was taken to highlight additional issues that were specific to SPKT recipients within the themes discussed as there is limited research with this group of transplant recipients.

Summary of Methods

Design. The study used qualitative telephone interviews and formed part of a larger mixed methods project.

Recruitment and procedure. Between June 2019 and August 2020, transplant recipients were recruited through studies 1 and 2 (outlined in Chapters 3 and 4) to take part in this interview study. Participants were informed about the intention to carry out interviews with participants on the original information sheets provided for studies 1 and 2 and were asked to give consent to be contacted for an interview. A sub-sample of individuals who returned a completed questionnaire pack were contacted by telephone, thanked for their participation, and invited to take part in a telephone interview. All individuals contacted and invited to take part in an interview agreed to take part. A purposive sample of six LDKT, seven DDKT, and six SPKT recipients were recruited from study 1 to include an approximately equal number of men and women and participants who had given a range of responses on the RDQoL (low, average, and high scores). A convenience sample of six SPKT recipients were recruited from study 2. All interviews were carried out by the researcher (KH) and no other researchers were present during the interviews.

The telephone interviews followed a semi-structured guide that included broad, open-ended questions and additional prompts. The interviews started by asking participants to describe their experience of living with CKD (and diabetes) prior to transplantation. These initial questions were asked to gain an understanding of participants' pre-transplant experiences to give context and aid understanding of

post-transplant experiences. Participants were then asked about the time when they received their transplant, and the impact of the transplant on their life. Responses on the QoL questionnaire (ADDQoL and/or RDQoL) were used to frame questions about how the participant's life was still negatively impacted by diabetes and/or CKD post-transplant. Aspects of life were selected for discussion based on those that the participant had indicated were most impacted and most important on the ADDQoL and/or RDQoL. For example, participants were asked: "can you tell me, in what ways does your renal condition impact on your leisure activities?" If not yet covered spontaneously, participants were asked about their satisfaction with their current treatment and ways in which they adjusted or coped with any difficulties post-transplant. Finally, participants were asked whether, prior to transplantation, they had any expectations about how life would be post-transplantation and whether these expectations had been met.

At the end of each interview the participant was thanked and asked whether there was anything else that they wanted to add about their experience. Participants were given another opportunity to ask questions about the research and permission was sought from participants to contact them in future for clarification if necessary. The interviews lasted between 20 and 104 minutes (60 minutes on average) and were audio recorded and transcribed verbatim by the researcher (KH). Whilst brief notes were taken during the interviews these were used to aid the interview and were not included in the analysis. Two participants were contacted briefly within approximately one week after their interview in order to clarify what had been said during the interview. A selection of transcripts were reviewed by supervisor AG for accuracy.

Analysis. The data were analysed thematically following Braun & Clarke's reflexive thematic analysis (Braun & Clarke, 2006, 2019a; Clarke & Braun, 2015). The analysis began with familiarisation, by transcribing, checking, and re-reading the transcripts. Transcription was conducted shortly after each interview. Initial coding involved labelling meaningful sections of the transcripts that were relevant to answering the research question. Codes were generated inductively from the data, but the analysis was also inevitably influenced by knowledge of previous research in the field. Next, codes with similar meanings or referring to similar topics were brought together to form themes. Ideas, themes, and interpretations were discussed with the supervisor AG throughout the process of analysis. Through discussion, larger themes including too many different ideas were broken down into sub-

themes. Lastly, the themes were named to describe their content. As previously mentioned, a contextualist approach was taken to the thematic analysis (Madill et al., 2000).

Findings

Table 6.1 presents the characteristics of the interview participants. The sample included 12 men and 13 women with an age range of 35 to 71 years old. On average, participants had had their transplant for about five years, although six SPKT recipients recruited from study 2 had had their transplants for approximately 12-20 months. Ten participants had received their transplants pre-emptively. Four SPKT recipients recruited from study 2 were interviewed after March 2020, during the COVID-19 pandemic.

All participants described an initial period post-transplant when they were recovering from surgery. During this time transplant recipients had frequent appointments and some experienced infections or acute rejection and spent more time in hospital. Two main themes were identified that helped to explain participants' experiences and QoL post-transplant: more freedom post-transplant and "it's not all rosy". "It's not all rosy" was divided into four sub-themes. Some patients were conscious of changes to their appearance due to pre-transplant and post-transplant treatments. Participants often also experienced continued and new health issues and this impacted on QoL, particularly as some still felt that they lived with restrictions and reduced ability. Participants often still felt uncertain about the future and some worried about graft loss. Three themes explain how participants adjusted/coped with issues post-transplant. Participants coped with difficulties and uncertainty with emotion-focused coping and most also recognised the importance of taking care of their health and, in turn, their transplant. Support from a variety of sources was still valued after transplantation. Lastly, tied to the theme of the importance of support, it was found that some participants experienced issues with continuity of care. Figure 6.1 provides a visual representation of the themes and sub-themes.

Table 6.1.

Characteristics of Interview Participants – Post-Kidney and SPK Transplant Experiences

Variable	**Sample** (*n* = 25)
Age *M* (range)	51.28 (35.00, 71.00)
Sex: male *n* (%)	12.00 (48.00)
Ethnicity *n* (%)	
White British/European	22.00 (88.00)
Indian	1.00 (4.00)
African	1.00 (4.00)
Mixed white and Asian	1.00 (4.00)
Education *n* (%)	
No qualifications	3.00 (12.00)
Basic qualification	12.00 (48.00)
Higher qualifications	10.00 (40.00)
Employment *n* (%)	
Unemployed	2.00 (8.00)
Part-time	9.00 (36.00)
Full-time	8.00 (32.00)
Retired	6.00 (24.00)
Married or living with partner *n* (%)	14.00 (56.00)
Transplant type *n* (%)	
LDKT	6.00 (24.00)
DDKT	7.00 (28.00)
SPKT	12.00 (48.00)
Months since transplant *M* (range)	60.02 (12.00, 90.50)
Pre-transplant treatment *n* (%)	
Pre-dialysis	10.00 (40.00)
PD	9.00 (36.00)
HD	6.00 (24.00)
Previous other transplant *n* (%)	5.00 (20.00)

Note. *M:* mean; LDKT: living-donor kidney transplant; DDKT: deceased-donor kidney transplant; SPKT: simultaneous kidney and pancreas transplant; PD: peritoneal dialysis; HD: haemodialysis.

Figure 6.1. Thematic map of kidney and SPK transplant recipients' experiences outlining how QoL is impacted and how patients cope.

More freedom post-transplant. Kidney-only and SPK transplant recipients reported that they felt healthier and had more energy compared to before transplantation. Participants who had previously been on dialysis, especially haemodialysis, reported having more time post-transplant. These improvements gave participants a sense of relief as they had more independence and, importantly, freedom to do the things they wanted to: "Well, it's just marvellous. Well, I'm as well as could be, yeh. Yeh, I mean go wherever I want, do what I want and enjoy life." (PID25, woman seven years post-DDKT.) Another participant said:

> …that's massively liberating. That really, on the whole, well I mean, yeh, all the time, I'm my own person. So long as I take the medicines and I can go wherever

I like, whenever I like and do whatever I like. So that's wondrous really. (PID30, man seven years post-LDKT.)

Even those who had felt able to carry on doing things prior to transplantation, despite being unwell or on dialysis, indicated that they were able to enjoy activities and life more, and could do more than they had previously done. Whilst some participants had managed to continue working up until their transplant and returned to work after a period of recovery, some of those who had stopped working due to their health problems were able to return to work post-transplant. Individuals also described being able to spend more time with family and friends, being more physically active, and being free to go on holidays abroad:

We like the holidays… and we can enjoy time with the grandkids and that now. So, we spend all our time with them like, you know. Just eh, Just. Just slow down and enjoy life a lot more… (PID28, man six years post-LDKT.)

Participants with an SPKT also described being free of their diabetes and its management. This meant that they no longer needed to think constantly about what they were eating, monitor their blood glucose, or administer insulin. Some participants described being more carefree: "I just enjoy life. I've got less worries on my shoulders. Less constant worries" (PID8, woman one-year post-SPKT). Individuals who had previously experienced hypoglycaemia expressed relief at no longer needing to worry about this and no longer needing to be prepared with snacks and insulin injections when they went out:

…I don't have to constantly manage my diabetes, so I don't have to worry about it at all, it's not something that I have to think about on a day, not even a daily basis, on an hourly basis. (PID11, woman one-year post-SPKT.)

SPKT recipients also no longer felt the need to eat when they did not really want to. Those with an SPKT and some with a kidney-only transplant described having more freedom in the variety of what they could eat post-transplant. Some SPKT recipients expressed joy at being able to eat sweet things when they wanted, within reason: "…I can eat hands full of Haribo, and look no, no blood sugar testing equipment, no injections." (PID10, man one-year post-SPKT.)

Those who had previously had a fluid restriction expressed great relief at being able to drink as much as they liked post-transplant:

It's a great impact that was. The, the relief that you have that you can actually drink fluids as much as you, you want, er, whereas before it was, like, very little,

cup of tea, you couldn't drink anything basically. (PID20, man seven years post-DDKT.)

Some participants reported that life had not changed much for them before their transplant because they did not become too unwell or had adapted well. Some participants reported that they did not let their health problems stop them from doing what they wanted, but after further discussion they revealed that there were ways in which life had improved and that they were able to do more post-transplant. A few individuals had not realised how unwell they were or the impact that their health was having on their life until after they received the transplant and felt better. Some participants felt that the transplant was life-saving/extending or described being back to "normal" post-transplant, suggesting that they felt life before the transplant was no longer normal due to their health condition(s): "I forget I've had it. To be honest, it's just not, life's back to normal and yeh, I literally forget I've had it until, you know, you're taking your tablets obviously." (PID27, woman seven years post-LDKT.) Other participants described getting their "life back", having a "new lease of life" or having a "second chance", also suggesting that individuals felt that their life had been in danger and that they were returning to a more normal life post-transplant. Participants described being grateful for their transplant, to the donor (both deceased-donors and living-donors), and the healthcare professionals who had been involved in their care: "I've had six more years of life than I would have had otherwise. So, I'll be forever grateful for that." (PID13, man seven years post-SPKT.)

"It's not all rosy." Whilst all participants described benefiting from having their kidney-only or SPK transplant, several were still negatively impacted in some way by having had CKD (and diabetes). As one participant put it: "I have a fantastically good life but I'm aware in the background that it's not all rosy." (PID14, woman seven years post-SPKT.)

This theme consists of four sub-themes: changes in appearance, continued and new health issues, restrictions and reduced ability, and uncertainty for the future. Not all participants experienced all or any of these negative outcomes and some seemed reluctant to admit any negatives as they were so pleased and grateful for their transplant.

Changes in appearance. Several participants spoke about experiencing changes in their appearance, some of which were caused pre-transplant and others which resulted from the transplant or side-effects of the anti-rejection medications. Changes in appearance included weight gain made worse by steroid medications, with some reporting that they had developed a round "moon face". Hair loss from the head, excessive body hair growth, and acne were also reported as side-effects experienced from the anti-rejection medications. Some participants also spoke about having scars from their various treatments for CKD and diabetes and from the transplant itself. A few individuals had been left with an enlarged abdomen due to the placement of the transplanted organ(s) at the front of the body. Participants were bothered to various degrees by the changes in their appearance with some indicating that they were not particularly concerned or felt that they had experienced positive changes in appearance post-transplantation, such as looking healthier. However, some participants found changes to their appearance upsetting and it had impacted their self-confidence. Participants discussed feeling uncomfortable when other people noticed their scars or other differences in their body, which were particularly difficult to conceal in the summer or on holiday:

> So, I've got lots of scaring on my stomach and I've got a fistula in my arm, so it's a bit, erm, not embarrassing as such, but it's just self-confidence in that, oh, I don't like people looking at me because of all my scars. (PID31, woman seven years post-LDKT.)

Two female participants in particular indicated that they were very upset by the changes to their appearance post-transplant and also felt that this had impacted their romantic relationships. Although one participant had been warned by healthcare staff, she had still not expected the severity of the changes. Another SPKT recipient described experiencing medication side-effects that impacted her appearance shortly after transplantation, which she found worrying. This participant did not feel that they had been sufficiently warned about these specific possible changes: "I was never told I would lose my hair, so to start losing hair, as a female with, with a very thick head of hair, losing it in clumps and clumps and clumps everyday was really emotional." (PID7, woman one-year post-SPKT.)

Continued and new health issues. Participants spoke about continuing to experience health issues related to having CKD and, for some, health issues related to having diabetes. A few also experienced complications relating to the transplant itself, such as hernias. Some participants indicated that whilst their energy levels

had improved post-transplant, they did not feel as energetic as they had hoped. Others felt that their energy levels had declined again in the years since transplantation, although it was sometimes acknowledged that this decline could be due to the natural aging process:

> I haven't got the energy like I had, but then I suppose because I'm older anyway, but, I haven't got the energy that I used to have. And because, erm, I do frequently get sick it takes me a lot longer to get well again… (PID23, woman five years post-DDKT.)

Several SPKT recipients still lived with complications from diabetes post-transplant such as neuropathy, diabetic retinopathy, or old wounds that had not fully healed properly. Whilst existing diabetic complications are not generally cured by an SPKT, their development can often be halted or slowed. However, a few participants who had had their SPKT for several years were disappointed that they were still experiencing a worsening of their diabetes complications:

> I was told that perhaps the diabetic damages, my feet and my eyes and, erm, would slow down, but they don't seem to have done, so they seem to be quite, my eyes continue to get worse and my feet do to a certain extent. (PID15, woman seven years post-SPKT.)

Participants often spoke about the negative impact that the anti-rejection medications had on their general health as well as frustrating side-effects such as delicate/thin skin, tremor, or cognitive/memory issues. Whilst some reported that side-effects had improved or disappeared after adjustments were made to their medications, several continued to live with them. A few participants who were several years post-transplant indicated they had not expected the extent of the side-effects they had experienced post-transplant. Some were wary of developing skin cancers and a few who were several years post-transplant had needed to have tumours/lesions removed. Several discussed being at higher risk of infections and acute illnesses, and some had experienced infections which resulted in hospitalisations. The increased susceptibility to infection and food poisoning was a cause of concern for several recent and long-term recipients. Participants also reported that minor illnesses, such as colds, tended to have more of an impact on them than they would on other people and could sometimes make them ill for weeks:

> I'm aware of some of the impacts of having a kidney and pancreas transplant has had on my current health, in that, erm, because I take immunosuppressants my

immune system is buggered, erm, basically. I am very prone to infections. So I've had sepsis three times. (PID14, woman seven years post-SPKT.)

Restrictions and reduced ability. Closely linked to participants' continued and new health issues, transplant recipients sometimes still felt restricted in some ways and/or still had some reduced physical ability post-transplant. Participants interviewed at approximately one-year post-SPKT were often still adjusting to life after transplantation and had, for example, not fully adjusted to being back at work or had not yet achieved the level of fitness that they desired: "I didn't do that much exercise and to be fair, I'm not sure how to start doing exercise since having had the operation because I'm so unfit. So I dare say it still is having an impact…" (PID8, woman one-year post-SPKT.) This was particularly true for the four SPKT recipients interviewed in 2020 during the COVID-19 pandemic. Participants transplanted not long before the pandemic felt that they had not yet been able to experience the full benefits of their SPKT because of the restrictions on travel, socialising, and work in the UK. Others felt they had lost some of the freedoms and benefits previously gained from the SPKT due to the pandemic. As transplant recipients were classed as highly vulnerable to the COVID-19 virus they were asked by the UK government to shield from others for several months and only leave their home for essential reasons. This was difficult and isolating for some participants. For example, one participant said: "…you're still having to stay inside. So, I think in terms of that, I found that really hard. And that's why I think some of the, there were certain questions which I think were swayed because of Covid..." (PID11, woman one-year post-SPKT.) Levels of concern about the virus seemed to vary but participants were looking forward to being able to do more in future, although it was unclear when this would be.

Some SPKT recipients were still negatively impacted by diabetes complications which continued to restrict certain activities that they could do. In particular, whilst some SPKT recipients had their driving licence reinstated post-transplant, those who were permanently severely visually impaired or continued to have problems with their eyes remained unable to drive. This caused significant frustration as it meant that they could not live as independently as they wished and had to rely on others for transport:

I've got a couple of friends that can drive, but you know. Again, that's quite depressing 'cause you're dependent on other people if you want something

> doing. I've always been used to me own independence and I find that quite hard… (PID13, man seven years post-SPKT.)

Some participants reported having reduced mobility or described needing to be careful not to injure themselves or their transplant. This in turn impacted on their ability and willingness to take part in certain leisure activities and exercise and meant that some who had their transplant for several years were not as fit as they felt they should be or wanted to be. Some participants with families indicated that this also had an impact on what activities they felt they could take part in with their children: "I can't, er, go, you know, go climbing mountains or on really long walking holidays or, erm, I couldn't do sports with my children or, er, it's those sorts of things." (PID29, woman seven years post-LDKT.)

The anti-rejection medication regimen was not often seen as an issue for transplant recipients, especially those who had been on more medications prior to transplantation. However, a few felt that they were somewhat restricted by their medication regimen and the need to take multiple tablets at different times of the day, with potentially dire consequences if they did not. The regimen was particularly difficult and frustrating when medications needed to be taken around food. A few also reported experiencing horrible feelings of increased hunger, which was labelled "Pred-hunger" and attributed to the medication Prednisolone by one participant. An increased risk of food poisoning due to the anti-rejection medications and the need to follow a strict medication regimen was sometimes found to make family outings or social gatherings difficult:

> So, my life is, does revolve a lot round, erm, taking the tablets, because the immunosuppressant ones have to be taken at particular times under particular conditions. Like these ones I'm just about to take now, two to three hours after food, so two, three hours after breakfast, so about 11 o'clock, and about an hour before more food, so you're sort of stuck. So you can imagine going out for the day, erm, you can't just think oh, yeh, off we go and no problems, I got to get these in at some point… (PID34, man seven years post-DDKT.)

Work was impacted to varying degrees depending on the individuals' situation, the type of job they were in, and the age of the individual. Some participants had already retired before they became unwell. Work was frequently negatively impacted when participants were unwell before their transplant and whilst some were able to continue working full-time, others had had to reduce their hours or were unable to work at all. Post-transplant, some participants indicated that they

could only work part-time or were still unable to work due to their health: “Well, I never could go back to work, because, erm, I spent so long in and out of hospital in the 2 years after the transplant…” (PID23, woman five years post-DDKT.)

Those in full-time work sometimes felt guilty or frustrated when needing to take time off to attend appointments or when they acquired an acute illness. Some felt that their career progression or finances were still impacted by their health issues post-transplant and that their future job opportunities were restricted by the need to have a flexible and supportive employer. A few participants reported concealing their health problems and transplant from colleagues as they did not want to be treated differently, and one indicated doing so in order not to lose job opportunities. The negative impact on work and finances was often frustrating and sometimes impacted participants’ self-confidence or self-esteem. One participant, in particular, highlighted that his struggle to get back to work after his transplant not only impacted his finances but left him feeling depressed:

> And also the fact that I couldn’t work and then having to fight to get benefits, and having to fight to get, you know, enough money to be able to live and the stress of that and it really, it really took its toll on me and I thought what is the point. (PID13, man seven years post-SPKT.)

Some participants felt that their living situation was restricted due to impacted finances or being tied to their healthcare team and/or support systems. A few felt unable to move away or travel for longer periods of time or were unable to afford the home that they wanted. Travel to certain countries was also restricted due to the risk of picking up diseases, such as malaria:

> …there are still limitations with the transplant, erm, that you still have to take into account. For example, things like, I can’t go to a country that is susceptible to malaria because I can’t have a live malaria shot because of my immunosuppressants. (PID11, woman one-year post-SPKT.)

Some found travel insurance very expensive, which could be an issue for individuals wanting to travel abroad, and some were wary of sun exposure due to their increased risk of skin cancers. However, limitations on travel were not often seen as being too detrimental; some participants did not necessarily want to go to riskier countries, and some were happy to take holidays within the UK where holiday insurance would not be required.

A few participants indicated that their health problems had restricted their family situation in some way. Although this is a complex topic which varied depending on

the individual circumstance, a few participants had avoided long-term romantic relationships or having children. These individuals did not want to expose loved ones to the difficulties and possible pain that could come with chronic ill-health and/or felt they may be unable to care for children due to their poor health. Others had not found a long-term partner or had experienced a relationship breakdown, possibly due to their health problems and the impact illness had on their life. A few participants discussed experiencing sexual dysfunction, which had negatively impacted relationships and/or self-esteem. A few also reported not being able to have children or being turned down from adopting/fostering a child. Some women had been advised against having children prior to transplantation and whilst some went on to have children anyway others had not. Not having a long-term partner or children was upsetting and a regret for some, but not all:

> I never wanted to be in the position where I would have a husband or children… where they could lose me. Do you understand what I mean? So, I gave up the right of being a mother. And it is a huge regret… (PID22, woman four years post-DDKT.)

Uncertainty for the future. Participants were aware that their transplants might fail or reject and were uncertain of how long the graft would last. Participants sometimes gave estimations of how long transplants last on average and some acknowledged that they were approaching this estimate. The feared consequences of a failed transplant included dialysis, needing another transplant, and even death. A few participants acknowledged that if they needed another transplant in future it might be more difficult to find a good match a second or, in some cases, a third time around. Some individuals spoke about having a shorter life-expectancy due to their health conditions and whilst a few seemed to accept this, others were troubled by this. For example, one participant was sometimes concerned that they might die prematurely, leaving their child without a parent and possibly missing out on seeing grandchildren:

> I know that's not going to last forever. I know that, erm, it will fail at some point and I'm likely to go back on dialysis. And the chances of me getting a match second time round are more limited, so yes, that does, that does impact a bit. And I know I'm not going to make old bones, I'm not going to live a long life, erm, because of my condition. I know that. Erm and it's when I see my son and things and given my age when I had my son I'm thinking, am I going to see grandchildren? (PID14, woman seven years post-SPKT.)

SPKT recipients who had only had their transplant for approximately 12 months also indicated that they sometimes worried about rejection or how long their transplant would last. One participant reported that their fear of graft rejection was highest shortly after their transplant, but it had already eased and they anticipated that it would ease further with time. However, a few participants who had had their transplant for several years indicated that the possibility of graft rejection/failure was frequently on their mind:

> I'm 7 years down that line, and so, you know, I've always got in the back of my mind, when is it gonna happen. I get a pain in my side, is it the kidney starting to go? Erm. Are my results ok. I go from blood test, to blood test, to blood test hoping that the results are still the same and not showing any deterioration. (PID24, man seven years post-DDKT.)

For some, graft rejection/failure would only come to mind when something triggered the thought such as a comment made by someone or a pain in the body. For example, one participant indicated that they only felt anxious about graft loss when they were approaching an appointment and the test results had so far eased this anxiety each time:

> But I always get myself wound up a little bit before I go [to an appointment] thinking, oh, is this gonna be the time when they say my creatine's risen or your function's gone down or- I always have that worry in the back of my head. But I can go on a Monday, Tuesday morning log onto the renal patient line, see my results and after that I'm fine again. (PID27, woman seven years post-LDKT.)

Participants also felt that they had limited control over whether their transplant would reject or fail, even if they took their anti-rejection medications as recommended and took care of themselves:

> As far as it's in my control, I feel that I do the things that I should, erm, try to look after myself and, but, yeh. A lot of it is out of my control, I think. It will just happen whether I, you know, I can't help that my pancreas may reject tomorrow, I feel that's out of my control. (PID15, woman seven years post-SPKT.)

A few SPKT recipients also reported uncertainty for their future in respect to diabetes complications. One participant was concerned about losing his sight completely, and two participants acknowledged that they would need to continue to reapply for their driving licence every three years due to diabetic retinopathy, with the possibility of losing their licence in the future which was a concern:

So, I'm not quite sure if I'm going to get to keep my licence because obviously the on-going problems with my eyes they might decide to take it off me, so that's another worry but it's out of my control at the moment. (PID7, woman one-year post-SPKT.)

Emotion-focused coping. Because participants sometimes felt that they had limited control over preventing their transplant from failing/rejecting, they often responded by doing what they could and otherwise tried not to think about it. Participants often indicated that they accepted their situation and emphasised the importance of 'getting on with it' and enjoying their lives rather than constantly worrying about graft loss or being down about things that they felt they could no longer do:

It impacts me but at the same time I'm ready, really ready to overrule that and say let's stop worrying about nothing. And then if it all happens then it happens doesn't it… and, erm, just don't put your life on hold simply because you had this thing that might or may not suddenly last. (PID30, man seven years post-LDKT.)

Similarly, a few participants reported trying to not think about worsening diabetes complications and carried on with things they could do. Some SPKT recipients reported symptoms of hypoglycaemia or hyperglycaemia, such as feeling very thirsty, which sometimes caused concern. One participant labelled this as "phantom highs". In response to these perceived feelings of fluctuating blood glucose levels, some participants still occasionally checked their blood glucose levels to provide reassurance that their pancreas transplant was still working:

I do occasionally do a finger prick test just, erm, because I panic a little bit, if I get thirsty I think oh am I having a high blood sugars, is the pancreas failing, but I do a blood test and it says no, it's like 4, 4 and a half, just feel thirsty 'cause you are thirsty. (PID9, man one-year post-SPKT.)

In contrast, others no longer checked their blood glucose levels as they did not feel the need or felt that to do so would be like taking a step back that they did not want to do since they were free of diabetes:

…they do actually have patients that check it [blood glucose levels], just because they like to know. But I think that's going back a step if you're wanting to still check your bloods. I, I don't see why you should have to when they're checking it all at the renal clinic every few months. (PID7, one-year post-SPKT).

More generally, during the interviews some participants made reappraisals of their

situation and tried to see things in a more positive light. For example, one participant reported that whilst their medications had made them more at risk of infections, they had helped to ease their arthritis. Others indicated that despite continuing to have health issues post-transplant, it was better than their experience prior to transplantation or to being on dialysis; one participant said: "…when I do feel a bit depressed, I have to think about that, where I was when I was on dialysis and then stop getting so upset about things not being quite right." (PID13, man seven years post-SPKT.)

Some participants indicated that they accepted their medication side-effects, because they needed to take the anti-rejection medications to help prevent their transplant from rejecting. For example, some indicated that they accepted changes to their appearance or felt that they could not complain because the transplant had saved their life or saved them from dialysis, and/or the medications were preserving their transplant:

> Well, it's not great but if I hadn't had the transplant chances are I wouldn't have been here anyway, or I would have been stuck on dialysis for however long. So, I'm quite happy to take the hair falling out than, than being stuck on dialysis all the time. (PID12, woman 18-months post-SPKT.)

Some participants also made downwards comparisons, indicating that they were lucky to have received a transplant or were better off than others:

> Rightly or wrongly, I just think you can do something and there's always someone much worse than you. Do you know what I mean? At least we have a condition where there can be, you know, transplants are available. (PID22, woman four years post-DDKT.)

However, a few individuals made unhelpful upwards comparisons, for example comparing themselves to others who had not had health problems or appeared to have had a better transplant experience, and this only made them feel worse about their situation.

Taking care of health and the transplant. Participants acknowledged the importance of taking their anti-rejection medications for maintaining the transplant. Some participants admitted to occasionally forgetting to take their medications; this was a particular issue for those experiencing cognitive/memory difficulties. However, none reported choosing not to take their medications. A few participants reported using pill boxes, alarms, or sticking to a routine in order to remember to take their medications and some indicated they would carry medications with them

when going out:

> I have my antirejection tablets at the side of my bed, so as soon as I get out of bed in the morning I take the anti-rejection and, er, I take them when I go to bed at night. And my other tablets are all set out in the box, 'cause I take another 5, 5 tablets during the day and, er, you know, I'm fine. Yeh, very rare do I ever miss any. (PID18, man six years post-DDKT.)

Several participants also felt that it was important for them to take care of their health and their transplant by trying to lead a healthy lifestyle. This included exercising, eating well, drinking water, and for some, limiting their intake of alcohol: "Basically, I know how to take the tablets, which I do. I know I, I don't drink [alcohol] so much, which I don't, so that helps. Erm. And I try and keep the weight off." (PID21, man two years post-DDKT.) However, some found it difficult to maintain or lose weight or to remember to drink the amounts of fluid advised post-transplant.

Some participants also described physically taking care of their transplant by being careful or not taking part in certain activities that they felt would risk injury to their torso/transplant. Participants acknowledged that it was generally more serious if they became unwell with other infectious illnesses or food poisoning and so took preventative measures such as avoiding sick people or not eating food that had been left out. Some reported being more aware of their body and looking out for signs that there might be problems and indicated that they would quickly seek medical advice if anything did not seem right:

> So I exercise and, er, I try to drink lots of water, eat healthy food, erm, er, plenty of fruit and vegetables, that sort of thing, plenty protein. And I feel that I know my body and I'll know if something, I think I'll know something sinister is going on. (PID29, woman seven years post-LDKT.)

The frequent clinic appointments and tests were also encouraging for some as they believed that any issues would be identified and dealt with: "Because, you know, they check your bloods and they check everything. And they can pick, if there's something not right they can pick it up, you see." (PID23, woman five years post-DDKT.)

A few participants felt it was their duty or responsibility to take care of themselves and their transplant as they had been given a "second chance", and they owed it to their donor to look after the transplant and live life to the full:

> I've taken a choice of not to drink [alcohol], whereas I know people who've had transplants and they're drinking as they used to drink but, you know, it's my choice not to have a drink. Er. That's everybody's individual choice, you know. So, I just, in me mind that somebody has given me something and I'll try and look after it, er, as much as I can… (PID20, man seven years post-DDKT.)

Importance of support. When asked about their sources of support several transplant recipients no longer felt they needed practical support and were independent, although they acknowledged that there were people they could turn to if necessary. Some participants had support but generally did not feel the need to talk about the transplant and their health issues:

> My parents are very good. Erm. I talk to them about most things really. And then my friends just are, you know, my friends are my friends, I mean, they're supportive in their own way. But it's not really something that I feel the need to talk to people about really. (PID26, man seven years post-LDKT.)

Others spoke about the support that they received and how this helped them. Support from family and friends included both practical and emotional support. Some participants reported that close friends and/or family would take them to appointments or attend appointments with them, help out with their healthcare, around the house, and/or with childcare. Friends and family also provided company, comfort, and reassurance:

> I have really good friends who are, who are just brilliant. I really could not have, erm, well I wouldn't be alive to be fair. Do you know what I mean? They all take it in turns to make sure that I was looked after at hospital, I stayed at a friend's for my recovery and all that kind of stuff. So, yeh, I have really good, good friends, they look after me. (PID22, woman four years post-DDKT.)

Another participant said:

> And it eventually dawned on me that she was looking at my scars. 'Cause I have a few of them. Erm. And my beloved said to me, "scars are like tattoos, just with a better history". And I thought, oh God, you're brilliant. (PID14, woman seven years post-SPKT.)

Some participants indicated that they had appreciated the support of other patients who were in a similar situation to them as they sometimes had a better understanding of what they were going through and/or could provide advice. Sometimes support was sought online, for example individuals would passively look

at kidney transplant Facebook groups to find out about other peoples' experiences and some would also interact with people in these groups. Participants indicated that they themselves had supported others by giving advice or speaking about their own experiences. Participants had varying attitudes towards support from other patients; some were not interested and for others it was very important and they sought out support if it was not provided through the renal unit:

> Doing it on social media now. I'm following, I've found a lot of pages… 'Cause I didn't have anybody to ask questions to [before the transplant]. I met a girl when I got admitted to [the hospital]…and she had a kidney and pancreas just a year before…So, we keep in touch now. Erm. I was asking her loads of questions on the day before I got the transplant, oh what about this, what about that? It was fine just speaking to somebody and we kept in touch after I got the transplant and I was like this is happening is this normal? And she was like, yeh, that's normal. (PID7, woman one-year post-SPKT.)

A few participants revealed that they were lacking support in some way, either from others in a similar situation or from close family who they felt lacked understanding. For example, one participant had a difficult recovery after his transplant and indicated that he would have benefited from further support and/or information to help him understand whether his experience was normal:

> 'Cause I just felt a bit in the dark. I didn't know if I was doing worse than anybody, better than anybody, I had no comparison. I had nobody else to talk to who'd gone through a similar thing... (PID13, man seven years post-SPKT.)

Several participants felt sufficiently looked after and supported by their renal team. Support from healthcare professionals was generally practical but also emotional as they could provide reassurance in relation to concerns about graft rejection. Participants described being able to call their transplant coordinator or their renal team if they had concerns about their condition and a few referred to using the Patient View website to check renal care test results. Participants were often mostly satisfied with the support and help received from healthcare professionals:

> …it's the actual transplant nurses' office. So you get straight through to them. Erm, so you can, you can, even just say "oh I don't feel right, something's not right can I have my bloods done" or, you know, anything. You're looked after that way. (PID17, woman seven years post-SPKT.)

A few participants discussed having accessed counselling to help process what they had been through with their health. This was not always accessed directly through

the renal/transplant unit and one participant described initial difficulties in accessing psychological support post-transplant.

> So just to be told that, oh it's normal [to experience mental health issues], we can't offer you any support was a bit upsetting, so that's when I then looked into things myself. (PID7, woman one-year post-SPKT.)

Issues with continuity of care. Whilst participants were often satisfied with their healthcare, some participants experienced problems with continuity of care between their various care providers. This was particularly an issue for those with comorbidities. Participants had mixed feelings about their General Practitioners (GP); some found them to be helpful in coordinating their care whilst others appeared to lack confidence in their GP and felt that they were not knowledgeable enough to help them. Some felt GPs even impeded their care at times; for example, participants expressed frustration when GPs did not understand the severity of their healthcare problems and had not prescribed any or enough anti-biotics for infections:

> So if I presented myself to the renal team when I became infected, they'd say, "look, you're gonna get these antibiotics, you need it now". Which contrasts with when I went to the GP and I had an infection and he said, "oh well, you'll be alright, just take your paracetamol and drink plenty of water and you'll be fine". Sent me off. That resulted me, with me going into hospital seriously ill in two weeks… (PID24, man seven years post-DDKT.)

Participants described stressful situations when they had tried to coordinate their various healthcare providers or when information had not been properly relayed between different care providers. For example, participants sometimes had difficulties in finding out if they could take certain medications and in some cases they had been prescribed medications that were in contraindication to the anti-rejection medications that they were already on, resulting in hospitalisation for one participant:

> I took these things and erm, this, maybe on the Thursday a lot happened and Fri-, Saturday evening I was so unwell we had to get the, erm, paramedics round and I ended up in the waiting room of [the hospital] until 1am. And it, it was a contraindication to this, this antibiotic, the yellow one, which, it erm, multiplied the power of the Tacrolimus by 25. (PID30, man seven years post-LDKT.)

At times participants were told contradictory information by different healthcare professionals, such as whether there were beds available at the renal unit. Participants also expressed frustration at having to explain themselves repeatedly to different healthcare providers, having to attend various clinics, and having multiple blood tests to track their transplant and health conditions. Sometimes participants did not feel that they had sufficient time to talk to healthcare professionals or found it difficult to discuss certain topics such as sexual dysfunction or medication side-effects:

> And that's another thing, when you go to the clinic, even if you were, sometimes I've gone, you know, once a week you see different people each time. You've got to tell them all about you. Because half the time they haven't got your notes there. (PID23, five years post-DDKT.)

Discussion

The study provides findings on kidney and SPK transplant recipients' experiences and how QoL is positively and negatively impacted post-transplantation. These findings can aid the interpretation of results from the quantitative measures of QoL used in studies 1 and 2, outlined in Chapters 3 and 4. The findings suggest that improvements in QoL from pre- to post-transplant are largely due to the increased freedom that individuals experienced after transplantation. However, QoL often continued to be negatively impacted in some way post-transplant. Whilst some were negatively impacted by changes to their appearance, several continued to be impacted by health issues and still lived with restrictions and reduced ability. Participants often continued to feel uncertain about their future, with some feeling anxious about graft loss. Support from family, friends, and healthcare professionals continued to be important post-transplant; however, some described poor continuity of care that caused additional stress. Participants described various emotion-focused coping strategies that they used, but they also tried to take care of their health and the transplant.

Benefit of transplantation. After an initial period of recovery, most participants reported experiencing improved health and energy which gave them the freedom to do and enjoy more, and various aspects of life became less impacted by CKD (as shown in study 1) and/or diabetes (as shown in study 2) post-transplant. Those who had been on dialysis and those with type 1 diabetes who received an SPKT were also freed from their restrictive and invasive treatments. Participants

enjoyed more dietary freedom in what they could eat post-transplant and SPKT recipients also gained more freedom in when they could eat and no longer worried about hypoglycaemia. ‘Freedom to eat as I wish’ has previously been found to be particularly important to the QoL of individuals with diabetes and interventions such as DAFNE, which teaches patients to adjust their insulin according to what they eat, have helped to improve dietary freedom and QoL (DAFNE Study Group, 2002). It is therefore understandable that SPK transplantation would improve diabetes-dependent QoL, as found in study 2. Participants who had experienced dialysis also appreciated the freedom to drink as they wished, although some indicated difficulties in drinking as much as they felt they should and some chose to limit or abstain from alcohol. Participants reported being able to enjoy leisure activities, go on holidays again, and spent more time with family post-transplant. Some participants described being back to “normal” or having a “new lease of life” post-transplant. These findings are in line with previous research which also found that transplant recipients often experienced health benefits and are able to do more and return to a more normal or new normal way of life after receiving a kidney or SPK transplant (Dahl & Moen, 2018; de Brito et al., 2015; Dos Santos et al., 2016; Lonargáin et al., 2017; Pinter et al., 2016; Tymstra, 2007).

Participants reported being grateful for the transplant and the care that they had received, which some felt had been lifesaving or prolonging. Gratitude is a common experience after transplantation (Pinter et al., 2016). Some recipients may find it difficult to discuss negative consequences of transplantation or continued health issues because they do not want to appear ungrateful. Previous research has noted that kidney recipients do not like to complain or voice disappointment and have reported feeling guilty if they did (Howell, Tong, Wong, Craig, & Howard, 2012; J. Jones et al., 2020; Orr et al., 2007; Schipper et al., 2014). Therefore, recipients may tolerate problems and choose not to discuss with others issues that they are having, such as medication side-effects (Howell et al., 2012; J. Jones et al., 2020; Schipper et al., 2014). Participants may be more willing to report issues on PROMs or if they are asked directly. In the current research, by referring to participants’ responses on the individualised condition-specific measures of QoL, it was possible to pinpoint aspects of life that were still negatively impacted and request more information about how they were impacted.

Changes to appearance. Several participants spoke about the ways in which their CKD (and diabetes) and its treatments, including transplantation and

medication side-effects, had impacted their physical appearance. Most participants tended to dismiss the impact of these changes in appearance, and some indicated that they accepted it (and other medication side-effects) as part of the necessary treatment. However, a few participants indicated that their appearance had a negative impact on their self-confidence and even romantic relationships. These findings have been noted by previous qualitative research which also found that some kidney recipients felt self-conscious about changes to their appearance (Boaz & Morgan, 2014; Schmid-Mohler et al., 2014) and this impacted on their feelings of being sexually attractive to others (Martell et al., 2015). A quantitative study found that over 80% of a sample of kidney recipients experienced cosmetic side-effects from their anti-rejection medications (Peters et al., 2004). Although a large proportion of the sample indicated that cosmetic side-effects impacted their 'ability to feel attractive' and around a third indicated it impacted their 'ability to feel comfortable in public' and 'ability to be intimate with their partner', the majority reported being 'happy to endure physical changes for the sake of having a transplant' (Peters et al., 2004, p540). This study also found that the prevalence and impact of cosmetic side-effects were under-estimated by healthcare professionals (Peters et al., 2004).

It is possible that some transplant recipients may experience body image dissatisfaction due to the impact of their chronic illness and its treatment on their appearance. Body image is the way a person perceives their body/appearance and includes their body-related feelings and attitudes (Cash, 1990, 2004). In one study, 26% of kidney transplant recipients reported moderate levels of body image disturbance and 5% reported high levels of body image disturbance (Sadeghian, Roudsari, Seyedfatemi, & Rafiei, 2016). Body image dissatisfaction has been associated with poorer mental health outcomes in general population samples (Jackson et al., 2014; Rosenström et al., 2013; Wilson, Latner, & Hayashi, 2013) and kidney transplant recipients (Yagil et al., 2015). In addition to dissatisfaction with appearance, changes in appearance due to a health condition might also serve as a (unwanted) reminder of the illness. Furthermore, at least one of the more recently transplanted SPKT recipients reported experiencing side-effects from the anti-rejection medications, including hair loss, that they had not expected, and this caused substantial concern during the first few months post-transplant. Hair loss is quite common among transplant recipients and has been linked to use of the medication Tacrolimus. However, hair loss can often be treated (Tricot et al., 2005). There is a need for individuals to be well-informed about the possible complications

and side-effects that they may experience post-transplant to avoid unnecessary worry. It would be beneficial for healthcare professionals to enquire whether patients have experienced changes in their appearance that trouble them and explore possible remedies. Individuals who struggle with changes in their appearance due to CKD, diabetes, and/or transplantation may benefit from additional support, for example from a psychologist, to help them to adjust. It should be noted that some participants felt their appearance had improved post-transplant and they felt they looked healthier, so negatively impacted body image is not a universal experience.

Health issues and living with restrictions. Continued and new health issues, attempts to prevent infection or protect the graft, and the need to attend appointments continued to place restrictions on many participants post-transplant. Some recipients who had had their transplant for several years felt that they did not have as much energy anymore. The current findings support previous qualitative research which found that kidney transplant recipients strive to live a normal life but often face continued health issues and frequent appointments which disrupt normality (Boaz & Morgan, 2014; Bogue Kerr et al., 2018; Dos Santos et al., 2016). SPKT recipients who had developed complications, such as severely impaired eyesight, continued to live with certain restrictions on what they could do and this sometimes impacted independence. Although often improved since before transplantation, a variety of aspects of QoL continued to be negatively impacted post-transplant. These varied depending on the individual. For example, whilst some participants had already retired prior to transplantation others indicated that their health problems had impacted their working life. Some participants had not been able to return to full-time work several years post-transplant. Others felt they had not progressed in their career as much as they would have otherwise or felt less able to change their job due to concerns that they would be unable to find a supportive employer who would be flexible regarding their healthcare needs. Similarly, some felt unable to move away because they felt tied to their job and/or to their healthcare providers. A systematic review found that around 40% of kidney recipients returned to work one-year post-transplant, although this varied across studies carried out in different countries (D'Egidio et al., 2019). Those with less education and those who stopped working prior to transplantation were less likely to return to work post-transplant (D'Egidio et al., 2019), so these individuals may especially benefit from being signposted to sources of support to help them return to some form of work if they wish to.

Some transplant recipients reported that their health and medication regimen placed certain restrictions or inconveniences on their social life or family life, especially when they had been recommended to take tablets around meals or wanted to avoid food that had been left out. Some felt that their health problems had restricted or impacted their family situation and they had avoided relationships or not felt able to develop serious romantic relationships. As highlighted in previous research and discussed in Chapter 5, some individuals may experience shame in relation to their chronic illness and this can have a negative impact on social and romantic relationships as individuals may avoid social interactions (Trindade et al., 2018). In particular, young adults may struggle to maintain or develop new relationships because of CKD and its treatment (E. Coyne et al., 2019), this may also then impact them in later life. A small number of participants in the current research who were in relationships indicated that their health problems had impacted on their partner and some still experienced sexual dysfunction, although this had improved post-transplant. A substantial proportion of kidney and SPK transplant recipients continue to live with sexual dysfunction (Pertuz, Castaneda, Rincon, & Lozano, 2014) and this may negatively impact romantic relationships and is associated with lower self-esteem (Martell et al., 2015; Muehrer, Keller, Powwattana, & Pornchaikate, 2006).

Furthermore, in relation to family, a few individuals discussed choosing not to have children due to their health problems. These participants felt they would not have been able to care for a child and that their health problems would cause distress to a child. Whilst one participant reported being satisfied with their decision to not have a family, another felt regret. Individuals and couples choose to be childfree, which is deciding against having children rather than being unable to have children due to fertility issues, for various reasons (Agrillo & Nelini, 2008). However, there appears to be a lack of research on choosing to be childfree within chronic illness and therefore it is not clear how common this is or what sort of impact this has on individuals. Other participants in the current study reported being advised against having children prior to their SPKT or were unable to have children or adopt, which had been upsetting. CKD and diabetes can reduce fertility in men and women (Condorelli, La Vignera, Mongioì, Alamo, & Calogero, 2018; Dumanski & Ahmed, 2019; Livshits & Seidman, 2009). Pregnancies in women with type 1 diabetes and/or CKD are at higher risk for complications and women are advised to seek pre-pregnancy care (R. Taylor & Davison, 2007). Women on dialysis may also be advised to avoid pregnancy until around one-year post-transplant (Wiles et al., 2019). There is limited research with CKD patients on pregnancy-related topics,

however those who have investigated this found that making decisions on whether to have children was complex and those who were unable to bare children experienced intense grief and sometimes guilt (Tong, Jesudason, et al., 2015). The current study highlights the need to explore further the impact of CKD (and type 1 diabetes) on the development of personal relationships and experiences of being childfree and/or childless in people with these conditions, to ensure that patients are provided with appropriate advice and support.

Impact of the COVID-19 pandemic. Four of the more recently transplanted SPKT recipients were interviewed in 2020 during the COVID-19 pandemic. In Chapter 4 it was reported that participants experienced significant improvements in diabetes-dependent QoL from pre- to post-SPKT, but improvements in renal-dependent QoL did not reach significance. Participants interviewed after March 2020 explained that the restrictions of the pandemic had impacted certain aspects of their QoL. Therefore, participants confirmed that their responses to the PROMs were impacted by the situation in the UK at the time. Improvements in diabetes-dependent QoL may have been more noticeable as patients no longer needed to attend to diabetes management and were no longer concerned about hypoglycaemia and diabetes complications, although a few were still impacted by pre-existing complications. In contrast, only one of the six SPKT recipients interviewed approximately one-year post-transplant had experienced dialysis prior to transplantation. Those who did not receive dialysis may not have experienced as much change in relation to their renal condition from pre- to post-transplant as those who did receive dialysis, especially due to the pandemic restrictions. Research on the impact of the COVID-19 pandemic on vulnerable groups is starting to emerge. A study with arthritis patients in the UK found that those who reported shielding scored significantly worse on the mental and physical health component scores of the SF-12 compared to patients who did not shield (Cleaton et al., 2021). However, it is possible that the patients who decided to shield were already worse off before the pandemic than those who decided against shielding. A mixed methods study with Lupus patients in the UK found that whilst well-being did not significantly change from early March 2020 (pre-lockdown) to June 2020. Participants reported varying experiences with some feeling fewer symptoms and reduced social pressure, whilst others experienced flare ups, fear, and isolation (Sloan et al., 2021). Participants in the current research will also have had differing experiences during the pandemic depending on factors such as where they lived and the extent to which they could continue with usual activities.

Uncertainty for the future. Several participants indicated that they lived with uncertainty for the future in regard to how long their transplant would last and whether they would need dialysis or another transplant in future, and this was quite distressing for some. The current findings support previous qualitative research which suggests that patients often face uncertainty throughout the CKD trajectory, including after transplantation (Martin, Stone, Scott, & Brashers, 2010), and the prospect of graft rejection/failure can be stressful (Boaz & Morgan, 2014; Dahl & Moen, 2018; de Brito et al., 2015; Jamieson et al., 2016; Lonargáin et al., 2017; Nilsson, Persson, & Forsberg, 2008; Pera et al., 2012). Although only a small proportion of transplant recipients (around 3-5%) experience high levels of intrusive anxiety regarding graft rejection, intrusive anxiety is negatively associated with psychological well-being (Forsberg et al., 2020; Nilsson, Forsberg, Bäckman, Lennerling, & Persson, 2011). The current findings highlight that, although most patients cope well with the uncertainty, it may be important to screen patients for intrusive anxiety about graft failure, so that those who experience it can receive appropriate support. Furthermore, a few SPKT recipients in the current study reported concern that their diabetes complications, in particular diabetic retinopathy, had worsened and would continue to worsen despite their transplant. This also contributed to uncertainty as participants were unsure about how this might restrict them further in future. Whilst pancreas transplantation can help to halt the development of diabetes complications, patients may still experience decline (Lindahl, Jenssen, et al., 2014; S. A. White et al., 2009) and need to be made aware that this can happen and offered appropriate support.

Coping post-transplant. Participants indicated that they tried to look after their health and take their anti-rejection medication to protect the graft, in line with the high levels of adherence reported on the RMQ. Whilst some admitted to occasionally forgetting, participants often believed that it was important to take the anti-rejection medications despite side-effects, which they accepted because the transplant kept them alive and off dialysis. Similarly, previous research has found that kidney recipients were motivated to take their medications due to fear of transplant rejection (Jamieson et al., 2016). Horne and Weinman (1999) argue that medication adherence is influenced by a cost-benefit assessment of the necessity of the medication for health and concerns over risks or adverse effects associated with that medication. When an individual's concerns about a medication outweigh its necessity for maintaining health, they will be less likely to adhere to the medication.

This theory has been supported by several studies across various chronic health conditions, including kidney transplant recipients (Bünemann et al., 2020; Foot, La Caze, Gujral, & Cottrell, 2016; Horne et al., 2013; Vankova, Mala-Ladova, Kubena, Maly, & Sulkova, 2018) and can help to explain why participants in the current research reported high levels of adherence despite often experiencing side-effects. Some participants also felt a sense of duty or obligation to healthcare professionals and/or their donor to look after their health and transplant (Pinter et al., 2016).

Although participants often wanted to take care of their health, some felt that they were not as fit as they should/could be or had difficulties losing or keeping weight off, especially when taking steroid medications for the graft. Patients may feel that there are several barriers to carrying out self-care recommendations such as exercise. For example, patients may find that recommendations are not clear enough on what type of exercise or how much exercise they should do. Similar issues have also been reported regarding diet and fluid intake (Gordon, Prohaska, Gallant, & Siminoff, 2009; Jamieson et al., 2016). Low levels of energy, motivation, and/or confidence, as well as physical issues, such as hernias, can also be barriers to exercise. Some patients may be concerned of hurting themselves or damaging the transplant if they are not careful in the exercise that they do (Gordon et al., 2009). The current and previous research suggests that some patients could benefit from further support and advice to improve their fitness and maintain a healthy weight post-transplant.

Despite taking their medications and trying to live a healthy lifestyle, some felt that they ultimately had limited control over whether their transplant would continue to function in future, supporting previous research (Nilsson et al., 2011). Therefore, participants also used a variety of emotion-focused coping strategies, although they did not always recognise this as coping. Participants reported trying to not think or worry about graft rejection/failure or worsening diabetes complications, and in general tried to “get on with it” and live their lives. Participants also accepted and reappraised their situation in a more positive light. A few SPKT recipients reported sometimes feeling symptoms of fluctuating blood glucose levels and occasionally monitored their blood glucose levels to provide reassurance that the pancreas transplant was still working. This finding is in line with previous research (Dahl & Moen, 2018), and 12-month post-transplant interviews conducted during the original ATTOM study (Gibbons et al., 2020). Although Kwiatkowski et al. (2005) reported that 14 of 19 SPKT recipients surveyed indicated that they checked their blood

glucose levels daily, participants in the current research were not checking as regularly. This difference may reflect variation by country (Poland compared to the UK) or a change in recommendations since 2004/2005 when SPKTs were even less common. The findings are in line with the stress and coping theory outlined by Lazarus and Folkman (1984) which suggests that individuals are likely to use emotion-focused coping to reduce distress in situations of limited control. If transplant recipients are already following health recommendations and adhering to anti-rejection medications, improving emotion-focused coping techniques to cope with uncontrollable aspects of the condition and uncertainty may be beneficial for those who struggle with this. As discussed in Chapter 5, interventions involving mindfulness, which focus on acknowledging and accepting thoughts and feelings in a non-judgemental way and being present in the current moment, might be beneficial for those who struggle with feelings of uncertainty and fears of graft rejection. A few small-scale mindfulness-based intervention trials have found promising results for improving anxiety, depression, stress, and sleep of organ transplant recipients (Gross et al., 2010; Kreitzer, Gross, Ye, Russas, & Treesak, 2005; Stonnington et al., 2016). For example, Kreitzer et al. (2005) found that six months after an eight-week mindfulness-based stress reduction intervention, organ transplant recipients reported significantly less uncertainty about their health and susceptibility to infection and other illnesses.

Support. Although some participants felt that they did not need support post-transplant, practical and emotional support from family and friends was found to be beneficial to several participants, which supports previous research (Been-Dahmen et al., 2018; Lonargáin et al., 2017; J. K. Low et al., 2017; Pinter et al., 2016). Practical and emotional social support can benefit individuals directly and/or indirectly (S. Cohen & Wills, 1985). Pisanti et al. (2014) found that social support appeared to act as a buffer between transplant-related stress and anxiety. Furthermore, advice or insight from others who had received a transplant was helpful for some participants in the current research, especially in the first year after transplantation. Some participants also spoke of providing advice to others who were going through dialysis and/or transplantation. Peer support may help to ease some of the feelings of uncertainty experienced post-transplant by providing reassurance and normalising experiences such as medication side-effects (Scott, Martin, Stone, & Brashers, 2011). This type of peer support was noticeably missing for a few participants. It is likely that some individuals would benefit from being

offered or signposted to additional support especially if they are struggling with recovery after transplantation.

Continuity of care. Support and advice from healthcare professionals, in particular the renal/transplant team, was reported as beneficial for easing concerns and receiving the necessary treatment. However, some participants described instances when they experienced issues with continuity of care, which caused additional stress at times. Some participants described frustration at repeating themselves to various healthcare professionals and times when they had been prescribed inappropriate medications or had not received the necessary care, sometimes resulting in hospitalisation. Haggerty et al. (2003) suggest that there are three main types of continuity of care: 1) relational continuity, when patients see the same clinicians; 2) information continuity, when information is communicated effectively across various healthcare providers; and 3) management continuity, when care is managed consistently and flexibly over time. Qualitative research with individuals attending a UK renal unit found that relational continuity was particularly important when individuals were experiencing a change in treatment or crisis, but they were otherwise happy to see different healthcare professionals and valued spending as little time at the unit as possible (Brand & Pollock, 2018). Participants were found to appreciate being known to some extent by their care team and valued the knowledge of the consultants, which was seen as superior to that of GPs. Continuity of care was also achieved through letters sent to patients and their GP, familiarity with the department, and individuals aiding the continuity of their care, for example by arranging to have blood tests prior to appointments (Brand & Pollock, 2018). However, Brand and Pollock (2018) only report the experiences of individuals who had not yet received any RRT and participants do not appear to discuss negative experiences such as those reported by some participants in the current study. It is possible that participants were satisfied with their treatment at that unit, whilst participants in the current study were from across the UK and referred to other services and not just the renal service. Continuity of care is important because it is associated with better patient satisfaction (Van Walraven, Oake, Jennings, & Forster, 2010) and lower mortality rates (Gray, Sidaway-Lee, White, Thorne, & Evans, 2018). Future research could explore further transplant recipients' experiences of continuity of care to identify ways in which care could be improved.

Study limitations. The current study included individuals who had had their transplant for several years as well as six SPKT recipients who had had their transplant for only 12-20 months. A limitation of the research is that four of the more recently transplanted participants were interviewed during the COVID-19 pandemic and their transplant experiences may be quite different from those interviewed prior to the pandemic. It will be useful to investigate how the pandemic continues to impact transplant recipients as they are particularly vulnerable to the COVID-19 virus due to their suppressed immune systems. Whilst the current research includes both kidney-only and SPK transplant recipients, care was taken to highlight additional issues within the themes that were specifically relevant to SPKT recipients.

Study implications. The research confirmed that transplantation was beneficial for patients with CKD and diabetes, but patients were often still negatively impacted in various ways. Some patients may need additional support to help them to cope with health issues and feelings of uncertainty that might continue to make them feel restricted in what they can do. Although not all patients are interested in peer support, some may particularly benefit from having more opportunities to speak with other patients to help normalise experiences and reduce feelings of uncertainty and isolation. As some participants had experienced issues with continuity of care, it is important that advice on the care needs of transplant recipients is made more easily available to GPs, pharmacists, and patients. For example, information on medications which would be contraindicated with anti-rejection medications should be shared. The use of telephone interviewing was particularly beneficial for the current study as it allowed for the continuation of the research despite the need to remain socially distanced during the pandemic. As video calling has become a more widely used and accepted method of communication during the COVID-19 pandemic, it might become a useful tool for future research for those participants who find this acceptable and have access to the necessary equipment.

Conclusions

In conclusion, from interviews with kidney and SPK transplant recipients it appears that QoL improved post-transplant due to increased freedom which allowed individuals to do more and enjoy more in life. SPKT recipients no longer needed to

manage diabetes and enjoyed more dietary freedom. Patients may still be negatively impacted post-transplant and not experience further improvements in QoL and other outcomes after 12-months post-transplant for several reasons. Changes in appearance can be upsetting for some and various aspects of life were still impacted or restricted post-transplant due to continued and new health problems. Transplant recipients also continued to live with uncertainty, particularly in relation to if and when their graft might reject or fail. Most participants reported that they tried to live healthily and protect their transplant by taking their medications, often despite side-effects. Participants also coped by using emotion-focused strategies such as not thinking about graft loss and "getting on with it", because they sometimes felt they had limited control over whether their graft would continue to function. Social support continued to be important post-transplant, this was most noticeable for those who had limited support. Therefore, some individuals may benefit from being offered or sign-posted to additional sources of support and advice. Unfortunately, some participants experienced problems with the continuity of their care, for example between GPs and the renal team, which was stressful at times. Despite this and the other issues discussed, participants' post-transplant experiences were overwhelmingly positive. Transplantation benefited patients, improved their QoL, and they were mostly satisfied with the treatment that they had received.

Chapter 7: Simultaneous Pancreas and Kidney Transplantation: A Qualitative Study of Partners' Experiences

Introduction and Aims

As shown in Chapters 3 to 6, diabetes, CKD, and their treatments often have a negative impact on individuals' QoL, but a functioning SPKT can improve QoL. In qualitative interviews patients also reported benefiting from support provided by others, including family. This supports previous research which suggests that social support is associated with better outcomes for patients with diabetes (Baek et al., 2014; Joensen et al., 2013; Song et al., 2017) and CKD (S. D. Cohen et al., 2007; Lilympaki et al., 2016; Mollaoglu, 2006; Rosenberger et al., 2010). However, some participants also felt that their health problems had had a negative impact on their relationships. Providing support and other stressors associated with chronic health conditions may impact on family members, especially those who are involved in an individual's care in some way (J. Low et al., 2008; Messina et al., 2018; Whittemore et al., 2018). It is important to consider the wider impact that health conditions have on families as this may in turn impact on their health and well-being and on how well they are able to support the individual.

Previous research, mostly using qualitative methods, has found that type 1 diabetes often has an impact on other family members with partners supporting aspects of diabetes management to varying degrees (Jørgensen, Pedersen-Bjergaard, Rasmussen, & Borch-Johnsen, 2003; Litchman et al., 2019; Trief et al., 2003). Experiences of severe hypoglycaemia can be frightening and a particular concern for the family, especially if the individual with diabetes has lost their awareness of hypoglycaemia (J. King, Overland, Fisher, & White, 2015; Lawton et al., 2014; Rintala, Paavilainen, & Åstedt-Kurki, 2013; Stuckey et al., 2016). Partners have reported trying to prevent severe hypoglycaemia by being watchful for early signs in the individual with diabetes and being prepared with snacks or treatments (J. King et al., 2015; Lawton et al., 2014; Trief et al., 2013). Some partners also report experiencing sleep disturbances related to night-time hypoglycaemia (Barnard et al., 2016; Jørgensen et al., 2003). Although some patients and family members have reported being able to incorporate diabetes management into normal life, others have adjusted their lifestyle to fit around diabetes and the associated complications, including hypoglycaemia unawareness. Partners may adjust physical/leisure

activities and mealtimes, and ensure that the individual with diabetes is not left unassisted for long periods of time (Lawton et al., 2014; Litchman et al., 2019; Rintala et al., 2013; Stödberg, Sunvisson, & Ahlstrom, 2012). Family members may experience emotional strain and frustration due to the impact of diabetes on their lifestyle and reduced spontaneity (Morris et al., 2006; Stuckey et al., 2016). Technologies such as CGMs and insulin pumps have been found to help couples manage diabetes together (Ritholz et al., 2014) and reduced concerns of hypoglycaemia (Barnard et al., 2016; Polonsky & Fortmann, 2020). However, they can also be the source of conflict (Ritholz et al., 2014), and can lead to increased anxiety and tension in the relationship for some (Polonsky & Fortmann, 2020).

Similarly, kidney disease has been found to impact on family members and research has particularly focused on the impact of dialysis on family caregivers, which often includes partners or adult children. Family caregivers of individuals on dialysis report experiencing fatigue due to their caring responsibilities, worry, and uncertainty about the future progression of the condition (Luk, 2002; Rabiei, Eslami, Abedi, Masoudi, & Sharifirad, 2016; Salehitali et al., 2018). Furthermore, CKD and treatment by dialysis can negatively impact caregivers' lifestyles as they are less able to socialise, plan ahead, and travel (Blogg & Hyde, 2008; DePasquale et al., 2019; Luk, 2002). This can sometimes result in caregivers feeling socially isolated (Ziegert, Fridlund, & Lidell, 2006). Caring duties can also negatively impact partners' work-life, and CKD-related sexual dysfunction can negatively impact romantic relationships (Salehitali et al., 2018; Y. White & Grenyer, 1999). Family members may even feel afraid that the patient with CKD may die (Frontini, Sousa, Ribeiro, & Figueiredo, 2020). A systematic review of quantitative studies reported that, compared to general population norms, caregivers of individuals on dialysis had worse outcomes on the SF-36, particularly on the mental health component scores (Gilbertson et al., 2019). The reviewers indicate that caregivers in seven out of nine studies reviewed reported levels of burden above the accepted threshold (score >20 out of 88) on the Zarit Burden Interview (ZBI; Zarit, Reever, & Bach-Peterson, 1980); however, the authors do not provide a reasoning for the importance of this threshold (Gilbertson et al., 2019).

Research with family members of kidney transplant recipients is more limited and has mostly involved quantitative assessment using a variety of measures. One qualitative study found that family caregivers of dialysis and kidney transplant patients had various unexpected experiences and often felt they had not been

prepared for their caring role (DePasquale et al., 2019). Participants reported being negatively impacted by CKD, but the study does not appear to have explored whether family members of transplant recipients experienced any benefits. In other research, partners of kidney transplant recipients reported less involvement in caregiving, fewer sexual relationship issues or social issues, and significantly better QoL on a scale of 0 to 100 compared to partners of individuals on dialysis (Morelon, Berthoux, Brun-Strang, Fior, & Volle, 2005). Some studies indicate that partners or family caregivers of kidney transplant recipients experience better mental and physical health, well-being, and sleep than those supporting individuals on dialysis or awaiting transplantation (Avşar et al., 2013; Avşar et al., 2015; Lindqvist, Carlsson, & Sjödén, 2000; Rasmussen et al., 2020). Caregivers of kidney transplant recipients have also reported less burden than caregivers of individuals on dialysis (Avşar et al., 2013; Avşar et al., 2015). However, findings are not always consistent. Rodrigue et al. (2010) found that partners of kidney transplant recipients reported better life satisfaction on the Quality of Life Inventory (Frisch, 1994) compared to partners of individuals awaiting kidney transplantation, but no other significant differences on the SF-36, Profile of Moods States (McNair, Lorr, & Droppleman, 1981), the Miller Social Intimacy Scale (Miller & Lefcourt, 2000), the Caregiver Strain Index (Robinson, 1983), and the Caregiver Benefits Index. The authors suggest the lack of improvement on these measures could be because partners continued to support the transplant recipients with their post-transplant treatment or comorbidities that continued to require care (Rodrigue et al., 2010). Rasmussen et al. (2020) also found no other significant differences between partners of individuals with or awaiting a kidney transplant on the Satisfaction with Married Life Scale (Johnson, Zabriskie, & Hill, 2006), the Revised Dyadic Adjustment Scale (Busby, Christensen, Crane, & Larson, 1995), the ZBI, and the PHQ-2 (Kroenke, Spitzer, & Williams, 2003) measure of depression.

A limitation of some of the previous qualitative studies is that it is not always clear whether the CKD patients being cared for were awaiting kidney transplantation or not, which could impact on the way families or caregivers feel about their situation and the future (e.g. Rabiei et al., 2016; Ziegert & Fridlund, 2001). Furthermore, participants in previous studies often included a variety of family members other than partners/spouses and none reported experiences of partners of pre-dialysis patients. As in quantitative research with patients, studies claiming to assess the QoL of caregivers have used measures such as the SF-36 which assess health status not QoL. Whilst quantitative studies provide some useful information about

possible benefits of kidney transplantation for family members/caregivers, they do not provide an in-depth account of individuals' experiences. Some of the measures used in research with partners of transplant recipients may not be particularly relevant, such as those that measure physical health/functioning. Furthermore, partners may not always consider themselves to be a carer or caregiver, so measures that are focused on caregiving, some of which were originally designed for use with family caregivers of patients with dementia (e.g. the ZBI), may not be seen as relevant. The measurement of caregiver burden is problematic because it is often conceptualised differently across studies and measures may not be able to encompass the range of experiences or may not be culturally appropriate (Bastawrous, 2013). As there is limited research with partners of kidney or SPK transplant recipients, qualitative research methods can be particularly useful for gaining a better understanding of partners' experiences. Through qualitative methods individuals can describe and explain in detail their experiences throughout the process that they have been through with their partner. Qualitative interviews allow participants to highlight issues that are of particular importance to them that may otherwise have been missed.

SPK transplantation is still a relatively new treatment that has the potential to impact positively on the lives of patients by treating both diabetes and CKD. Whilst it is anticipated that those closest to SPKT recipients also benefit once their partner receives an SPKT, this has not yet been studied. Insight into the experiences of patients' families is important for understanding the wider impact of diabetes, CKD, and transplantation. Therefore, the current study aimed to address this knowledge gap by qualitatively exploring the experiences of partners of individuals who have had diabetes and CKD and underwent SPK transplantation by asking: (a) If and how partners are impacted by diabetes, CKD, and wait-listing for SPKT? (b) How do individuals support their partner with diabetes and CKD? (c) What impact does SPK transplantation have on partners? (d) How do partners cope throughout the experience of wait-listing and SPK transplantation?

Summary of Methods

Design. Qualitative semi-structured telephone interviews were used to explore the experiences of partners of SPKT recipients both prior to and after transplantation.

Recruitment and Procedure. SPKT recipients and those awaiting an SPKT who took part in study 1 and 2, outlined in Chapters 3 and 4, were informed about this interview study with partners in their study information sheet. Participants were asked to indicate whether they had a long-term partner (relationship of at least 12 months) and to provide consent and contact details for the researcher (KH) team to contact their partner about the study. Of the 18 SPKT recipients who took part in the ATTOM follow-up study 14 had a long-term partner and nine of these provided consent for their partner to be contacted about the interview study. From study 2, six (one relationship broke down since recruitment) of the 11 SPKT recipients had a long-term partner, and all gave consent for them to be contacted about the interview study. Two additional participants who were six months post-SPKT also gave permission for their partner to be interviewed and were subsequently invited to take part. Where possible, potential participants were contacted directly by telephone to invite them to take part in this interview study. A study invitation, information sheet, consent form, and a brief questionnaire pack were posted to individuals who indicated willingness to take part and to those who could not initially be contacted by telephone. As it was originally intended that both partners in a couple would not be interviewed to avoid any potential matching of data and loss of confidentiality, two partners of SPKT participants recruited through the ATTOM follow-up study were not invited to take part as the SPKT recipient themselves took part in interviews. This eligibility criterion was later removed due to recruitment difficulties to increase the number of potential participants, but it was ensured that data were anonymised and not matched in any way. Therefore, of the 17 potential participants, 15 were invited to take part in the study and eight returned consent forms and subsequently took part in a telephone interview between July 2019 and January 2021.

Participants were informed that the study aimed to investigate their personal experiences as partners of SPKT recipients and how they were impacted by their partner's diabetes, CKD, and the transplant process. Participants were asked to complete a brief questionnaire pack prior to the interview which included questions about the individual's demographics including age, gender, education level, and employment. The questionnaire also included the single item measure of generic QoL, and the EQ-5D-5L, EQ-VAS, and W-BQ16, to provide an understanding of the participants' QoL, health, and well-being. Participants were contacted by telephone for the interview at a time that suited them and given an opportunity to ask questions about the research prior to the interview. All interviews were conducted by the researcher (KH) and no other researchers were present at the time.

The interviews followed a semi-structured interview guide. As all participants had been in their relationships with the SPKT recipients prior to transplantation, all were asked questions about their experiences both before, during, and after the event. Broad open-ended questions were used to allow participants to tell their story. The interviews started by asking participants about their experience before their partner received an SPKT including how they felt when their partner was diagnosed with CKD and when they were added to the transplant waiting list. Participants were asked about if/how they supported their partner and what impact this had on their QoL. Participants were then asked about the time when their partner received the SPKT and what impact this has had on their QoL since. Partners were asked about if/how they continue to support their partner post-transplantation and how they coped throughout the experience. The interviews lasted around 53 minutes on average, ranging from 39 to 75 minutes. With consent from the participants, the interviews were audio-recorded and then transcribed verbatim for analysis. Although brief notes were taken during the interviews these were used mainly to aid the interview discussion and were not included in the analysis. A selection of the interview transcripts were reviewed by the supervisor AG for accuracy.

Analysis. The data were analysed using NVivo 11 software and Braun and Clarke's reflexive thematic analysis (Braun & Clarke, 2006, 2019a; Clarke & Braun, 2015). The researcher (KH) became familiarised with the data by conducting each interview, transcribing each interview, and then re-reading the transcripts whilst making notes on points of interest. Each interview transcript was added to the NVivo project shortly after having been conducted and transcribed. Meaningful sections of the transcripts were initially coded in NVivo 11 and where relevant, the same codes were used to label multiple sections of the transcripts. Once the transcripts had initially been coded the researcher began to group related codes together under preliminary themes. Through discussion with the supervisor AG, who was familiar with the interview data, the initial themes were further revised, defined, and eventually named. The transcripts were re-read to ensure that the final themes reflected well the stories that the participants gave about their experiences with their partner's health conditions and their journey through SPK transplantation. The analysis was inductive as it sought to develop themes that were grounded in the data, but the analysis was also inevitably influenced by awareness of findings from previous research conducted with similar groups of partners of individuals with a chronic health condition. A contextualist approach was taken towards the research

and the analysis, acknowledging that knowledge is context specific and is influenced by culture and other factors (Madill et al., 2000).

Findings

Table 7.1 presents the demographic characteristics of the eight participants, which included four men and four women ranging in age from 42 to 61 years. The time since the participants' partners had received their SPKT ranged from approximately six to 90 months. All but one participant reported that their partner had already developed diabetes before they met them, but they had not yet been diagnosed with kidney failure. Prior to transplantation, all of the participants' partners had been on insulin treatment for their diabetes and three had received dialysis to treat their CKD. None of the participants considered themselves to be their partner's carer at the time of their interview after their partner's transplant. Participants' scores on the included measures varied, although on average participants reported a good level of health (*M* = 80.38, *range* = 55.00-90.00) and QoL (*M* = 1.13, *range* = -1.00- +3.00), and moderate well-being (*M* = 28.63, *range* = 8.00-42.00).

Table 7.1.

Characteristics of Interview Participants – Partners of SPKT Recipients

Variable	**Sample** (*n* = 8)
Age* *M (range)*	52.14 (42.00, 61.00)
Sex: male *n* (%)	4.00 (50.00)
Ethnicity *n* (%)	
White British/European	7.00 (87.50)
Indian	1.00 (12.50)
Education *n* (%)	
Basic qualification	2.00 (25.00)
Higher qualifications	5.00 (63.00)
Missing	1.00 (12.50)
Employment *n* (%)	
Part-time	4.00 (50.00)
Full-time	4.00 (50.00)
Length of relationship in years *M (range)*	24.3 (9.00, 45.00)
Months since partners SPKT *M (range)*	37.9 (5.50, 90.50)
Chronic condition *n* (%)	4.00 (50.00)
Generic QoL *M (range)*	1.13 (-1.00, 3.00)
EQ-VAS *M (range)*	80.38 (55.00, 90.00)
EQ-5D-5L utility *M (range)*	0.89 (0.64, 1.00)
W-BQ16 overall score *M (range)*	28.63 (8.00, 42.00)
Positive Well-Being *M (range)*	6.75 (0.00, 11.00)
Negative Well-Being *M (range)*	2.88 (0.00, 9.00)
Energy *M (range)*	5.63 (0.00, 10.00)
Stress *M (range)*	4.88 (2.00, 9.00)

Note. *M*: mean; Energy: Energy subscale of W-BQ16 (0-12, higher scores indicate better energy); EQ-VAS: EQ-5D-5L utility: EuroQoL-5 Dimension-5 Level utility score (-0.28- +1, state worse than death to optimal health state); EuroQoL Visual Analogue Scale of perceived health status (0-100, higher scores indicate better perceived health); Generic QoL: Generic Quality of Life (-3- +3, indicates extremely bad to excellent quality of life); Negative Well-Being: Negative Well-Being subscale of W-BQ16 (0-12, higher scores indicate worse negative well-being); Positive Well-Being: Positive Well-Being subscale of W-BQ16 (0-12, higher scores indicate better positive well-being); Stress: Stress subscale of W-BQ16 (0-12, higher scores indicate more stress); W-BQ16: Well-Being Questionnaire 16-item version (0-48, higher scores indicate better general well-being).
*****Missing data from one participant.

Five main themes were identified from the interviews and are presented in the thematic map in Figure 7.1. Participants often felt that they had a responsibility to care for the partner, this theme consists of two sub-themes: (a) in it together - supported the partner's healthcare, and (b) took on more responsibilities. Some participants

indicated that although they had not necessarily been asked to, they felt that these caring roles were their responsibility to their partner/family. Participants were also found to have been living with worry especially prior to the partner's transplant and some had prioritised their partner over their own well-being at times. When asked about how they coped throughout the process of their partner being unwell with diabetes and CKD and receiving an SPKT, participants indicated that they 'got on with it' and had utilised other sources of support at times. The final theme, relief and freedom post-transplant, can be seen as a sub-theme to living with worry, but is presented last to aid the flow of the findings.

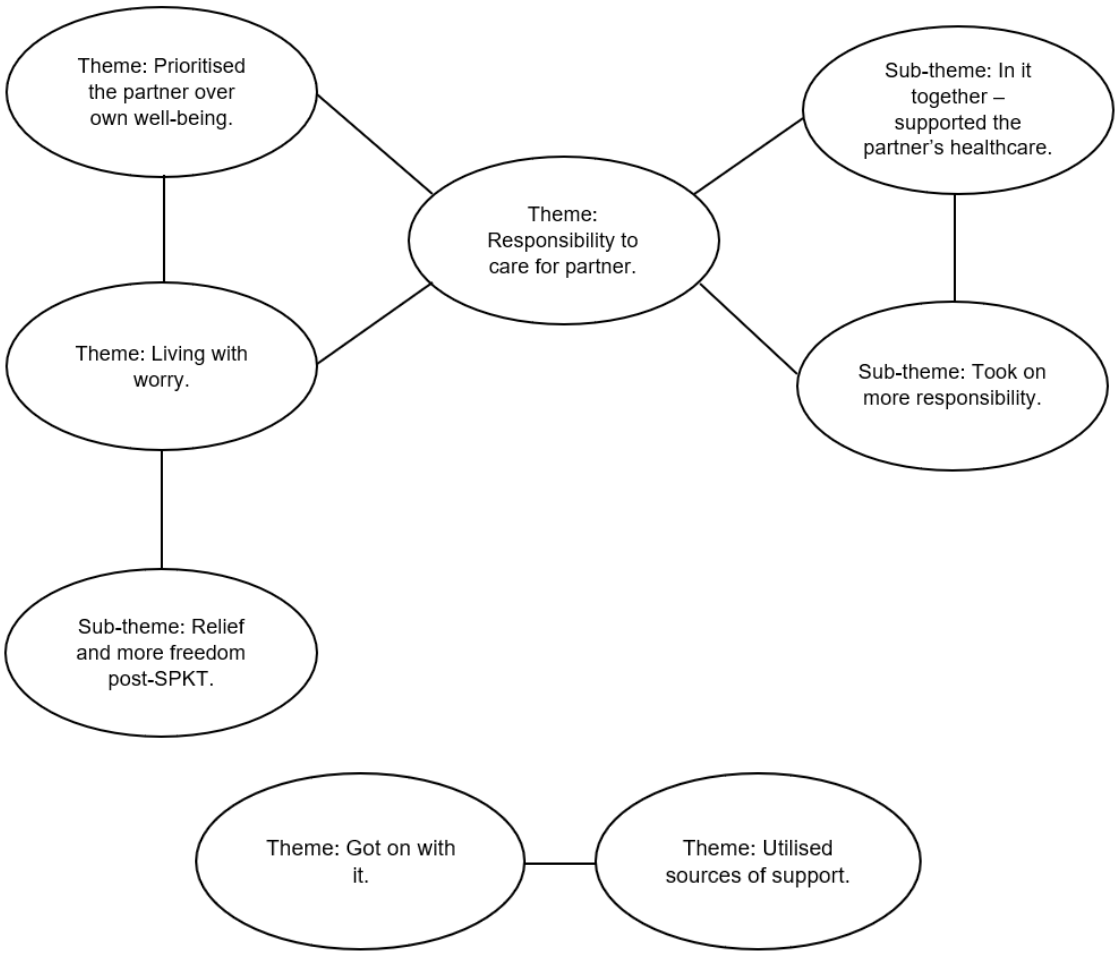

Figure 7.1. Thematic map of the pre- and post-transplant experiences of partners of SPKT recipients.

Responsibility to care for the partner.

In it together – supported the partner's healthcare. Participants generally reported that prior to transplantation their partner had managed their diabetes

regimen themselves, but they sometimes reminded their partner to check their bloods and would generally keep an eye on them. In particular, participants looked out for signs that their partner might be experiencing hypoglycaemia, as for some, they were no longer able to detect this themselves. Some had become adept at identifying when their partner's blood glucose levels were becoming low due to particular changes in appearance or behaviour:

> Whenever somebody's starting to go low they start, erm, their behaviour becomes very repetitive, er, and also there was, something happened to her eyes. I can't explain it to you, but I could tell from her eyes that she was starting to go low. (PID5, husband of SPKT recipient.)

This monitoring extended to planning ahead to avoid hypoglycaemic episodes altogether, such as ensuring their partner had a proper breakfast if they were doing something active in the day, and ensuring they had something sugary to hand in case their partner started to experience hypoglycaemia whilst out. Hypoglycaemia was sometimes reported to have become more frequent with the progression of CKD. A few participants reported that the use of insulin pumps had helped their partner to manage their blood glucose levels. Some participants had assisted their partner when they experienced hypoglycaemia by providing something sugary or administering glucagon injections when they were unable to get their partner to ingest something. Participants described situations when they had been unable to wake their partner in the morning or had found them unconscious. In extreme situations some had needed to call for an ambulance for assistance. These severe episodes of hypoglycaemia were especially distressing and had left a lasting impression on participants: "So she ended up having really, quite serious, life threatening crashes that er, ambulances and, you know, me injecting the, er, the hypo-stop, and, er, doing that a couple of times. That was quite, quite a scary situation." (PID3, husband of SPKT recipient.)

Once partners had been diagnosed with late-stage CKD, participants described supporting their partner with their healthcare in various ways such as attending appointments together, making important healthcare decisions together, and helping their partner to follow more restricted dietary recommendations:

> So, as opposed to her going by herself, I could go, er, and if there was a change I could go "right, tell me this, tell me this," sort of… I'm quite au fait with the medical side. So I could ask the questions and go "right, what's the consequences of this?" (PID1, husband of SPKT recipient.)

One participant in particular described rising to the challenge of catering for their partner's increasingly restricted diet prior to transplantation as she felt a sense of responsibility to keep him well enough to avoid the need to start dialysis:

> So, of course, I felt that it was my responsibility to make sure that I kept his diet as close as I could to what he should be having to try and keep him off dialysis for as long as possible. (PID7, wife of SPKT recipient.)

Participants whose partners started on PD prior to transplantation indicated that they mostly took charge of their own treatment, however participants described assisting them at times. For example, one participant described helping to set up their partner's APD machine and assisted his partner when the machine malfunctioned during the night:

> But her machine every night would go wrong, so I knew what to try, you know, through trial and error for things going wrong with that machine. We eventually became quite experts the pair of us at figuring it out. (PID4, husband of SPKT recipient.)

Participants frequently used 'we' when discussing their experiences which gave the impression that they were in it together with their partner who had diabetes and CKD. Although not the case for all participants, some reported feeling that the overall shared experience of their partner's health problems had brought them closer because they had experienced it together or had needed to have a good understanding of their partner in order to support them effectively:

> Yes, it makes you much more understanding, er, of what she's going through because you've had to understand it to then try and to help where you can. (PID1, husband of SPKT recipient.)

Another participant said:

> I know she was the patient but because we'd both experienced the whole process of it together, I think that that actually brought us, er, closer together. Erm. And I think we just have a better understanding of each other because of that. (PID3, husband of SPKT recipient.)

However, for a few, the health conditions may have eventually come between the participant and their partner. One participant reported that their partner had become consumed by their own health problems and treatment. This caused them to feel less united and left the participant feeling forgotten and sometimes resentful towards their partner's health conditions and the dialysis machine: "And just, in terms of, kind of, just general day to day things, you know, like, he became so

absorbed in his illness and his appointments. You know. He almost forgot about me." (PID8, wife of SPKT recipient.)

Another participant indicated that their partner had struggled with their diabetes management and was often resistant to their help and help from others. This caused tension as the help that they offered was sometimes rejected, and this caused the situation to be more stressful.

> …during the run up to the transplant, erm, her being resistant to, to my, erm, advice and stuff. 'Cause I could see her doing things that I could tell were gonna make her hypo in the night, and I knew then that I would have to deal with that. (PID5, husband of SPKT recipient.)

Some participants continued to attend post-transplant appointments with their partner, which were initially very frequent and time-consuming but eventually became less frequent. One participant described having particular difficulties getting to and from these initial post-transplant appointments due to their partner's poor health, making this an especially stressful time:

> …first of all I thought, how are we gonna do this? …she's so weak, [she] can barely walk to the end of the room without feeling tired. How are we gonna get home? How are we gonna get her up and down here? 'Cause they tell you you got to come in twice a week and then that goes on a month, and then it goes to, like, once a week for the next month and then, like, once a fortnight and on and on it goes, but that first month was hell. (PID4, husband of SPKT recipient.)

Some participants also reported initially learning about and supporting their partner with their new anti-rejection medication regimens: "…we'd got to get used to using different drugs than we had been used to and, erm, so we sort of did it together, so that we both knew what we were doing with it." (PID7, wife of SPKT recipient.) Participants did not discuss the post-transplant medication regimen in depth and generally felt that there had been no real issues with their partner taking the medications.

Took on more responsibilities. In addition to supporting their partner's healthcare, most participants found that they took on more responsibilities when their partner was unwell or when they were recovering from the transplant operation. Participants described doing more of the driving, childcare, shopping, or chores around the home, often on top of continuing to work in a full-time or part-time job.

> Taking the kids to school, doing all the, everything, every household chore, every household necessity was done by me as well as working at the same time. She couldn't drive, she couldn't see anything, her eyesight deteriorated so bad… (PID4, husband of SPKT recipient.)

Some participants also reported acting as a messenger between the partner and other family members, keeping others informed when the partner was unwell or during the transplant. For one participant this became an additional stressor when they were struggling to process what was happening themselves and keep track of all the information provided by the doctors: "I found it really hard trying to keep people informed and it was like, I'm going through this, and I know you're concerned but you're just wearing me out." (PID8, wife of SPKT recipient.)

Participants often described experiencing an initial intense period of time when their partner received their SPKT and were recovering from the operation. During this time partners often needed additional support and participants continued to carry out tasks they had taken on prior to the transplant. However, this had eased for most by about six months post-transplant.

Living with worry. Participants often described living with persistent worry prior to their partner's SPKT. Participants worried for various reasons, and some described particularly upsetting incidents such as finding their partner had collapsed due to hypoglycaemia. One participant was especially afraid that their partner might experience hypoglycaemia whilst driving, which would potentially put their lives at risk: "I mean, obviously, there are some aspects are much, much scarier than others. Driving. Erm. And just being absolutely sure that, you know, he tests before getting in cars." (PID2, wife of SPKT recipient.) Others were particularly concerned that their partner would become unwell or experience severe hypoglycaemia during the night or when they were not around to assist them. A few participants reported checking their partner each morning to ensure that they had made it through the night, or they would check on their partner when they were away for the day to try to ease concerns that something might have happened to them:

> The first thing that I used to do in the morning was I used to, erm, actually lean over and make sure she was still breathing and that she hadn't had a diabetic coma in the night and died. (PID5, husband of SPKT recipient.)

Another participant said:

> …if I was gonna go out and do something with some friends then I would make a point of staying in touch with him throughout the day or the night, and, sort of, sending messages. And then if he didn't reply, I would worry, like, is there something going on or, erm, has anything happened or is he just sleeping. (PID6, wife of SPKT recipient.)

Prior to transplantation, participants also worried about other diabetes complications that their partner had already developed and the prospect of further complications in the future. Participants were concerned about the impact that diabetes complications would have on their partners QoL and future survival. In particular, diabetic retinopathy, which could result in severe visual impairment, was seen as a frightening and debilitating complication of diabetes:

> I remember a couple of times she did actually collapse, you know, so it was always a bit of a worry. But I think the biggest fear for me was for her losing her sight, I remember that thinking, mm, this is not good. (PID4, husband of SPKT recipient.)

The onset of CKD was described as slow for some, occurring over several years, but relatively quickly for others. Participants often described feeling shocked by their partner's diagnosis of kidney failure and/or when partners had needed to start dialysis. Uncertainty and mixed feelings were reported in response to their partner being added to the transplant waiting list. Some participants were relieved when their partner was added to the waiting list as this was seen as a positive step. However, participants also described feeling very anxious as they perceived the transplant to be extremely serious and frightening and the outcome was unknown: "I mean, when they first suggested the transplant, erm, I was reasonably freaked out about it as it was. It just seemed such a, sort of, horrendous thing." (PID2, wife of SPKT recipient.) Another participant said: "So yeh, it was, you know, mixed emotions really. Excitement that it could happen, scared that it might happen and go wrong, scared that it's not gonna happen, anxious. You just don't know…" (PID8, wife of SPKT recipient.) One participant described losing hope after their partner had spent many months on the waiting list without a call and their health was deteriorating: "18 months then on the transplant list. That 18 months, it just went on forever. And honestly, we'd given up on ever getting a phone call, it's [the transplant] never gonna happen." (PID4, husband of SPKT recipient.)

Whilst some reported feeling lucky that their partner had received their transplant at their first call, others experienced several calls when the transplant did not go ahead. Whilst these false alarms could be stressful, one participant reported that it had prepared them for when their partner eventually did receive their transplant. Some participants described having worried for their partner's life at times as they became increasingly unwell prior to transplantation or when they faced complications during or after the transplant operation. For some, the extreme experiences of their partner's health problems were quite distressing:

> …just being in that place [the intensive care unit] is, you know, quite an intense realisation that, you know, that this really is a matter of whether she lives or whether she dies. So that's quite, you get quite a strong, er, realisation at that point. (PID3, husband of SPKT recipient.)

After transplantation, participants reported being careful to not pass on infectious illnesses to their partner and this was particularly relevant to participants who were interviewed during the COVID-19 pandemic in 2020/2021. Participants described having been worried by the COVID-19 virus as they were aware that their partner was particularly vulnerable to it due to their immunosuppressant medications:

> It [COVID-19] was really, really scary at first. It was just, oh gosh, actually [my partner] is high risk, this is, you know, quite severe, he's in that top group and, erm, you know, I need to, to be extra careful for his health… (PID6, wife of SPKT recipient.)

However, participants had become used to taking precautions to avoid contracting the virus and passing it on and described taking extra care to stay safe. For some, the restrictions of the pandemic were a continuation of those that they had experienced prior to or initially after their partner's operation:

> So really, everyone's gone on this quarantine for Covid, we were already on it. So it wasn't a big culture shock to Covid coming along… (PID4, husband of SPKT recipient.)

Some participants also felt concerned about how long their partner's graft would work and worried that it might suddenly stop working one day. This concern was common to both participants whose partner had only had the transplant for around 6 months and those whose partner had had the transplant for years:

> I know this could happen to anyone any day but because of all the pressure that has been on his body I do think, you know, could he wake up one day we're back

> to square one or his body rejects it or it's not working. But I guess you can't think like that can you? (PID8, wife of SPKT recipient.)

Prioritised the partner over own well-being. Some participants indicated that prior to transplantation and during the transplant recovery period, they had prioritised their partner's health problems and caring for their partner over their own well-being. A few felt that their life was 'on hold' whilst their partner was on the transplant waiting list as they never knew when their partner would be called in to the hospital for the transplant. Due to concerns over missing transplant opportunities some participants had avoided traveling, especially abroad. Participants described having restricted their personal activities as they worried about leaving their partner unassisted for long periods of time or had limited time to focus on themselves. This meant that some participants had stopped doing things that they enjoyed, had avoided taking up new activities, or had missed social events in order to be around for their partner: "I didn't have a social life, erm, the, the things that [I] enjoyed doing I stopped doing." (PID5, husband of SPKT recipient.) Another participant said:

> You know, it isn't till you actually stop and think that, erm, you know, how many things you've sort of turned down because, you know, it's just easier not, not to do it. You know? I wouldn't get involved with going to classes with somebody and that sort of thing and, er, you know, on a regular basis because it would always mean taking me away. (PID7, wife of SPKT recipient.)

Participants reported benefiting from being able to work from home, flexible working hours, and having an understanding employer who allowed them to take time off to support their partner. However, it was clear that balancing work and supporting the partner was challenging at times, especially when the partner with diabetes and CKD became particularly unwell. This meant that some participants missed opportunities to work or worked odd hours to make up for missed time: "But I had the ability to work in the evening, so I was always working late, catching up on the work that I'd missed during the day and, yeh, that seemed to go on forever." (PID4, husband of SPKT recipient.)

Some participants indicated that the stress that they lived with whilst their partner was unwell may have negatively impacted their own health and well-being. For some this included having neglected aspects of health, such as taking regular exercise. One participant indicated they had stayed strong and well whilst their

partner was unwell and later in the interview described relief at having developed their own health problems after their partner had received their transplant as they would have struggled to cope with both:

> I'm not the healthy one in this house. I've had a couple of health issues since, more recently... I think probably that, you know you have to, sort of, you have to do the being the strong person and holding it all up and then… once the pressures off it all goes quietly to pieces a bit, so. Yeh, I mean, I saved having health problems till it was safe, definitely not on purpose. (PID2, wife of SPKT recipient.)

A few participants indicated that they had not always felt able to talk about how they were feeling when they were struggling because they saw it as their responsibility to remain strong for the partner going through the health problems and possibly wanted to protect their partner:

> …it wasn't about me so therefore, you know, this is not something that I'm gonna, erm, you know, that I can kind of express any feelings about because this really is all about somebody else and, er, I suppose that is, that is the way that all of the people around the situation accepted that it was…it was mostly focused on, you know, we're, I suppose we need to consider that we are the fortunate ones and it's, it's [my wife] that our focus and concentration and strength needs to be mustered for her really. (PID3, husband of SPKT recipient.)

This may have had a detrimental effect on the mental health of at least one participant, because they had felt unable to process what was happening and lived with a lot of stress on a day-to-day basis as they tried to remain strong and support their partner prior to transplantation:

> I would say I supressed quite a lot through the actual process, because we were on autopilot. So you couldn't really let it come to the forefront, you couldn't deal with your emotions because, because you actually had to be aware of what was actually happening all around you and, you, you couldn't be ill. You couldn't allow yourself to be… off the ball, 'cause you needed to be focused on, on the task at hand, and that, that was getting from one day to the other. (PID5, husband of SPKT recipient.)

Participants sometimes struggled as a result of their caring role on top of other responsibilities that they were juggling prior to and/or initially after their partner's transplant. This was particularly true for those also caring for someone other than their partner, such as children. For example, one participant indicated that due to

her various responsibilities including supporting her partner and another elderly relative, she did not have the time to focus on her own well-being or do things to benefit herself and as a result ended up feeling burnt out for a time.: "…I got quite spent, you know, at one point. I thought I'm just starting to feel a bit like an empty vessel, you know, I'm giving out and I've got no time to put anything back in." (PID7, wife of SPKT recipient.)

'Got on with it.' When asked about how they coped participants often reported having 'got on with it'. Some participants indicated that prior to their partner's transplant they tried to accept their situation and tried to 'get on' with life as best they could despite their partner's health problems. Some participants indicated they had tried not to dwell on negatives or that they would 'get on' with life and deal with things, such as the transplant, when they happened:

> You adapt, you adapt very quickly. You have to. 'Cause otherwise if you don't you will make yourself miserable. If you just, you know, if you just dwell on it too much, the negatives of it, you just have to get on with it you know. (PID4, husband of SPKT recipient.)

Another participant said:

> I don't think there was ever really a strategy, just kind of, got on with it. This is what's going on, this is how things are and you know, this is what might happen but it's in the future so until it does we'll just keep on keeping on, I think. (PID6, wife of SPKT recipient.)

A few participants indicated that they had no choice but to cope and 'get on with it' because they felt responsible for their partner and other family members: "Everyone says that it's amazing what I cope with but when you're faced with these things you just cope don't you? And I've got little ones, so I had no choice." (PID8, wife of SPKT recipient.)

Utilised sources of support. Participants described utilising other sources of support in their partner's care prior to transplantation and/or during their partner's initial recovery period after the transplant. Some participants benefited from being able to share some of the caring responsibilities, such as having other family members or friends help with meal preparation or checking on the partner when they were away. This allowed participants to continue with activities that were important to them, such as work, without worrying as much about their partner's well-being whilst they were not around to help them:

> …with my job I was away a lot, so obviously while I was away we had to make sure that, that somebody rung her in the morning, er, made sure she was with us and all the rest of it… (PID1, husband of SPKT recipient.)

However, participants may not always have had sufficient sources of support available or did not feel confident that others could provide the necessary support and this then put more pressure on the participant themselves. For example, one participant felt that their partner had become quite reliant on their care/support prior to transplantation and did not feel that others were knowledgeable enough to provide the same level of support:

> So she'd become very reliant, even, to the support and that that I was [providing], although there would've been other people that could've stepped in and done what I would've done. Because I, I lived with it every day, erm, her family were nowhere near as, erm, switched on about it as I was, and I suppose that freaked her out. (PID5, husband of SPKT recipient.)

Participants generally felt they had been well informed about their partner's CKD and transplantation and acknowledged that their partner had received good care and support from the renal team prior to transplantation and when issues arose post-transplant:

> They [the renal/transplant team] were really good and we have maintained a relationship with them, that, that means that you can, if you've got any queries you just ring up and they'll go yes fine. (PID1, husband of SPKT recipient.)

Participants reported that their partner benefited from support or information provided by other patients who were going through the same health problems or had received a transplant. For example, some participants reported having attended useful events prior to transplantation where they and their partner could speak to transplant recipients to find out about their experiences and what to expect. One participant reported having referred back to and been reassured by experiences they had been told about at one such event:

> …and a few times, you know, I'd say to [my husband] oh, do you remember the lady that we spoke to and she said this, you know, oh yes of course. And it does help when you know what other people have experienced. (PID7, wife of SPKT recipient.)

However, another participant who did not recall having the chance to attend such an event, highlighted that they would have benefited from having more information on what was usual during the initial post-transplant recovery. The participant suggested

providing a booklet of information on what you might expect each day of the recovery after the SPKT:

> Because what would have been really useful in the hospital is if somebody gave him a list of, you know, on day one this is kind of how you're gonna feel and on day two, day seven, like, and just, just little insights that it's normal to feel like this and it's normal for this to be going on. (PID6, wife of SPKT recipient.)

Although participants were included in discussions about their partners healthcare if/when they attended appointments with them, they were not necessarily provided with support themselves. One participant reported having struggled with the challenges of their partners health problems prior to the transplant but had only been able to access suitable support privately after their partner received a transplant:

> But there's been nothing really there for me, erm, it's all been privately I've had to do it… my wife could, she's got a, erm, counsellor that she can contact through the NHS, erm, who's very good, but there's nothing there for the partners. (PID5, husband of SPKT recipient.)

The first few months after transplantation were often particularly challenging, especially for those whose partners experienced complications during and/or after the operation. One participant described this initial period after their partner's transplant as especially isolating and lonely as their partner spent a long period of time at the hospital recovering from complications post-transplant:

> I think during the period of the transplant while she was in hospital, erm, even though you've got family around you it does feel like a very lonely existence… Sometimes I would travel to [the hospital], sit next to the bed for nearly, sort of, 3 or 4 hours and she would not be conscious during that time at all. I think that was, erm, that was very difficult. (PID3, husband of SPKT recipient.)

Some participants benefited personally from receiving emotional support from friends and family which helped them to process and cope with what they were going through prior to and during the transplant process: "I've got a very good friend, erm, I can talk to her, erm, and then, you know, we usually both get things off our chest and feel a lot better…" (PID7, wife of SPKT recipient.)

Relief and freedom post-SPKT. After an initially worrying and stressful recovery period, participants felt great relief that their partner had received a successful SPKT. Participants were relieved to see their partner's health had

improved and some felt that their partner's life had been saved by the transplant: "…it was an absolute new lease of life. You know, it was life changing for her. That double transplant changed her life, gave her her life back. Gave her her energy back, gave her her health back, everything." (PID4, husband of SPKT recipient.)

Participants were happy to see their partner regain certain aspects of their independence that had previously been lost due to their poor health. For example, due to health and eyesight improvements one participant's partner was able to drive again and go out independently. Patients were able to take a more active parenting role and spend more time doing activities with family. Another participant's partner was able to return to work after being unable to work prior to the transplant:

> He has now gone back to a part-time job, just over the last month or so, erm, just a couple of shifts a week, but it's making him really happy, you know, he's really pleased to have this reason to get up and go out and go to work and he's, he's getting paid. (PID6, wife of SPKT recipient.)

Participants were still supportive of their partner post-SPKT, but often no longer had as much of a caring role, with some indicating that they no longer needed to support their partner more than any other partner would. Participants were glad that their partner had more dietary freedom, which made meal-times easier for some: "It doesn't matter if we have a dinner at, you know, 5 o'clock or 10 o'clock, you know, nothing matters any longer like that, and it's wonderful." (PID7, wife of SPKT recipient.) Similarly, a few were relieved that their partner no longer needed to follow a PD regimen and were pleased to have regained space in their homes that had been taken up by supplies. Participants described returning to 'normal' life and having more freedom to do things, such as travel: "…well we've been able to, er, travel again, we've gone abroad again. [My wife's] got back into work again… So, I suppose it feels a little bit more normalised." (PID3, husband of SPKT recipient.)

In particular, participants were relieved that they and their partner no longer needed to worry about diabetes management and the risk of further diabetes complications:

> It was just amazing that something that had dominated his life for so long could be sorted out… it's just made such a difference. You know? That he doesn't have to be terrified of diabetic eye damage getting any worse or all the, all the awful things. (PID2, wife of SPKT recipient.)

Participants no longer worried that their partner would experience hypoglycaemia and felt more able to take part in activities together:

> Not having to worry about that [hypoglycaemia] now, is, yeh, that's a huge difference and I think it has been, I think it has been the biggest advantage to her having, er, the transplant, the kidney and pancreas together, meaning she's not diabetic anymore, that has transformed her and transformed how we do things. (PID3, husband of SPKT recipient.)

The fear that something bad, such as severe hypoglycaemia, would happen to their partner when they were not around to help had also eased post-SPKT. This relief and having more time for themselves allowed participants to refocus on their own health and well-being. Some had taken time to improve their mental health and/or fitness and were able to take part in individual activities that they enjoyed, which some had neglected prior to transplantation and during the initial recovery period:

> Whenever you were going to do something you enjoyed, you could actually enjoy it because you weren't constantly worrying about what was happening at home, or what was happening to the wife. Erm. Whenever I was going to do things, I was able to do it for longer. Erm. So, so it just gave you that freedom that I hadn't had for years. (PID5, husband of SPKT recipient.)

Another participant said:

> I think we started to do more of our own things… I just do, you know, if I wanna go somewhere I'll go and do that, if I want to sit and play [music] for a couple of hours, I'll do that. (PID3, husband of SPKT recipient.)

A few participants who had experienced some relationship difficulties prior to their partner's transplant indicated that they had started to notice improvements, although they acknowledged that they were still working on this. The few who were interviewed six months after their partner's transplant were still adjusting to life post-transplant. In particular, some participants interviewed during the COVID-19 pandemic in 2020/2021 indicated that the restrictions of the pandemic prevented them from experiencing the full benefits of their partner's transplant. For example, some had not yet been able to travel abroad. Some felt the restrictions of the pandemic had given their partner time to rest and had raised awareness of good hygiene practices. Participants had hope and looked forward to doing more in the future once the restrictions of the pandemic lifted:

> Well, I think once the restrictions are lifted it will give me a bit more freedom... I'll be able to, if I wanted to go out, I could go out. Erm. I could go out for the day and leave [my husband] and he would be fine. (PID7, wife of SPKT recipient.)

Another participant said:

> And, and now we've got hope, we can go away, we can do normal things again. You know. Only 'cause this [Covd-19 pandemic] has been an exception, otherwise we would have been away on holiday enjoying ourselves. (PID5, husband of SPKT recipient.)

Discussion

The study presents findings from qualitative interviews exploring the experiences of partners of SPKT recipients. Whilst participants did not consider themselves to be their partner's carer at the time of the interviews post-transplant, participants had had various roles in supporting their partners and took on additional responsibilities when their partner was unwell. Participants indicated they had lived with persistent worry prior to their partner's transplant and had often prioritised their partner over their own well-being. Participants experienced a sense of relief when the partner's transplant was successful. When asked about how they had coped, participants described having 'got on with it', indicating that they had no choice but to cope and try to be strong for their partner. Those who were also able to utilise support from others indicated that this had been beneficial.

Supporting the partner with diabetes and CKD. Participants often indicated that they were in it together with their partner. Some participants found that the experience of supporting their partner with their health conditions or through the transplant process had brought them closer together. However, others found that the health conditions and associated difficulties put a strain on their relationship, particularly if the partner was resistant to support or became too focused on their health problems. Whilst partners can provide useful support in helping individuals to manage their diabetes through a generally supportive and encouraging attitude, by preparing appropriate meals/food, and reminders; partners can also hinder patients if they are perceived to be 'nagging' (Trief et al., 2003). Some individuals with diabetes may be resistant to support if they want to retain more independence, do not want to burden their partner, or they lack trust in their partner's ability to help (Litchman et al., 2019; Trief et al., 2003). However, partners may feel frustrated and helpless if they are not involved in the diabetes management (Morris et al., 2006). It is important to remember that individuals with chronic health conditions and their partners may perceive support/caring behaviours differently (Litchman et al., 2019). The concept of miscarried helping has been described as when a family member's attempts to help an individual with a chronic

illness are perceived negatively, perhaps because it is seen as excessive or inappropriate, and can result in relationship conflict and possibly poorer health outcomes (J. C. Coyne, Wortman, & Lehman, 1988). Partners who try to exert health-related social control by monitoring and influencing adherence to diabetes recommendations (Lewis & Rook, 1999) may experience more burden, especially if the individual with diabetes is resistant to help and adherence is poor (August, Rook, Parris Stephens, & Franks, 2011). In the current study, although transplantation helped to improve participants' situations, some felt that they still needed to work on their relationship with their partner due to the impact that the conditions had had before the transplant.

Living with worry due to diabetes and CKD. Participants lived with a lot of worry prior to their partner's transplant. Some participants had been especially worried that their partner would experience severe and even life-threatening hypoglycaemia during the night, whilst driving, or when they were not around to assist them. Participants reported previous experiences when their partner had had severe hypoglycaemia and they had needed to assist them, and had even needed to call for emergency services to help. These situations had been stressful and frightening and fuelled participants' worry. Research into fear of hypoglycaemia has mainly focused on the patients themselves, or on parents of children with type 1 diabetes (Gonder-Frederick, 2013). Very few studies appear to have quantitatively investigated fear of hypoglycaemia in partners, although it has been highlighted as a key concern in qualitative research and can lead partners to become watchful of the individual with diabetes and to feel the need to check on them by phone when they are away (J. King et al., 2015; Lawton et al., 2014; Trief et al., 2013). One quantitative study found that spouses of individuals who had experienced severe hypoglycaemia in the past year engaged in more preventative behaviours and experienced more worry about hypoglycaemia. These spouses also experienced higher levels of conflict due to diabetes compared to spouses of individuals who had not experienced hypoglycaemia in the past year (Gonder-Frederick, Cox, Kovatchev, Julian, & Clarke, 1997). A study which developed a measure of diabetes distress for partners found that higher scores were associated with younger age, being female, partner's HbA1c, number of previous severe hypoglycaemic episodes, lower relationship satisfaction, less satisfaction in diabetes knowledge, and less comfort and satisfaction with their partner's healthcare providers. Around 30% of the sample of partners were found to have diabetes-related distress (Polonsky, Fisher, Hessler, & Johnson, 2016). Although some participants in the

current research reported that technology such as CGMs and insulin pumps had helped their partner with diabetes management, some still experienced hypoglycaemia. Further research into fear of hypoglycaemia and diabetes distress among partners may be beneficial as this could be targeted by healthcare professionals within interventions. Evidence suggests that CKD is a risk factor for more frequent hypoglycaemia (Moen et al., 2009), so partners of those awaiting an SPKT may benefit from advice and support in this area. As technology improves and becomes more widely available, for example the ability to share real-time data from CGMs, this will possibly also help couples living with type 1 diabetes (Polonsky & Fortmann, 2020).

Concerns of hypoglycaemia and more general worries about the partner's health problems led some participants to prioritise their partner over their own health and well-being. This manifested in various ways, including limiting time spent on individual leisure and social activities. This lack of focus on their own well-being had a negative impact on some and participants experienced high levels of stress or isolation at times. Those with other caring responsibilities, such as those with children or elderly relatives, were particularly at risk of stress. Some participants had suppressed their feelings during difficult times as they tried to remain strong in order to support their partner. These findings are consistent with previous qualitative research which also found that family members of individuals with diabetes or on dialysis adjust their lifestyle and prioritise the unwell family member, sometimes resulting in feelings of social isolation (Blogg & Hyde, 2008; Lawton et al., 2014; Y. White & Grenyer, 1999; Ziegert & Fridlund, 2001; Ziegert et al., 2006). Worry and stress associated with having a partner with a chronic health problem may increase the risk of anxiety and depression. A systematic review found around 35% to 55% of caregivers of individuals on dialysis suffered from depression, although some research suggested similar rates of depression compared to general population samples (Gilbertson et al., 2019). Persistent stress may put partners in caregiving situations at risk of developing health conditions themselves, particularly if they neglect aspects of a healthy lifestyle, such as sufficient exercise (Segerstrom & Miller, 2004; Vitaliano, Young, & Zhang, 2004). As maintaining independence and taking part in enjoyable leisure activities can be especially beneficial for individuals in caring roles (Ziegert et al., 2006), partners need to be actively encouraged to make time for their own well-being and health needs.

Coping. Similarly to the findings from patients reported in Chapters 5 and 6, when asked about how they coped participants often reported that they 'got on with it'. Getting on with it included emotion-focused coping strategies such as trying to have a positive attitude and not dwelling on negatives. Furthermore, in relation to staying strong and prioritising the individual with diabetes and CKD, some participants tried to keep their concern to themselves or suppressed their emotions to protect the partner. This is sometimes referred to as protective buffering and is a type of relationship-focused coping (J. C. Coyne & Smith, 1991). Relationship-focused coping extends upon Lazarus and Folkman's stress and coping theory, which is focused on individual coping, and suggests that people will use strategies to try to maintain the relationship. Protective buffering is generally considered to be less adaptive as it can negatively impact the individual and satisfaction with the relationship. On the other hand, active engagement, which entails being involved in discussions and problem solving together in relation to the health condition, is considered a more adaptive method of relationship-focused coping (J. C. Coyne & Smith, 1991; Falconier, Jackson, Hilpert, & Bodenmann, 2015). As participants often also supported their partner's healthcare it is likely that they used both active engagement and protective buffering whilst coping with their partner's health problems.

Support. Participants also benefited from other sources of support, and it is possible that this helped to prevent some individuals from becoming overwhelmed. Family members and/or friends provided emotional support to the participant directly or enabled participants to share caring responsibilities. However, some participants did not receive sufficient support at times, making their experiences prior to transplantation and during the initial transplant period more stressful. Previous research has shown that social support is negatively associated with burden (Tao et al., 2020) and depression reported by caregivers of individuals on dialysis (Asti, Kara, Ipek, & Erci, 2006; Shukri, Mustofai, Md Yasin, & Tuan Hadi, 2020). Another study found social support moderated the impact of caregiver burden on anxiety (Shukri et al., 2020). Provision of psychological support is understandably more likely to be offered to patients than partners. Healthcare professionals could explore with patients awaiting an SPKT and their partners, ways in which they could use other sources of support to ensure that partners are able to attend to their own health and well-being needs. Some partners may also benefit from being signposted to sources of psychological support if it is not available to them through the renal or transplant unit. Peer support from those living with the same health conditions or

who have already received an SPKT can also be beneficial for patients and their partners to help them know what to expect and normalise experiences. Individuals with CKD and their partners may want to access informal or formal peer-support at various times throughout the disease progression and need to be provided with opportunities to speak with other patients, especially as some may not request support themselves (F. Taylor et al., 2016). Participants were generally satisfied with information provided by healthcare professionals and their understanding of their partner's condition. However, the current findings suggest that there is a need for more information on what to expect during the initial post-transplant recovery period, which was a particularly stressful time for several participants.

Impact of transplantation on partners. SPK transplantation resulted in great relief and more freedom for partners, highlighting the wider benefit of transplantation for family members. A particular benefit of the SPKT was that participants were no longer worried that their partner would experience hypoglycaemia and this meant that they were more able to take part in activities, both together and individually. Participants no longer worried about other diabetes complications, and a few enjoyed more dietary freedom together with their partner. These findings are unique to the current study as research has not previously explored experiences of partners of SPKT recipients. Participants whose partners had been on PD prior to transplantation also reported relief that they no longer needed to follow a dialysis regimen and they had regained space in their home. Participants were happy to see their partner's health improve and that they had a new lease of life and regained more independence. Some participants who had previously overlooked their own health and well-being felt able to refocus on themselves again and do things that they enjoyed. These findings are in line with Chapters 4 and 6 which show that SPKT recipients themselves experienced improvements in QoL and reported having more freedom post-transplant. The findings are also consistent with previous research which found that partners of individuals with a kidney transplant were less likely to feel burdened, that they did not have enough time to themselves, or that their social life suffered due to caring for their partner compared to partners of patients on dialysis (Rasmussen et al., 2020). This relief and freedom experienced by partners post-transplant could help to explain why in previous research caregivers of kidney transplant recipients reported better QoL (measured on a VAS; Morelon et al., 2005), and better physical health, mental health, and sleep compared to caregivers of individuals on dialysis (Avşar et al., 2013; Avşar et al., 2015; Lindqvist et al., 2000).

It should be noted that some participants in the current study were interviewed during the COVID-19 pandemic during which time the UK population lived with enforced social restrictions. Research suggests that the prevalence of distress in the UK general population initially worsened from 2019 to April 2020 but returned to pre-pandemic levels by September 2020 (Daly & Robinson, 2021). Some participants who were interviewed during the pandemic indicated that they had not yet been able to experience the full benefits of their partner's transplant. Whilst participants were concerned about their partner's susceptibility to the virus, they also felt that they had already adjusted to living with restrictions due to their partner's illness and initial recovery period. Participants were still generally very positive about their partner's transplant and had hope for the future when they would be able to do more once the restrictions of the pandemic were lifted. Consistent with findings from previous research with partners of kidney transplant recipients (Morelon et al., 2005), some participants indicated that they occasionally worried about how long their partner's transplant would last and whether they might become unwell again. However, this did not seem to be as much of a pervasive worry as that experienced prior to the partner's transplant. Partners may still benefit from additional advice and support after transplantation to ease lingering concerns or to help couples to improve aspects of their relationship that may have been impacted by their health conditions. Some promising results have been found in studies investigating Cognitive Behavioural Skills Training and Relationship Counselling interventions for couples with a chronic condition, although the majority of interventions have been carried out with couples with cancer (Berry, Davies, & Dempster, 2017). Intervention research is needed to explore what types of support would be most beneficial for couples throughout the process of SPK transplantation.

Study limitations. The current study provides insight into the experiences of long-term partners who remained in their relationships. It is important to note that the sample did not include those in newer relationships or those whose relationship had broken down completely, whose experiences may have been very different. There may have been a selection bias in those who chose to take part the research. For example, the majority of participants in the current study had higher level education. Furthermore, a previous study found that partners of kidney transplant recipients who reported greater relationship satisfaction were more likely to take part in research than the partners of those with less relationship satisfaction (Hagedoorn et al., 2015). One issue that was not examined in the current study was

whether there were any differences in experiences of men and women. In a much larger qualitative study with 52 couples aged ≥65 years where one member of the couple had type 1 diabetes, women were more likely to report supporting their partner with diabetes by preparing meals, carrying treatments or snacks in case of hypoglycaemia, attending appointments, and picking up prescriptions (Litchman et al., 2019). Men were found to provide more support regarding their partner's diabetes technology, such as troubleshooting issues and reminding them to check their blood glucose readings. In quantitative studies, women have been found to report more diabetes distress in relation to their partner's diabetes (Polonsky et al., 2016) and more fear of hypoglycaemia in response to their children's diabetes (Gonder-Frederick, 2013) compared to men. It was beyond the scope of the current study to explore whether these types of gender differences were present. A larger study of couples awaiting and/or in receipt of an SPKT would allow investigation of whether there are differences in the experiences of men and women and whether they have different support needs. Whilst the current study aimed to explore partner's experiences as individuals, future research could include both members of each couple and investigate how couples cope together (dyadic coping) throughout the process of SPK transplantation to help identify ways in which couples could maintain relationship satisfaction.

Study implications. The findings of the current study indicate that partners are often negatively impacted by diabetes and CKD and live with a lot of worry about the partner with diabetes and CKD. In particular, some partners may benefit from additional support in dealing with hypoglycaemia before transplantation. As partners may prioritise the individual with diabetes and CKD over their own well-being, they need to be encouraged to continue to pursue their own activities and maintain their own health and well-being. For example, pre-transplant information sessions often provided by renal units could include information about maintaining well-being for partners as well as those waitlisted for a transplant. Patients and their partners could be sign-posted to available resources offered at the renal/transplant unit or through relevant charities. Additional support and/or information about the initial post-transplant recovery period may also be beneficial to prepare patients and their partners for transplantation.

Conclusions

In conclusion, this is the first qualitative study to report on the experiences of partners of SPKT recipients. Partners provided support to individuals awaiting and in receipt of an SPKT in various ways and often took on additional responsibilities when their partner was unwell. Partners of individuals with diabetes and CKD lived with pervasive worry and some neglected their own health and well-being whilst they focused on staying strong and supporting their partner. The initial few months after transplantation can be an especially worrying and difficult time for partners and they may benefit from additional support and information on what to expect at this time. However, partners were very positive about SPK transplantation. Transplantation was felt to be beneficial, not only for patients, but also for their partners as it relieved worry and enabled them to live more freely and refocus on their own health and well-being.

Chapter 8: General Discussion

Overview of Research Findings

The research used mixed methods to assess the impact of diabetes, CKD, and their treatments, including pancreas and/or kidney transplantation, on patients' QoL and other PROs. Specifically, study 1 aimed to follow-up individuals who took part in the original ATTOM detailed PROMs study to assess: (a) whether PROs changed from pre- to post-transplantation; (b) whether SPK and kidney-only transplant recipients' PROs changed further from the 12-months post-transplant follow-up of the original ATTOM study to the current follow-up approximately six/seven-years later; (c) how LDKT recipients' PROs at follow-up compared with those of DDKT recipients. There is still limited prospective longitudinal PROMs research on SPK transplantation, particularly which have used genuine measures of QoL. Furthermore, SPK transplantation is a relatively new treatment whose clinical outcomes have improved since 2000 (Lindahl, Jenssen, et al., 2014), and is less common than kidney-only transplantation. Therefore, study 2 collected PROMs data prospectively from patients awaiting an SPKT and followed up participants longitudinally in order to assess the impact of SPK transplantation on QoL and other PROs. As patients' perceptions of their illness may impact their response to and experience of the illness, study 2 included an assessment of whether participants' illness perceptions changed from pre- to post-SPKT and whether illness perceptions are associated with well-being, generic QoL, condition-specific QoL, and treatment satisfaction. Qualitative interviews were used to explore further patients' experiences prior to SPK transplantation and after SPK and kidney-only transplantation to understand better how QoL is impacted and to aid interpretation of the quantitative studies. In addition, study 3 explored the experiences of partners of SPKT recipients using qualitative interviews. Overall, the research provides insight into the wider impact of CKD, diabetes, and transplantation and will help to inform patients considering transplantation about what to expect.

Study 1: ATTOM detailed PROMs follow-up study. In the original ATTOM study patients were recruited as transplant recipients, wait-listed matched controls, or incident dialysis patients. Participants completed some PROMs at recruitment, others at three-months, and all PROMs again at 12-months follow-up during the original ATTOM study (Gibbons et al., 2021; Gibbons et al., 2020). A sub-sample of participants, who were recruited as matched controls on the transplant waiting list

and subsequently received a transplant, provided both pre- and post-transplant data. In the current research, a sample of the ATTOM detailed PROMs study participants were followed-up and completed PROMs approximately six/seven years after taking part in the original study. Analyses were carried out on a sub-sample of 39 kidney recipients who provided pre-transplant data at recruitment to the original ATTOM study and post-transplant data at the current follow-up. Significant improvements were found in renal treatment satisfaction and renal-dependent QoL, indicating that QoL was less negatively impacted by the renal condition post-transplant. These participants had had their transplants for approximately 55 months (ranging from 17 to 92 months). There were too few SPKT recipients with pre-transplant data to assess pre- to post transplant outcomes. In the main sample of participants who were recruited to the ATTOM study post-transplant, SPKT recipients' outcomes remained stable across the three post-transplant time points. Only health status was found to have improved significantly from recruitment shortly after transplantation to 12-months post-transplant after correcting for multiple testing. In the sample of kidney-only transplant recipients, significant improvements were identified from recruitment/three-months data collection to 12-month follow-up in renal-dependent QoL (RDQoL AWI), health status, and health utilities. Scores on these PROs, as well as renal treatment satisfaction, remained stable from 12-months to the six/seven-year follow-up and were significantly better than at recruitment/three-months post-transplant. Lastly, no significant differences were identified between LDKT and DDKT recipients on any of the PROMs at the current follow-up. These participants had had their transplants for approximately 68 months (ranging from 14.5 to 95 months). However, in analyses of the sub-sample of participants with pre- and post-transplant data there was a trend towards LDKT recipients having reported better renal treatment satisfaction when controlling for pre-transplant scores. Overall, the results suggest that PROs remained stable from 12-months to six/seven-years post-transplant. SPK and kidney-only transplant recipients were still negatively impacted by their CKD (and diabetes) several years post-transplant. LDKT recipients do not appear to report significantly better outcomes than DDKT recipients.

Study 2: Simultaneous pancreas and kidney transplantation: A longitudinal study of patient-reported outcomes. PROMs data were collected from patients registered on the waiting list for an SPKT at three transplant units in the UK and participants were followed up longitudinally. Eleven participants were followed up approximately 12-months post-SPKT and nine were followed up 12-

months post-recruitment whilst still awaiting an SPKT. SPKT recipients reported significantly improved generic QoL, perceived health status, well-being, and renal and diabetes treatment satisfaction from pre- to post-transplantation. Diabetes-dependent QoL, but not renal-dependent QoL, improved significantly from pre- to post-SPKT. The results indicate that although SPKT recipients were still negatively impacted by having had diabetes and a renal condition, they were less impacted by having had diabetes post-SPKT. The illness perceptions data suggests that participants had reappraised their condition from pre- to post-SPKT. After transplantation participants felt that the renal condition had fewer consequences and symptoms (identity), and participants were less concerned about their renal condition. Participants also felt they had more personal and treatment control over their renal condition post-SPKT. Outcomes remained stable over time for wait-listed participants, although there was a trend towards a decline in renal treatment satisfaction. Comparisons between wait-listed participants and SPKT recipients indicated they were not significantly different at follow-up on generic QoL, renal- and diabetes-dependent QoL, health status, utilities, and well-being. At follow-up SPKT recipients did, however, report significantly better renal and diabetes treatment satisfaction on both the status and change versions compared to participants who remained wait-listed. Due to the small sample, the study may not have detected other potential differences between the two groups. Furthermore, a disproportionate number of SPKT recipients completed follow-up PROMs during the COVID-19 pandemic. Despite this, the pre- to post-transplant analyses suggest that SPK transplantation is beneficial for recipients and resulted in improved outcomes and more positive illness perceptions. Scores on the individualised condition-specific measures of QoL suggest that patients were still negatively impacted by diabetes and CKD post-transplant.

Experiences of patients awaiting simultaneous pancreas and kidney transplantation: Qualitative findings. The experiences of patients with CKD and diabetes who were wait-listed for an SPKT were explored in qualitative semi-structured telephone interviews. Six participants on the transplant waiting list were interviewed about their experiences and responses to the individualised measures of condition-specific QoL. Six participants interviewed approximately 12-months post-SPKT also discussed their pre-transplant experiences. Diabetes was often considered a struggle and invasive, with some believing that their poor diabetes management as an adolescent or young adult had contributed to their CKD and subsequent need for a transplant. Several participants described struggling to

achieve and maintain control of their blood glucose levels and anxiety about hypoglycaemia. The need to think constantly about diabetes management was sometimes invasive. Some felt that their diabetes posed restrictions that had a negative impact on their QoL. However, when patients became unwell with CKD the combination of diabetes, CKD, and their treatments became more restrictive to participants' lives, and it was sometimes difficult for participants to separate the impact of the two conditions. In particular, fatigue, hypoglycaemia, and dialysis restricted various aspects of participants' lives. Participants indicated that they were (or had been) uncertain about their future, whether/when they would receive a transplant, and what impact transplantation would have. Some participants who were settled in their routine and/or still felt quite well were apprehensive about whether transplantation might have negative consequences. Some indicated that practical and emotional support from family, friends, and other patients had been beneficial to cope with the conditions and their treatment. The study provides insight into patients' experiences of awaiting SPK transplantation in the UK and the impact of insulin-treated diabetes and CKD on QoL.

Quality of life after kidney and simultaneous pancreas and kidney transplantation: Qualitative findings. Qualitative interviews were carried out with kidney and SPK transplant recipients recruited from the ATTOM follow-up study and the longitudinal SPKT study (studies 1 and 2). Participants' post-transplant experiences were explored to find out how QoL was impacted by CKD, diabetes, and transplantation. Participants' QoL improved post-transplant through the enhanced freedom that they experienced, which allowed them to do and enjoy more in life. This freedom was gained through improved health and energy levels and because participants no longer needed to carry out frequent dialysis treatment or diabetes management. Various aspects of life improved post-transplant. SPKT recipients especially gained more dietary freedom and were no longer worried about hypoglycaemia. However, it was "not all rosy" as most participants were still negatively impacted in some way by their CKD and diabetes. Changes in appearance due to the various treatments over the years were accepted by some, whilst for others it had impacted their self-confidence. Participants also continued to experience health issues, and some still felt restricted in certain ways. Some participants were negatively impacted by uncertainty for their future and worry about graft longevity. Several participants who had only had their SPKT for approximately 12 months were still adjusting to life post-transplant and felt they had not experienced the full benefits of their transplant due to restrictions relating to the

COVID-19 pandemic. Support from family, friends, other patients, and healthcare professionals was important to transplant recipients as they navigated recovery, periods of poor health, and sometimes reduced physical ability. Some participants described experiencing issues with continuity of care. Overall, the qualitative findings complimented the quantitative results as participants experienced improvements in QoL and treatment satisfaction from pre- to post-transplantation but were still negatively impacted in various ways, even several years later.

Study 3: Simultaneous pancreas and kidney transplantation: A qualitative study of partners' experiences. Eight partners of SPKT recipients who took part in study 1 or 2 were interviewed to explore their experiences and the impact of SPK transplantation. Partners supported the patient in various ways and sometimes took on additional responsibilities, especially prior to and initially after transplantation. Partners often experienced pervasive worry prior to the patients' transplant, particularly about hypoglycaemia and their partner's declining health. Specifically, some partners were concerned that the patient would become unwell when they were not around to assist them and avoided leaving them on their own for extended periods or worried about them when they did. Partners prioritised the patient over their own health and well-being at times and focused on being strong for the patient. Utilisation of other sources of support was helpful, including emotional support and having friends or family check on the patient when they couldn't. After transplantation and an initial period of recovery, which was often particularly stressful, partners experienced a great sense of relief. Some indicated that they could refocus on their own health and well-being post-SPKT and spent more time on activities that they enjoyed. Partners interviewed during the COVID-19 pandemic reported that whilst they had not yet experienced the full benefits of the transplant, such as being able to go abroad on holiday again, they had renewed hope that they would be able to do more in future. The study highlights the impact of CKD and diabetes on patients' families and the wider benefit of transplantation, not just for the patient. The pancreas transplant, in addition to the kidney, relieved partners of their pervasive worry about hypoglycaemic events and the development of other diabetes complications. Partners may benefit from being encouraged to maintain their own health and well-being while waiting for the transplant. Additional information and support on how to prevent hypoglycaemic events could help to reduce worry; for example, patients could be encouraged to use technology, such as CGMs, to help manage glucose levels with support from their partner. Some partners may also benefit from receiving more information on what to expect in the

period directly after transplantation. Partners could be signposted to additional sources of support, such as relevant charitable organisations.

Strengths of the Research and Implications for Practice/Policy

Benefit of mixed methods research. The current research highlights the importance of a mixed methods approach to examining complex issues such as transplantation. The use of a mixed methods design was beneficial for the current research as statistical analyses of PROMs data provided a more generalisable assessment of the impact of transplantation and long-term outcomes, whilst the qualitative interviews allowed for more in-depth investigation of patients' experiences and improved understanding of the responses given to the QoL measures. The overall research findings were strengthened as the quantitative and qualitative results were generally in agreement. They both showed that transplantation led to improvements in QoL, but QoL was often still negatively impacted in various ways. Without the qualitative interviews the impact of the COVID-19 pandemic on the PROs would have been speculative and certain findings would have been missed, such as problems with continuity of care. Whilst the RSSQ used in the quantitative research asks about participants' satisfaction with various aspects of the renal service associated with continuity of care, it does not ask about continuity between renal specialists and healthcare providers that patients see in other locations, such as in general practice.

The impact of transplantation on PROs, including QoL. It is often assumed that transplantation will improve patients' health and QoL. Much of the previous research into PROs of CKD and kidney transplantation have used measures which are more accurately described as measures of health status or functioning rather than QoL. A strength of the current research is that individualised measures of condition-specific QoL were used, as well as other PROMs of treatment satisfaction, health status, and well-being, so that a variety of outcomes could be assessed. The original ATTOM study found kidney-only and SPK transplant recipients improved across several PROs, including renal-dependent QoL and treatment satisfaction, from pre- to approximately 12-months post-transplant (Gibbons et al., 2021; Gibbons et al., 2020). Similarly, in the ATTOM follow-up (study 1), a sub-sample of kidney transplant recipients with pre- and post-transplant data were found to report significantly improved renal treatment satisfaction and renal-dependent QoL, suggesting that patients are less impacted by CKD post-

transplant. In study 2, significant improvements were found in diabetes-dependent QoL, generic QoL, well-being, and treatment satisfaction from pre- to post-SPKT.

Both the current research and Gibbons et al. (2020) found that EQ-5D-5L health utility scores did not significantly improve from pre- to post-SPKT. Similarly, in analyses of DDKT recipients in the original ATTOM study and kidney-only recipients in the current ATTOM follow-up, utility scores did not improve significantly from pre- to post-transplant. This suggests that the EQ-5D-5L utilities may not be sensitive to change after transplantation and should not be relied upon alone in the assessment of SPK or kidney transplantation. Currently NICE recommend that the EQ-5D-3L is used to assess treatments whilst further work is carried out on the EQ-5D-5L value set. The EQ-5D-5L was used in the current research as this is what was used in the original ATTOM study. Previous research has questioned the content validity of the EQ-5D for patients with diabetes, as patients have reported that the EQ-5D omits important elements such as dietary restrictions and the impact of diabetes on social functioning and relationships (Matza et al., 2015), aspects of life which are included in the ADDQoL. This could help to explain why the utility scores did not show significant improvements after SPK transplantation. As previously discussed, the EQ-5D utility scores are calculated by converting participants' responses into scores acquired through utility tasks carried out with a sample of the general population. This means that scores reflect the general population's perceptions of health states rather than patients' perceptions. Furthermore, as a generic measure that asks about 'your health today', it is difficult to know the extent to which scores reflect the impact of CKD and/or diabetes specifically or the impact of other unrelated comorbidities and acute illness. This further highlights the benefit of using condition specific individualised measures of QoL, such as the ADDQoL and RDQoL.

Due to findings from the qualitative interviews 12-months post-transplant during the original ATTOM study, it was anticipated that transplant recipients might experience further improvements in QoL and other PROs with a longer follow-up. However, study 1 indicated that SPK and kidney-only transplant recipients' PROs remained stable between the 12-month follow up and the current six/seven-year follow up. Whilst PROs did not improve after 12 months post-transplant, it is encouraging that scores also did not worsen significantly. Furthermore, treatment satisfaction remained high across the three time points. In particular, diabetes treatment satisfaction reached its maximum possible score on average by 12-months post-SPKT and remained stable six/seven years later. Scores on the measures of

condition-specific QoL indicated that SPK and kidney transplant recipients were often still negatively impacted by having had CKD and diabetes several years after transplantation.

Transplantation is a treatment and not a cure. This combination of initial improvements and long-term stability in outcomes can be explained by the qualitative findings. The interviews showed that participants had gained greater freedom post-transplant to do and enjoy more in life, which had improved their QoL. This freedom was gained through having more energy and no longer needing to attend to demanding CKD and diabetes treatment regimens. However, it is important that transplantation is not seen as a cure as patients still experienced continued negative impacts. Participants explained that they still experienced continued and new health issues, and this sometimes restricted their lives and reduced their physical ability to do certain activities. Some felt uncertain about their future and how long their transplant would last, and a few struggled with changes to their appearance as a result of their conditions and treatment. These issues often impacted various aspects of participants' QoL. It should be noted that some participants had few problems and felt the negative impact on their QoL was minor. However, possible medication side effects and other limitations of transplantation should be communicated to all patients so that they have realistic expectations of transplantation.

Participants interviewed approximately 12-months post-SPKT reported some similar issues to those several years post-transplant although they had not yet been impacted by long-term use of immunosuppressant medications. Those interviewed during restrictions of the COVID-19 pandemic indicated this had prevented them from experiencing the full benefits of the transplant and had impacted their responses on the PROMs. Furthermore, several participants had received their transplant before ever starting on dialysis, therefore there may not have been as great an impact of the transplant on renal-dependent QoL. This could help to explain why renal-dependent QoL did not significantly improve for recent SPKT recipients in study 2. In contrast, significant improvements in diabetes-dependent QoL were found despite the pandemic restrictions because participants no longer needed to manage diabetes or the threat of hypoglycaemia and had gained greater dietary freedom. As previously discussed, dietary freedom has been highlighted as important for QoL and is often greatly impacted by diabetes (DAFNE Study Group, 2002; Wee et al., 2006). Whilst some participants in the current research reported

checking their blood glucose levels post-transplant, this was generally carried out infrequently when the individual felt the need for reassurance that their pancreas transplant was still working. SPKT recipients also reported being careful with their diet and opted for healthy choices out of preference or a desire to avoid weight gain, but most did report enjoying foods that they would have avoided prior to transplantation. In contrast, SPKT recipients in the original ATTOM detailed PROMs study did not report a significant improvement in diabetes-dependent QoL, and still restricted their diet and continued to monitor their blood glucose levels 12-months post-SPKT (Gibbons et al., 2020). It is possible that since results of the original ATTOM study were reported back to clinicians at the transplant centres that patients are no longer encouraged to bring blood glucose readings to clinic. It is important that new diabetes management and dietary freedoms are communicated via routine care to patients so that they do not continue to live with unnecessary restrictions or burden.

Implications for partners. The research also found that SPKT recipients' partners reported relief post-transplant. One of the main reasons for this feeling of relief was that partners no longer worried about hypoglycaemia or the development of other long-term diabetes complications. This meant that patients and their partners were able to enjoy doing more together, such as going on holidays abroad and taking part in leisure activities. Some partners also felt more able to take part in individual activities without worrying about their partner. Fears of frightening complications, such as visual impairment due to diabetic retinopathy, were also eased. SPK transplantation therefore benefited patients and their families, which has not often been considered in the literature. This provides additional evidence for the importance of offering SPKTs to patients with insulin-treated diabetes and CKD.

Implications for choosing a LDKT or DDKT. One of the main benefits of LDKTs is that transplants can be planned before the patient has started dialysis. However, there is evidence to suggest that patients who receive an LDKT (Wu et al., 2017) or a pre-emptive transplant are already advantaged, such as having fewer comorbidities (Abramowicz et al., 2016). Previous findings and the results of the current research suggest that LDKT and DDKT recipients are often comparable across PROs, especially several years post-transplant and when possibly confounding variables are controlled for (de Groot et al., 2013; Griva et al., 2002; Lai et al., 2020; Zimmermann et al., 2016). The finding that the two transplant types are comparable needs to be communicated to individuals when they are making

decisions about which type of transplant(s) they are willing to consider. It should be noted that the current research does not take into account patients who died or lost graft function as only individuals with working transplants were included in comparison analyses. In the UK, the five-year unadjusted graft and patient survival rate is around 92% and 95% respectively for LDKTs, whilst it is 87% and 88% for DBD kidney transplants, and 86% for both patient and graft survival for DCD kidney transplants (NHSBT, 2020a). Therefore, it is possible that there may have been small differences in early graft loss that were not taken into account and findings do not reflect the experiences of individuals who experienced graft loss. Despite this, the findings suggest that DDKTs should not be seen as an inferior choice for those who cannot or choose not to consider an LDKT.

The experiences of living donors and the impact of kidney donation on those donors was beyond the scope of the current thesis. Previous research indicates that kidney donation can be a positive experience and donors have a similar or longer life expectancy compared to general population samples (Reese et al., 2015). However, there are often methodological concerns, such as short follow-up and participant attrition. It has also been argued that comparisons to general population samples are inappropriate as donors are often healthier than the general population since they go through a rigorous health assessment prior to donation (Ommen et al., 2006). As there is evidence to suggest that some donors regret their decision to donate (Holscher et al., 2018; Maple et al., 2017; Wirken et al., 2019) and little is currently known about the long-term impact of donation on health and well-being, especially of younger donors <30 years old (Reese et al., 2015), pressure should not be put on patients or their families to identify a living donor. Not all patients will be able to identify a living donor, or they may feel that living-donor transplantation is not the right option for them for various reasons. Patients and potential donors must continue to be fully informed about the potential risks of donation and care needs to be taken to avoid overemphasising the possible benefits of LDKTs compared with DDKTs. Future research that investigates the long-term outcomes of donation would contribute usefully to the debate about the pros and cons of LDKT versus DDKT. Donors might be followed longitudinally from pre- to several years post-donation with donors being compared with matched controls rather than general population samples.

Importance of support for patients and their partners. In the ATTOM follow-up (study 1) kidney recipients with a partner reported significantly better

generic QoL and well-being than those without when included as a covariate in the comparisons of DDKT and LDKT recipients. Similarly, previous research has indicated that individuals with CKD who are married are less likely to experience depressive symptoms (Szeifert et al., 2010; Wang et al., 2021). From the qualitative interviews it was found that support from others, including family, friends, other patients, and healthcare professionals was important to patients throughout the transplantation process. In interviews with partners, it was found that they had sometimes prioritised the patient over their own well-being, but some benefited from support from friends and other family members when their partner was unwell and/or newly transplanted, enabling them to continue with their own activities. Although participants across each of the qualitative studies were asked about their social support, it was particularly evident that support was important where it was insufficient. Romantic partners may be a main source of support due to their proximity and involvement in one another's lives; however, not all partners will provide sufficient support or the right type of support, and satisfaction with the relationship may also influence outcomes (S. D. Cohen et al., 2007; Frazier, Tix, & Barnett, 2003). It should not be assumed that anyone has adequate support simply because they have a partner. Chronic health conditions, such as diabetes and CKD, can also impact on patients' relationships, in particular individuals who become unwell at a young age may find it difficult to develop and maintain new relationships (E. Coyne et al., 2019; Roberti et al., 2018; Vanstone et al., 2015). Support received from other family members or friends is therefore also important and individuals without a partner may receive sufficient support from them. Patients and their partners need to be encouraged to use other sources of support (such as other family and friends) or formal support from a psychologist if needed, so that both are sufficiently supported and have time to focus on their own well-being.

Furthermore, both patients and partners highlighted the benefit of gaining insight from other patients, especially about transplantation, and this also helped to normalise patients' experiences. However, for some, peer support had not been readily available and they either lacked this support or had to seek support for themselves. The findings are in line with previous research that identified peer-support as helpful for gaining insight into the possible future progression of CKD and tips on coping with treatment. Peer support can help normalise patients' and carers' experiences and reduce feelings of isolation (Hughes et al., 2009; F. Taylor et al., 2016). Not all patients or their partners will want to access formal or informal peer support, or they may want to access support at different times through-out the

CKD trajectory. Taylor et al. (2016) found that some patients and carers dismissed the idea of formal peer support due to unfamiliarity with the term and others indicated that they would be uncomfortable requesting peer support because they did not want to appear 'needy' or critical of the healthcare professionals. The current research indicates that it would be beneficial for healthcare providers to encourage informal peer support or offer opportunities for formal peer support by connecting patients and their partners with others. The benefits of peer support could be highlighted, and patients made aware that they could also provide support back to others if they wish. In particular, patients awaiting or recently in receipt of an SPKT may benefit from contact with SPKT recipients specifically, rather than kidney-only recipients.

Healthcare support and service satisfaction. The support and care that patients receive from healthcare professionals is also important. In the ATTOM follow-up, kidney transplant recipients reported high levels of satisfaction for several items on the RSSQ including 'how you are treated as a person by the staff' and 'the extent to which staff are caring and supportive'. SPKT recipients in the ATTOM follow-up and the longitudinal SPKT study also reported high levels of satisfaction with staff support, in particular 'discussing with staff any problems that you may have'. Despite these positive findings, in both studies 'social worker advice and support' and 'psychological advice and support' were within the five lowest rated items (indicating least satisfaction) on the RSSQ for kidney-only and SPK transplant recipients. A recent study conducted in 2017 mapped the psychosocial staff members employed at each of the 84 renal units in the UK and found that none of the units reached recommended benchmarks of having one whole-time equivalent social worker per 100 RRT patients. Only five units employed one psychologist or counsellor per 500 RRT patients (Seekles, Ormandy, & Coyne, 2019). The variations in provision of psychosocial support may be partly due to the lack of a clear set of guidelines (Seekles et al., 2019). Furthermore, patients attending dialysis units with greater availability of psychosocial staff were significantly less likely to report distress than those at other units (Seekles, Ormandy, & Kamerāde, 2020). In qualitative research, UK-based renal staff reported that although they believed distress was high among patients with CKD and kidney failure, there was no official process to identify distressed patients, and renal staff did not always know when to refer patients on to psychological services (Combes et al., 2019). Several renal staff members also reported feeling uncomfortable dealing with patients' emotional issues (Combes et al., 2019).

The current thesis and previous research described here highlight a need for wider availability of social workers and psychologists and clearer processes and ease of access to social and psychological support. Healthcare professionals could sign-post patients to sources of formal support where available and remind them of its availability at various stages of the illness as part of routine care, rather than in response to specific requests. Renal nurses could also be given additional training to identify patients in distress and to provide brief psychological support to patients, although it is acknowledged that it may be difficult for nurses to find time to support patients further. As several SPKT recipients' partners reported persistent worry prior to the transplant, it is important that information is provided to patients' families, signposting them to available resources, such as speaking to their GP or a relevant charity helpline. A limitation of the current qualitative research was that, whilst support was discussed with patients, unmet support needs were not explored in depth. Future research with transplant recipients and patients awaiting transplantation might usefully identify additional specific unmet support needs.

Some participants interviewed post-transplant described issues with continuity of care, which was an additional stressor at times. For example, some participants described situations when they had not been readily prescribed antibiotics to treat infections, had difficulties finding out if they could take certain medications, or had been prescribed medications in contraindication of their anti-rejection medications. This sometimes resulted in hospitalisation or prolonged sickness. In particular, mixed reports were given about contact with GPs, with some feeling that their GP did not understand their condition or that there was poor communication between their various healthcare providers. Some participants disliked being treated by different and unfamiliar clinicians and the need to repeat their medical history on multiple occasions to different people. Not all reports were negative; participants also recounted positive relationships that they had built with their renal care providers who they felt supported by. Continuity of care is important as it is associated with patient satisfaction, decreased healthcare use (Van Walraven et al., 2010), and even reduced mortality (Gray et al., 2018). As outlined in Chapter 6, three types of continuity of care have been identified: relational continuity, information continuity, and management continuity (Haggerty et al., 2003). Few studies have examined continuity of care in CKD patients in the UK. Brand and Pollock (2018) found that relational continuity was particularly important at times of change or crisis but otherwise patients' priority was to spend as little time at the

renal unit as possible. Patients valued the knowledge of renal clinicians over GPs and felt that information continuity could be achieved without seeing the same clinicians through effective patient notes and written communication between GPs and the renal unit (Brand & Pollock, 2018). Relational continuity may be less important when patients trust the record-keeping of their patient notes, but issues with information and management continuity can lead to confusion, dissatisfaction, and can be detrimental to the health of patients, particularly those with comorbidities (Cowie, Morgan, White, & Gulliford, 2009). The findings of the current research highlight the need for better information provision on medications that can and cannot be taken with anti-rejection medications, and improved sharing of information especially between GPs and renal/transplant teams. This could help to improve patients' confidence and sense of continuity of care and avoid unnecessary stress for patients.

Adherence to anti-rejection medications. Previous research suggests that around 36-55% of kidney transplant recipients have poor adherence to anti-rejection medications (Gokoel et al., 2020). In the current research, self-reported adherence to anti-rejection medications on the single item measure of the RMQ was high across both studies 1 and 2. In general, participants also indicated on the RMQ that they did not find it difficult/inconvenient to take their anti-rejection medications as recommended. In the qualitative interviews, participants said that they took their anti-rejection medications, often despite side-effects. However, some participants found their medication regimen inconvenient when they wanted to have a day or evening out and, whilst none made the decision not to take their medication, a few reported that they occasionally forgot. The findings are in line with the necessity-concerns framework (Horne & Weinman, 1999) as interview participants appeared to believe that the necessity of taking their anti-rejection medications to preserve the graft outweighed their concerns about side-effects or inconvenience. Previous research has shown that non-adherence to anti-rejection medications in kidney recipients is associated with greater concerns and weaker beliefs about the necessity of the medication (Bünemann et al., 2020; Chisholm-Burns et al., 2012; Weng, Yang, Huang, Chiang, & Tsai, 2017). The findings indicate that medication beliefs could usefully be targeted by healthcare professionals to improve adherence by addressing patients' concerns and reinforcing the importance of the medications for graft longevity. As forgetfulness can also lead to non-adherence (Chisholm-Burns et al., 2012; Cossart, Staatz, Campbell, Isbel, & Cottrell, 2019), techniques to combat forgetting also need to be recommended to patients. Adherence is complex

and does not just involve whether patients take their medications or not, but also whether they take them at the right times and under the right conditions. As adherence was not a main focus of the research other assessments of adherence, such as electronic monitoring or pill counts, were not used and adherence was not discussed in-depth.

Limitations of the Research and Implications for Future Research

Impact of the COVID-19 pandemic. The fact that some participants in studies 2 and 3 completed follow-up measures and interviews during the COVID-19 pandemic means that their experiences and outcomes may not accurately reflect the impact of transplantation during non-pandemic times. Furthermore, more of the SPKT recipients than the wait-listed participants in study 2 completed measures during the pandemic, which may also partly explain the lack of difference between the two groups at follow-up. As found in mixed methods research with Lupus patients in the UK, experiences during the pandemic will have had varied effects on patients' lives and their well-being (Sloan et al., 2021). It is likely that many different factors will have influenced the impact of the pandemic, with evidence suggesting that those of lower socioeconomic status, with pre-existing mental and physical health issues, and those from ethnic minority groups were more likely to experience a decline in mental health in the UK (Pierce et al., 2021). It is possible that SPKT recipients' PROMs scores and experiences post-transplant would have been more positive if there had not been a pandemic shortly after they received their transplants. The ATTOM follow-up study was not impacted by the pandemic, because data collection had already been completed. Further research will be needed to establish the long-term impact of the pandemic on very vulnerable individuals, such as transplant recipients, so that they can be provided with appropriate advice and support.

Sample size. The main limitation of the current research is the small sample sizes in the quantitative studies. Brysbaert (2019) recommends that at least 100 participants are needed in each group for between-group comparisons and 50 for within-group analyses. As the current research is under-powered, this may have resulted in type 2 errors. In addition, more complex analyses were not carried out on data from study 2. Further prospective longitudinal research with larger samples of SPKT recipients would be beneficial to investigate variables associated with QoL

post-transplant. This could help in tailoring information on transplantation for particular patients and could also highlight which patients might need additional support or identify changeable variables that could be targeted in interventions. As transplantation techniques and post-transplant immunosuppression treatments improve, further longitudinal research on PROs will be useful to help patients awaiting transplantation know what to expect post-transplant. As treatment improves, further research comparing those receiving DDKTs and LDKTs on both clinical outcomes and PROs will help to identify whether differences emerge, and to provide the most up-to-date information to patients considering their treatment options. In addition, research with longer follow-up times will help patients to know what to expect in the long-term.

Small sample of patients from ethnic minority groups. A further limitation of the current research is that only a small proportion of the participants were from ethnic minority groups and therefore the findings may not represent all patients' experiences of kidney and SPK transplantation in the UK. The original ATTOM detailed PROMs study only included patients who had English as a first language. Similarly, staff at the three sites involved in study 2 were asked to only recruit patients who were fluent in English. The main reason for this was because not all of the PROMs included in the research were available or validated for use in other languages and the qualitative interviews could only be conducted in English. This most likely excluded some patients from being able to take part. Despite the small sample size in the ATTOM follow-up, ethnicity was a significant covariate in comparisons of LDKT and DDKT recipients, indicating that ethnic minority participants reported significantly worse renal-dependent QoL compared to white participants. However, possible differences in experiences and QoL of ethnic minority patients could not be fully explored in the qualitative element of the research due to the nature of the sample.

In the UK, a disproportionate percentage (~30%) of patients on the kidney transplant waiting list are from ethnic minority groups (NHSBT, 2012, 2020b) and in the ATTOM programme it was found that Asian and Black patients were less likely to be pre-emptively listed for a transplant (Pruthi et al., 2020). People from ethnic minority groups spend longer on average on the kidney transplant waiting list compared to white patients, although waiting times for SPKTs appear to be more similar for each ethnic group (NHSBT, 2020b). These factors could influence the experiences of ethnic minority patients. In previous qualitative research, UK South

Asian patients reported that dialysis was restrictive and sometimes conflicted with cultural needs, such as attending prayers (S. Sharma et al., 2019). Participants also reported difficulties in interacting with healthcare professionals, often due to a language barrier (S. Sharma et al., 2019; Wilkinson et al., 2012). Indo-Asian patients on PD or with a kidney transplant have reported significantly worse physical, mental, and kidney disease-specific outcomes on the KDQoL-SF compared to white patients, although there were no significant differences by ethnicity for patients on HD (Bakewell, Higgins, & Edmunds, 2001). As there is still limited research which has investigated the experiences and PROs of ethnic minority patients with CKD or a kidney/SPK transplant in the UK, this is an area of research that needs further attention so that efforts can be made to improve patient care and address disparities (Wilkinson, Brettle, Waqar, & Randhawa, 2019).

Inclusion of PROMs in patient care. One way to address the issue of small sample sizes could be through routine collection of PROMs data as part of usual patient care. Routine collection of PROMs available in multiple languages would remove one of the obstacles currently preventing inclusion of more members of ethnic minority groups in research. This would allow for the collective assessment of CKD and diabetes treatments and could also be used to improve treatment on an individual patient level. PROMs such as the RSSQ could be used to identify strengths and weaknesses in specific renal units and highlight issues such as a need for increased social worker and psychologist input, further staff training, or better referral systems to other services. PROMs can empower patients, as they provide an opportunity for them to reflect on their condition and treatment, and aid patient-centred care and communication between patients and healthcare professionals, by raising healthcare professionals' awareness of certain issues that their patients face (Greenhalgh et al., 2018). Patients, especially transplant recipients, may not want to complain or discuss issues that they are having, such as medication side-effects, because they do not want to appear ungrateful (J. Jones et al., 2020; Orr et al., 2007; Schipper et al., 2014). If patients are asked directly or invited to complete PROMs, they may feel more able to report issues. For example, some patients who experience issues with changes in appearance or sexual dysfunction may not feel able to initiate discussion on these topics with healthcare professionals due to embarrassment. Such issues could be raised through the use of PROMs, such as the RDQoL, that ask specific questions about these aspects of life. This could enable clinicians to make appropriate referrals, recommendations, or adjustments to patients' treatments. In this way individualised measures would be

particularly useful as they would identify those patients who are bothered by specific issues or value the aspect of life that is impacted by their condition. Electronic collection of PROMs (ePROMs) data could be especially useful and would limit the additional work involved in routine data collection. Patients could be asked to complete measures at home or in the waiting room at the renal unit and ePROMs results could be instantly available to clinicians to discuss with patients in their appointments. PROMs completed between appointments could alert clinicians to unanticipated issues or decline in health and well-being and could even be used as an indicator for the frequency of appointments needed where appropriate (Aiyegbusi et al., 2019).

Whilst there is support for the idea of utilising PROMs in routine care of CKD patients, with ePROMs projects underway (Aiyegbusi et al., 2019; Kyte et al., 2020) and plans to possibly incorporate PROMs data in annual reports of transplantation in the UK, it is currently unclear how successful PROMs interventions are at improving patient outcomes especially as this can also depend on methodological factors (Boyce & Browne, 2013; Greenhalgh, Long, & Flynn, 2005; Valderas et al., 2008). An evaluation of a UK-based programme to assess PROs after surgical treatment for groin hernias, varicose veins, and hip and knee replacement found that it had not resulted in improved services (Varagunam, Hutchings, Neuburger, & Black, 2014). The measures used in this trial included the EQ-5D, Oxford Hip Score (Dawson, Fitzpatrick R, Carr A, & Murray, 1996), Oxford Knee Score (Dawson, Fitzpatrick, Murray, & Carr, 1998), and the Aberdeen Varicose Vein Questionnaire (Garratt et al., 1993), which all predominantly assess health status and/or physical functioning. It was concluded that the main reason for the lack of impact was that feedback of the PROMs results to clinicians and patients was insufficient and difficult to interpret (Varagunam et al., 2014). It has also been suggested that care providers were not convinced of the usefulness of the PROMs, so had not used the data to make changes (Kyte et al., 2016).

Lessons need to be learned from previous research and attempts to integrate PROMs into routine care to ensure that effective systems are put in place to collect and use PROMs data in ways that are cost-effective and beneficial to care. The intended use of the PROMs data will need to be clearly stated and understood by those involved, results will need to be effectively presented to aid usage, and healthcare providers may need to be trained and convinced of the usefulness of PROMs to ensure they are used as intended (Aiyegbusi, Kyte, Cockwell, Anderson,

& Calvert, 2017). Although there are some existing guidelines (International Society for Quality of Life Research et al., 2015), further research will be needed to address which PROMs will be most useful, when and how frequently data need to be collected, and how the data can be incorporated into research and used to improve patient care (Anderson, Calvert, Cockwell, Dutton, & Kyte, 2019). As no single PROM will cover all outcomes of interest to researchers and patients, it may be beneficial to incorporate multiple different measures (Aiyegbusi, Kyte, Cockwell, Marshall, et al., 2017), possibly at different times to ensure patients are not over-burdened. Ways of identifying whether the use of PROMs has achieved what was intended will also need to be established.

Illness perceptions. It was originally intended that in study 2, illness perceptions would be investigated in more depth in relation to the measures of QoL, well-being, and treatment satisfaction. However, due to the small sample size more complex analyses could not be carried out on the data. SPKT recipients reappraised their illness after transplantation and perceived that their renal condition had fewer consequences and symptoms (identity) and was less concerning post-transplant. SPKT recipients also felt they had more personal and treatment control over their renal condition, in-line with previous research with kidney-only recipients (Griva et al., 2012). The direction of the correlations both at baseline and after SPK transplantation in the current research are generally in line with previous research on direct relationships between illness perceptions and well-being across a variety of health conditions (Hagger et al., 2017; Hagger & Orbell, 2003). The correlations indicate that worse emotional representations, consequences, and identity perceptions were associated with poorer outcomes, whilst treatment control perceptions were associated with some better outcomes. As the correlational analyses were cross-sectional, causality cannot be inferred. Furthermore, because other factors were not controlled for in the analyses, it is not clear whether the associations between illness perceptions and the PROs are independent of other factors, such as disease severity. Research with larger samples of CKD patients and transplant recipients would help to clarify associations between illness perceptions with QoL and treatment satisfaction. This could help to identify whether illness perceptions could be targeted to help improve patient outcomes.

Despite the high levels of perceived control reported by SPKT recipients on the Brief IPQ in study 2, several kidney-only and SPK transplant recipients who took part in the interviews felt that they ultimately had limited control over whether their

transplant would eventually reject or fail in future. Elsewhere, almost half of a sample of transplant recipients reported high levels of 'lack of control' (Nilsson et al., 2011). The qualitative data indicated that participants tried to take care of their health and transplant, but some were not as fit as they would have liked to be. Some transplant recipients also reported weight gain after transplantation, which is a commonly reported issue (Aksoy, 2016) that can have negative health implications for graft and patient survival (Ducloux, Kazory, Simula-Faivre, & Chalopin, 2005; Hoogeveen et al., 2011). The current research did not measure other health behaviours; therefore, this could not be investigated quantitatively. Future research could investigate relationships between renal patients' illness perceptions, such as perceptions of control over the renal condition and coherence/understanding, and adherence to health behaviours such as regular physical activity. If illness perceptions are associated with health behaviours in transplant recipients, they could be targeted to help improve outcomes (Breland et al., 2020). Previous intervention research which targeted patient's maladaptive illness perceptions have reported encouraging results in relation to improving exercise (Broadbent et al., 2009; Keogh et al., 2011) and activity (Siemonsma et al., 2013). For example, an intervention for patients with poorly controlled type 2 diabetes challenged inaccurate and negative perceptions of diabetes and set out action plans to improve self-management (Keogh et al., 2011; Keogh et al., 2007). The intervention helped to improve patients' concern, perceptions of control, and their understanding of type 2 diabetes, including the link to a sedentary lifestyle. At six-months follow-up, self-reported adherence to dietary and exercise recommendations, as well as well-being, had improved (Keogh et al., 2011). If interventions targeting illness perceptions can help to improve well-being and health behaviours, they may also help to improve QoL.

Overall Summary and Conclusions

The thesis presents findings from mixed methods research involving a longitudinal follow-up of the ATTOM detailed PROMs study and a prospective longitudinal cohort observation study of patients awaiting SPK transplantation. The research adds to the literature by using several PROMs including individualised condition-specific measures of QoL. Furthermore, the quantitative results are supported by qualitative findings and provide information on the short- and long-term outcomes of transplantation. In order to understand the wider impact of diabetes, CKD, and

transplantation on patients' families, partners of SPKT recipients were interviewed about their personal experiences.

Results of the quantitative analyses should be interpreted with caution as, due to the small sample sizes, type 2 errors may have occurred. Despite this, in a sub-sample of kidney recipients from the ATTOM detailed PROMs follow-up study, significant improvements in renal treatment satisfaction and renal-dependent QoL were found from pre- to post-transplant. PROMs scores remained stable from 12-months to approximately six/seven-years post-transplantation for both kidney and SPK transplant recipients, with scores on the condition-specific QoL measures indicating that participants were still negatively impacted by CKD and diabetes several years post-transplant. No significant differences were found between DDKT and LDKT recipients on any of the PROMs at follow-up, although there was a trend indicating that LDKT recipients reported better treatment satisfaction when controlling for pre-transplant scores in a sub-sample of participants. In the longitudinal SPKT study, significant pre- to 12-months post-transplant improvements were found on measures of diabetes-dependent QoL, diabetes and renal treatment satisfaction, well-being, and health status. Health utilities measured by the EQ-5D-5L and the impact of the renal condition on QoL (RDQoL AWI scores) did not improve significantly.

Interviews about patients' experiences of diabetes, CKD, and wait-listing for an SPKT revealed that patients often found diabetes management a struggle and/or invasive, and the combination of diabetes and CKD symptoms and treatment was restrictive and negatively impacted QoL. Patients felt uncertain for their future but were hopeful for a successful transplant. Interviews on post-transplant experiences and QoL revealed that some participants' responses to questionnaires in study 2 had been impacted by restrictions imposed during the COVID-19 pandemic, possibly explaining why renal-dependent QoL scores did not improve significantly. Overall, kidney and SPK transplantation were found to reduce the impact of CKD and diabetes on QoL by providing recipients with the freedom to do more with more enjoyment. SPKT recipients gained more dietary freedom and no longer worried about or experienced hypoglycaemia. However, continued and new health issues resulting from CKD, diabetes, and the anti-rejection medications often continued to restrict participants in various ways, and some were negatively impacted by changes in their appearance. Partners of SPKT recipients were found to have lived with persistent worry prior to the transplant and some had prioritised the patient over

their own well-being. Transplantation led to a great sense of relief and partners were also able to do more, although some had not yet experienced the full benefits due to the restrictions of the COVID-19 pandemic. Social support and support from healthcare professionals can help patients and partners to cope better with chronic illness and this was particularly noticeable where individuals indicated they had insufficient support. This suggests that some patients and their partners may benefit from being signposted to and encouraged to use available sources of support.

Overall, the research findings suggest that kidney and SPK transplantation are beneficial for the QoL of patients and their families. Healthcare professionals need to ensure that patients contemplating having a transplant understand that transplantation is a treatment and not a cure. Potential recipients need to know how previous transplant recipients felt they were negatively impacted by transplantation and immunosuppressant treatment post-transplant, as well as the positive impact, so that they can make informed decisions about what type of transplant would be right for them. This would also help to create realistic expectations of transplantation, avoid disappointment post-transplant, and optimise outcomes such as treatment satisfaction and QoL. As transplantation techniques and immunosuppression treatment improve clinical outcomes, it will be important to continue to assess the impact of CKD treatments and transplantation on PROs. This might be best achieved through routine collection and assessment of PROMs as part of patients' care, which could also be useful for improving patients' care on a collective and individual level.

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Appendix A.

Table of Patient-Reported Outcome Measures

Table A1

Patient-Reported Outcome Measures

Measure	Type	N. items	Domains	Notes
15D Sintonen, (2001)	Generic	15	Breathing; mental function; speech (communication); vision; mobility; usual activities; vitality; hearing; eating; elimination; sleeping; distress; discomfort and symptoms; sexual activity; depression.	Each item has 5 response options. Utility scores can be calculated from 0 to 1 based on preference weighted scores from the general population.
36-item Short Form Health Survey (SF-36) Ware & Sherbourne, (1992)	Generic	36 12 6	Physical functioning; social functioning; role functioning; emotional functioning; bodily pain; mental health; vitality; general health.	The response options vary from 2 to 6 options across the measure. Scores can be calculated for each domain, or overall physical and mental component scores can be calculated. Shorter 12- and 6-item versions are available.
Audit of Diabetes-Dependent Quality of Life (ADDQoL) Bradley et al. (1999)	Individualised condition-specific	19	Each item assesses a different aspect of life and an overall score of diabetes-dependent QoL can be calculated.	Each item has two parts to assess the impact of diabetes on each aspect of life (5-point scale response) and the importance of each aspect of life (4-point scale response). Weighted impact

				scores can be calculated for each aspect of life and an overall average weighted impact score can be calculated which indicates the extent to which diabetes impacts on QoL.
Brief Illness Perceptions Questionnaire (Brief IPQ) Broadbent, Petrie, Main, & Weinman (2006)	Condition-specific	9	Identity; consequences; timeline; personal control/cure; treatment control/cure; emotional representations; illness coherence/ understanding; cause.	Each item is scored on a 10-point Likert scale and can be considered individually or an overall score can be calculated, which indicates how threatening the illness is perceived as. The final item asks the respondent to list in rank order the three most important causes of their illness.
Centre for Epidemiological Studies – Depression (CES-D) Radloff (1977)	Condition specific	20	Depression.	Each item has a 4-point response scale. An overall score can be calculated with higher scores indicating worse symptoms.
Diabetes Quality of Life measure (DQOL)	Condition-specific	46	Satisfaction; impact; diabetes worry; social/vocational worry.	Each item has a 5-point Likert scale response option. Scores can be

The DCCT Research Group (1988)				calculated for each domain as well as for an overall score.
Diabetes Treatment Satisfaction Questionnaire (DTSQ) Bradley (1994)	Condition-specific	8	Diabetes treatment satisfaction.	Each item has a 6-point Likert scale response option. A total score can be calculated from items 1, 4, 5, 6, 7, and 8. Items 2 and 3 are single item measures of unacceptably high and low blood glucose levels.
EuroQoL-5 Dimension (EQ-5D) Brooks & the EuroQoL Group (1996)	Generic Utility	5	Mobility; self-care; usual activities; pain/discomfort; anxiety/depression.	Respondents are asked to indicate a response that 'best describes your health today'. Available in 3-level or 5-level response versions. Utility scores can be calculated based on general population preference scores.
EuroQoL Visual Analogue Scale (EQ-VAS) Brooks & the EuroQoL Group (1996)	Generic	1	Health status.	Visual analogue scale of 'health today' from worst imaginable to best imaginable (0-100).
Gastrointestinal Quality of Life Index (GIQLI)	Condition-specific	36	Gastrointestinal symptoms; emotions; physical function;	Each item has a 5-point response scale. Scores can be calculated for each

Eypasch et al. (1995)			social function; medical treatment.	domain and an overall score can be calculated.
Hospital Anxiety and Depression Scale (HADS) Zigmond & Snaith, (1983)	Condition-specific	14	Anxiety and depression.	Each item has a 4-point response option. Scores can be calculated for anxiety and depression.
Revised IPQ (IPQ-R) Moss-Morris et al. (2002)	Condition-specific	71	Timeline acute/chronic; timeline cyclical; consequences; personal control; treatment control; emotional representations; illness coherence/ understanding; cause.	The measure can be adapted to assess illness perceptions of any illness. Respondents are first asked whether they experience common symptoms (identity). This is followed by items scored on a 5-point Likert scale to assess the remaining domains. Lastly respondents are asked to list in rank order what they believe are the three most important causes of their illness.
Kidney Disease Quality of Life Short Form (KDQOL-SF; also KDQOL-36)	Condition-specific	79 36	Symptoms and problems; effects of kidney disease; burden of kidney disease; work status; cognitive function; quality of social interaction; sexual	Each item has 5 response options. Scores can be calculated for each domain. A KDQOL-36 version is also available which includes KDQOL

Hays, Kallich, Mapes, Coons, & Carter (1994)			function; sleep; social support; dialysis staff encouragement; patient satisfaction. As well as the SF-36 generic domains.	items assessing symptoms and problems; effects of kidney disease; burden of kidney disease; and the SF-12 physical and mental items.
Problem Areas in Diabetes (PAID) Polonsky et al. (1995)	Condition-specific	20	Diabetes distress.	Each item has a 5-point Likert scale response option. An overall diabetes distress score can be calculated, higher scores indicate more distress related to diabetes.
Patient Health Questionnaire (PHQ-9; PHQ-2) Kroenke, Spitzer, & Williams (2002)	Condition-specific	9 2	Depression.	Each item has a 4-point response option. An overall depression score can be calculated. A version with only 2 items is available (PHQ-2).
Renal Dependent Quality of Life (RDQoL) Bradley (1997)	Individualised condition-specific	21	Each item assesses a different domain and an overall score of renal-dependent QoL can be calculated.	Each item has two parts to assess the impact of the renal condition on each aspect of life (5-point scale response) and the importance of each aspect of life (4-point scale response). Weighted impact scores can be calculated for each

				aspect of life and an overall average weighted impact score can be calculated which indicates the extent to which the renal condition impacts on QoL.
Renal Transplant Quality of Life (ReTransQOL) questionnaire Gentile et al. (2008)	Condition-specific	85 32	Physical health; mental health; medical care; fear of losing the graft; treatment.	Originally developed in French. Each item has a 5 or 6-point Likert scale response option. A shorter, 32 item version (RTQ V2) is also available. Scores can be calculated for each domain.
Renal Treatment Satisfaction Questionnaire (RTSQ) Barendse, Speight, & Bradley (2005)	Condition-specific	13	Renal treatment satisfaction.	Each item has a 6-point Likert scale response option. A total score can be calculated from the 13 items.
Schedule for the Evaluation of Individual Quality of Life (SEIQoL) McGee, O'Boyle, Hickey,	Individualised generic	5	Five domains or 'cues' that are most important to the QoL of the individual completing the measure.	The SEIQOL uses an interview-style method which asks the patient/ participant to identify five areas of their life which are most important to their QoL. These are then

O'Malley, & Joyce (1991)				rated on a VAS from 'as good as it could possibly be' to 'as bad as it could possibly be'. A task is then carried out to calculate weights for each domain or 'cue'. A global index can be calculated for analysis.
Transplant Effects Questionnaire (TxEQ) Ziegelmann et al. (2002)	Condition-specific	24	Worry about the transplant; guilt regarding the donor; disclosure; responsibility; and medication adherence.	Each item is scored on a 5-point Likert scale. Scores can be calculated for each domain.
Well-Being Questionnaire (W-BQ) Bradley & Lewis (1990)	Generic	16 12	Positive Well-Being, Negative Well-Being, Energy, Stress.	Each item has a 4-point Likert scale response. Scores can be calculated for each domain as well as an overall well-being score. There are various versions; the 12-item version includes Positive Well-Being, Negative Well-Being, and Energy subscales.
World Health Organisation Quality of Life measure (WHOQOL)	Generic	100 26	Physical health; psychological; social relationships; environment; independence; spirituality/religion.	Each item has a 5-point Likert scale response. Scores can be calculated for each domain. A shorter 26-item

WHOQOL Group (1994)	Also includes single item measures of QoL and health.	version is available called the WHOQOL-BREF, which includes items from the first four domains listed.

Appendix B.

Study 1 Renal Clinic Invitation Letter Template

To be addressed to patients from PIs in the standard format used by each hospital.

Dear _____,

You may remember that approximately 6 years ago you took part in some research called ‘Access to Transplantation and Transplant Outcome Measures’ (ATTOM). You also completed some questionnaires on quality of life and treatment satisfaction as part of the detailed patient-reported outcome measures (PROMs) sub-study carried out by researchers at Royal Holloway, University of London. We would like to thank you for taking part in this research programme. It ended in 2014 and from the data collected we found that people who had a transplant did have better quality of life one year after transplantation compared with before the transplant. People who were still on dialysis and/or were waiting for a transplant had worse health, but the same quality of life over the same time period. A subset of participants who completed questionnaires also took part in an interview study and we found that not everyone had yet fully adjusted to life with their new kidney (or pancreas + kidney) one year after receiving their transplant.

What we still don’t know is how quality of life changes in the following years since being wait-listed for a transplant or having a transplant. Several more people are likely to have changed treatment, or received a transplant since then, and we are interested in the impact that this has had on their quality of life over this longer period of time. We are contacting you again now because we would like to see how you are doing since last completing questionnaires for the ATTOM detailed PROMs study.

Participation in this follow-up study would involve completing some questionnaires. You may also be invited to take part in an interview about your experiences. Please complete the form enclosed to let us know whether or not you are willing to consider participating in this follow-up study and send this to the research team at Royal Holloway in the envelope provided. Alternatively, or if you have questions, please contact the PhD student, Katie Hann, who is conducting this follow-up study. Email: Katie.hann.2008@live.rhul.ac.uk, Telephone: 01784 443718.

Participation in research is voluntary; just because you took part in the original ATTOM study does not mean that you have to take part in the follow-up. Your healthcare will not be impacted whether you decide to take part in this study or not.

Thank you for taking the time to consider this research.

Yours sincerely,

Appendix C.

Study 1 Invitation Response Form

ATTOM detailed PROMs follow-up study (version 1.1)

Thank you for taking the time to consider this research.

Please indicate below whether or not you are interested in taking part in this follow-up study:

☐ No, I am not interested in taking part because (it will be helpful to know your reason(s) but you are of course free to leave this section blank)

.....

.....

.....

☐ Yes, I am interested in taking part.

If you are interested in taking part, please provide your contact details below so that the research team from Royal Holloway can contact you and send you a study pack.

Name _____

Telephone _____

Postal address _____

_____

_____

Email address _____

Project ID: 242848 Version 1.1 27.06.18

Appendix D.

Study 1 Invitation Letter Template for Kidney-only Recipients and Dialysis Patients

Katie Hann BSc, MSc
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PARTICIPANT ADDRESS

DATE

Dear…,

You may remember that approximately 6 years ago you took part in some research called 'Access to Transplantation and Transplant Outcome Measures' (ATTOM) and you completed some questionnaires on quality of life and treatment satisfaction as part of the detailed patient-reported outcome measures (PROMs) sub-study. We would like to thank you for taking part in this research programme. It ended in 2014 and from the data collected we found that people who had a transplant did have better quality of life one year later. People who were still on dialysis and/or were waiting for a transplant had worse health, but the same quality of life over the same time period. A smaller number of people also took part in an interview study and we found that not everyone had yet fully adjusted to life with their new kidney (or pancreas + kidney) one year after receiving their transplant.

What we still don't know is how quality of life changes in the following years since being wait-listed for a transplant or having a transplant. Several more people are likely to have changed treatment, or received a transplant since then, and we are interested in the impact that this has had on their quality of life over this longer period of time. We are contacting you again now because we would like to see how patients are doing since last completing questionnaires for the ATTOM study.

Enclosed you will find an information sheet explaining our research and what taking part will involve. If you are interested in taking part please read this information first. You will also find enclosed a consent form and a questionnaire pack. If you are happy to take part, we would ask that you sign the consent form and complete the questionnaires and post them back to us at Royal Holloway, University of London in the envelope provided. Please contact the PhD student, Katie Hann, at Royal Holloway if you have any questions (see contact details above).

Participation in research is voluntary; just because you took part in the original ATTOM study does not mean that you have to take part in the follow-up. Your healthcare will not be impacted whether you decide to take part in this study or not. If you do not wish to take part, we would be grateful if you could return the uncompleted questionnaire pack to us in the envelope provided.

Thank you for taking the time to consider this research.

Yours sincerely,

Appendix E.

Study 1 Invitation Letter Template for SPKT Recipients

Katie Hann BSc, MSc
PhD Student

Health Psychology Research Unit
Orchard Building
Royal Holloway
University of London
Egham, Surrey, TW20 0EX

+44 (0) 1784 443718
Katie.hann.2008@live.rhul.ac.uk

PARTICIPANT ADDRESS

DATE

Dear…,

You may remember that approximately 6 years ago you took part in some research called 'Access to Transplantation and Transplant Outcome Measures' (ATTOM) and you completed some questionnaires on quality of life and treatment satisfaction as part of the detailed patient-reported outcome measures (PROMs) sub-study. We would like to thank you for taking part in this research programme. It ended in 2014 and from the data collected we found that people who had a transplant did have better quality of life one year later. People who were still on dialysis and/or were waiting for a transplant had worse health, but the same quality of life over the same time period. A smaller number of people also took part in an interview study and we found that not everyone had yet fully adjusted to life with their new kidney (or pancreas + kidney) one year after receiving their transplant.

What we still don't know is how quality of life changes in the following years since being wait-listed for a transplant or having a transplant. Several more people are likely to have changed treatment, or received a transplant since then, and we are interested in the impact that this has had on their quality of life over this longer period of time. We are contacting you again now because we would like to see how patients are doing since last completing questionnaires for the ATTOM study.

Enclosed you will find an information sheet explaining our research and what taking part will involve. If you are interested in taking part please read this information first. You will also find enclosed a consent form and a questionnaire pack. If you are happy to take part, we would ask that you sign the consent form and complete the questionnaires and post them back to us at Royal Holloway, University of London in the envelope provided. Please contact the PhD student,

Katie Hann, at Royal Holloway if you have any questions (see contact details above).

We would also like to involve some patients' partners in an interview study to find out about their experiences of the transplant process and its impact on them. If you have a partner that would be interested in taking part in an interview, please indicate this on the consent form and provide their contact details.

Participation in research is voluntary; just because you took part in the original ATTOM study does not mean that you have to take part in the follow-up. Your healthcare will not be impacted whether you decide to take part in this study or not. If you do not wish to take part, we would be grateful if you could return the uncompleted questionnaire pack to us in the envelope provided.

Thank you for taking the time to consider this research.

Yours sincerely,

Katie Hann

Appendix F.

Study 1 Information Sheet for Kidney-only Recipients and Dialysis Patients

ATTOM detailed-PROMs follow-up study (version 1.1)

Invitation

You previously took part in the Access to Transplantation and Transplant Outcome Measures (ATTOM) study. We would now like to invite you to take part in a follow-up study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take some time to read the following information carefully and discuss it with friends, relatives and your renal team if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

1. What is the purpose of the study?

From the ATTOM study we found that those who received a transplant had better quality of life and other outcomes compared to those who remained on the waiting list. However, it appears there were initial differences between those who received a transplant and those who remained on the waiting list. Furthermore, from interviews with some people who had received a transplant we found that they had not fully adjusted to having their new kidney or pancreas and kidney 12 months after they received it.

The aim of the current study is to find out about how those who participated in the ATTOM detailed Patient-Reported Outcomes Measures (PROMs) sub-study are doing several years later. More people who took part in ATTOM are likely to have changed treatment or received a transplant since they were last followed up, and we are interested in the impact that this has had on their quality of life over this longer period of time. We would also like to interview some participants about their experiences of living with a transplant, to gain a more in-depth understanding of the impact that this has on their lives.

Altogether, the research will give us a much better understanding of the impact of chronic kidney disease treatments on peoples' lives, which could help to advise other patients in future.

2. Why have I been invited?

You have been invited to take part in this research because you have had a renal condition that required treatment, and you previously took part in the ATTOM sub-study investigating quality of life and other patient-reported outcomes. We would like to know how your quality of life and other outcomes have changed since you last took part in ATTOM.

3. Do I have to take part?

Participation in this follow-up study is voluntary, it is up to you to decide whether or not to take part. The standard of healthcare that you receive will not be affected whether you decide to take part or not. If you decide to take part you are still free to withdraw at any time and without giving a reason. Once reports have been written we will not be able to remove your data. You will not be identifiable from any of the reports.

4. What will happen to me if I take part and what do I have to do?

If you decide to take part in this follow-up research, please read and complete the consent form by initialing in each box and signing the form. You should keep one completed copy of the consent form and send the other to the researchers at Royal Holloway, University of London.

We would like you to complete the enclosed questionnaire pack and return it to us in the stamped-addressed envelope provided. The questionnaire pack includes a general information questionnaire that asks about your age, gender, ethnicity, education, health and healthcare treatments for your renal condition. The questionnaire pack also includes questionnaires about your quality of life, well-being, treatment satisfaction and other patient-reported outcomes. This one-time questionnaire pack will take between 45-60 minutes to complete. If you would like to take part but are unable to complete the questionnaires without assistance, you can contact the research team at Royal Holloway for help or to arrange to complete consent and the questionnaire pack over the telephone (see below for contact details).

If you give consent, you may also be invited to take part in a telephone interview about your experiences of transplantation and living with a transplant if you have received one. Not all participants who take part in the questionnaire study and who consent to be contacted for an interview will be contacted for an interview. We will select individuals to be interviewed so that we have a sample including men and women of different ages and with a range of responses on the patient-reported outcomes. The interview will last about one hour, but this depends on how much you would like to say. We would like to audio-record the interview so that it can be typed up and analysed for our research. If you are contacted but no longer wish to be interviewed you are free to withdraw without giving a reason.

You will not be required to attend any extra clinics, have additional tests or receive extra drugs or medicines. Your standard treatment will not be affected in any way by participating or not participating in the study.

5. Is there a drug or procedure being tested?

There are no drugs, medical devices or other treatments being tested in this study. There will be no change to your treatment or standard of care.

6. Are there any side effects from taking part?

There are no side effects from taking part in this study because we are not testing any new medicines.

7. What are the possible disadvantages and risks of taking part?

There are no risks to your health or any changes to your treatment if you agree to take part in this study. You will be required to complete some questionnaires and this would require some of your time, about 45-60 minutes. If you are contacted for an interview this will also take about one hour of your time. Although unlikely, there is a small risk that you may become upset when completing the questionnaires. Advice is available from Prof Clare Bradley, Professor of Health Psychology, Health Psychology Research Unit, Orchard Building, Royal Holloway, University of London: email c.bradley@rhul.ac.uk, telephone 01784 443708/01784 443714.

Information on kidney disease and support can be found on the Kidney Care UK and the National Kidney Federation (NKF) UK websites:
https://www.kidneycareuk.org/get-support/
http://www.kidney.org.uk/

A free helpline is also provided by the NKF on: 0800 1690936

8. What are the possible benefits of taking part?

There may be no direct benefit to you if you take part; however, the information we get from this study may help healthcare professionals to advise and treat future patients.

9. What happens when the research study stops?

At the end of the research your care continues as usual. You may be contacted to take part in future research but only if you consent to this.

10. What if something goes wrong?

Since the study is only asking you to fill in questionnaires, and take part in a telephone interview, it is very unlikely that anything will go wrong. Regardless of this, if you wish to complain about any aspect of the way you have been approached or treated during the course of this study, you can. In the first instance please contact Prof Clare Bradley, Professor of Health Psychology, Orchard Building, Royal Holloway, University of London: email c.bradley@rhul.ac.uk, telephone 01784 443708/01784 443714.

11. Will my taking part in this study be kept confidential?

Royal Holloway, University of London is the sponsor for this study based in the United Kingdom. We will be using information provided by you in order to undertake this study and we will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained.

Royal Holloway will use your name and contact details to contact you about the research study and to oversee the quality of the study. Individuals from Royal Holloway and regulatory organisations may look at your research records to check the accuracy of the research study. The only people at Royal Holloway who will

have access to information that identifies you will be people who need to contact you to follow-up or invite you to take part in an interview, or to audit the data collection process.

Royal Holloway will keep identifiable information about you from this study for 5 years after the study has finished/ until 2025. You can find out more about how we use your information by contacting the PhD student, Katie Hann, on the details provided below.

12. What will happen to the results of the research study?

The results of this study will be submitted for publication in national and international journals. You will not be identified in any reports or publications. At the end of the study a newsletter will be produced to provide details of our findings. This can be sent to you if you indicate an interest in receiving it (on the consent form).

13. Who is organising and funding the research?

This follow-up study is part of a PhD studentship, supported by Royal Holloway, University of London.

14. Who has reviewed the study?

The study has been reviewed by an NHS Research Ethics Committee.

15. Contacts for Further Information

If you do require additional information on this research or if you wish to complete the measures over the telephone, please contact the PhD student, Katie Hann:

Miss Katie Hann
Orchard Building
Royal Holloway, University of London
Egham, Surrey
TW20 0EX
Tel: 01784 443718
Email: Katie.hann.2008@live.rhul.ac.uk

For independent advice you can contact your local Patient Advice and Liaison Service (PALS) by visiting www.nhs.uk and searching for 'Find Patient advice and liaison services (PALS)' then entering your postcode.

Alternatively, you can contact the Cambridge office:

Patient Advice & Liaison Service
Cambridge University Hospitals NHS Foundation Trust
Addenbrooke's Hospital
Hills Road
Cambridge
CB2 2QQ
Tel: 01223 216756

Thank you for taking the time to read the study information. We hope you agree to take part in this study.

Appendix G.

Study 1 Information Sheet for SPKT Recipients

ATTOM detailed-PROMs follow-up study (version 1.1)

Invitation

You previously took part in the Access to Transplantation and Transplant Outcomes Measures (ATTOM) study. We would now like to invite you to take part in a follow-up study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take some time to read the following information carefully and discuss it with friends, relatives and your renal team if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

1. What is the purpose of the study?

From the ATTOM study we found that those who received a transplant had better quality of life and other outcomes compared to those who remained on the waiting list. However, it appears there were initial differences between those who received a transplant and those who remained on the waiting list. Furthermore, from interviews with some people who had received a transplant we found that they had not fully adjusted to having their new kidney or pancreas and kidney 12 months after they received it.

The aim of the current study is to find out about how those who participated in the ATTOM detailed Patient-Reported Outcome Measures (PROMs) sub-study are doing several years later. More people who took part in ATTOM are likely to have changed treatment or received a transplant since they were last followed up, and we are interested in the impact that this has had on their quality of life over this longer period of time. We would also like to interview some participants about their experiences of living with a transplant, to gain a more in-depth understanding of the impact that this has on their lives. In addition, we would like to interview some of the partners of people who have received a transplant because chronic illnesses and life events such as receiving a transplant also affect patients' families.

Altogether, the research will give us a much better understanding of the impact of chronic kidney disease treatments on peoples' lives, which could help to advise other patients in future.

2. Why have I been invited?

You have been invited to take part in this research because you have had a renal condition that required treatment, and you previously took part in the ATTOM sub-study investigating quality of life and other patient-reported outcomes. We would like to know how your quality of life and other outcomes have changed since you last took part in ATTOM.

3. Do I have to take part?

Participation in this follow-up study is voluntary, it is up to you to decide whether or not to take part. The standard of healthcare that you receive will not be affected whether you decide to take part or not. If you decide to take part you are still free to withdraw at any time and without giving a reason. Once reports have been written we will not be able to remove your data. You will not be identifiable from any reports.

4. What will happen to me if I take part and what do I have to do?

If you decide to take part in this follow-up research, please read and complete the consent form by initialing in each box and signing the form. You should keep one completed copy of the consent form and send the other to the researchers at Royal Holloway, University of London.

We would like you to complete the enclosed questionnaire pack and return it to us in the stamped-addressed envelope provided. The questionnaire pack includes a general information questionnaire that asks about your age, gender, ethnicity, education, health and healthcare treatments for your renal condition. The questionnaire pack also includes questionnaires about your quality of life, well-being, treatment satisfaction and other patient-reported outcomes. This one-time questionnaire pack will take between 45-60 minutes to complete. If you would like to take part but are unable to complete the questionnaires without assistance, you can contact the research team at Royal Holloway for help or to arrange to complete consent and the questionnaire pack over the telephone (see below for contact details).

If you give consent, you may also be invited to take part in a telephone interview about your experiences of transplantation and living with a transplant if you have received one. Not all participants who take part in the questionnaire study and who consent to be contacted for an interview will be contacted for an interview. We will select individuals to be interviewed so that we have a sample including men and women of different ages and with a range of responses on the patient-reported outcomes. The interview will last about one hour, but this depends on how much you would like to say. We would like to audio-record the interview so that it can be typed up and analysed for our research. If you are contacted but no longer wish to be interviewed you are free to withdraw without giving a reason.

Lastly, we would like you to indicate whether you have a long-term partner who may be willing to take part in a telephone interview. By ‘long-term partner’ we mean a partner with whom you have been in a relationship for at least the past year. If you have a partner who may like to take part, please provide their contact

details on the form provided and we will contact them directly. It is not our aim to interview couples, however if both you and your partner would like to take part in an interview you will be interviewed individually. We will keep what you say confidential from each-other and analyse what you say separately.

You will not be required to attend any extra clinics, have additional tests or receive extra drugs or medicines. Your standard treatment will not be affected in any way by participating or not participating in the study.

5. Is there a drug or procedure being tested?

There are no drugs, medical devices or other treatments being tested in this study. There will be no change to your treatment or standard of care.

6. Are there any side effects from taking part?

There are no side effects from taking part in this study because we are not testing any new medicines.

7. What are the possible disadvantages and risks of taking part?

There are no risks to your health or any changes to your treatment if you agree to take part in this study. You will be required to complete some questionnaires and this would require some of your time, about 45-60 minutes. If you or your partner are contacted for an interview this would also take about one hour of your time or theirs.

Although unlikely, there is a small risk that you may become upset when completing the questionnaires. Advice is available from Prof Clare Bradley, Professor of Health Psychology, Health Psychology Research Unit, Orchard Building, Royal Holloway, University of London: email c.bradley@rhul.ac.uk, telephone 01784 443708/01784 443714.

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https://www.kidneycareuk.org/get-support/
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Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained.

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Royal Holloway will keep identifiable information about you from this study for 5 years after the study has finished/ until 2025. You can find out more about how we use your information by contacting the PhD student, Katie Hann, on the details provided below.

12. What will happen to the results of the research study?

The results of this study will be submitted for publication in national and international journals. You will not be identified in any reports or publications. At the end of the study a newsletter will be produced to provide details of our findings. This can be sent to you if you indicate an interest in receiving it (on the consent form).

13. Who is organising and funding the research?

This follow-up study is part of a PhD studentship, supported by Royal Holloway, University of London.

14. Who has reviewed the study?

The study has been reviewed by an NHS Research Ethics Committee.

15. Contacts for Further Information

If you do require additional information on this research or if you wish to complete the measures over the telephone, please contact the PhD student, Katie Hann:

Miss Katie Hann
Orchard Building
Royal Holloway, University of London
Egham, Surrey
TW20 0EX
Tel: 01784 443718
Email: Katie.hann.2008@live.rhul.ac.uk

For independent advice you can contact your local Patient Advice and Liaison Service (PALS) by visiting www.nhs.uk and searching for 'Find Patient advice and liaison services (PALS)' then entering your postcode. Alternatively, you can contact the Cambridge office:

Patient Advice & Liaison Service
Cambridge University Hospitals NHS Foundation Trust
Addenbrooke's Hospital
Hills Road
Cambridge
CB2 2QQ
Tel: 01223 216756

Thank you for taking the time to read the study information. We hope you agree to take part in this study.

Please keep a copy of this information sheet and a signed consent form for your records.

Appendix H.

Study 1 Consent Form for Kidney-only Recipients and Dialysis Patients

CONSENT FORM

ATTOM detailed PROMs follow-up study (version 1.1)

Name of Researcher: Katie Hann (Chief investigator – Prof. Clare Bradley)

Please read each statement carefully	**Please initial box**
1. I confirm that I have read and understand the information sheet dated 10.10.18 (version 1.2) for the above study. I have had the opportunity to ask questions and any questions that I have asked have been answered satisfactorily.	☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason and without my medical care or legal rights being affected.	☐
3. I understand that I have been asked to complete a questionnaire pack including patient-reported outcome measures, and I agree to this.	☐
4. I understand that I may be asked to participate in an interview with the PhD student and I give my permission to be contacted to arrange an interview. (If you prefer not to do an interview leave this box and the one below blank.)	☐
5. I agree with the audio-recording of the telephone interview if invited.	☐
6. I would like to be sent a newsletter detailing the findings at the end of the study.	☐
7. I would be interested in being involved in other research in future and I consent to being contacted for this. (If you prefer not to be invited to take part in other future research please leave this box blank.)	☐

.....	.....	.....
Name of Patient	Date	Signature
.....	.....	.....
Researcher	Date	Signature

Please keep one copy and send one copy to the researchers with the questionnaire pack.

Appendix I.

Study 1 Consent Form for SPKT Recipients

CONSENT FORM

ATTOM detailed PROMs follow-up study (version 1.1)

Name of Researcher: Katie Hann (Chief investigator – Prof. Clare Bradley)

Please read each statement carefully	**Please initial box**
1. I confirm that I have read and understand the information sheet dated 10.10.18 (version 1.2) for the above study. I have had the opportunity to ask questions and any questions that I have asked have been answered satisfactorily.	☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason and without my medical care or legal rights being affected.	☐
3. I understand that I have been asked to complete a questionnaire pack including patient-reported outcome measures, and I agree to this.	☐
4. I understand that I may be asked to participate in an interview with the PhD student and I give my permission to be contacted to arrange an interview. (If you prefer not to do an interview leave this box and the one below blank.)	☐
5. I agree with the audio-recording of the telephone interview if invited.	☐
6. I would like to be sent a newsletter detailing the findings at the end of the study.	☐
7. I would be interested in being involved in other research in future and I consent to being contacted for this. (If you prefer not to be invited to take part in other future research please leave this box blank.)	☐

8. Do you have a long-term partner? (Please circle response below)

Yes No

If yes, may we contact them to invite them to take part in an interview?

Yes No

Continues on next page.

I understand that you may contact my partner to invite them to take part in an interview if I provide their contact details ☐

.....	.....	.....
Name of Patient	Date	Signature
.....	.....	.....
Researcher	Date	Signature

Please keep one copy and send one copy to the researchers with the questionnaire pack.

Appendix J.

Study 1 Contact Details Form for SPKT Recipients' Partners

Your partner's contact details

As part of the PhD research project, we would also like to explore the experiences of the partners of individuals who have had a transplant. If you have a partner who may like to be invited to complete a questionnaire and take part in a telephone interview, please provide their contact details below.

Name _____

Telephone _____

Postal address _____

_____

_____

_____

Email address _____

For more information or to ask questions please contact the research team:

Ms Katie Hann, PhD Researcher
Dr Andrea Gibbons, Research Fellow
Prof Clare Bradley, Professor of Health Psychology

Health Psychology Research Unit,
Royal Holloway, University of London,
Egham, TW20 0EX.
Telephone: 01784 443718 or 01784 44371

Appendix K.

Study 1 General Information/Demographic Questionnaire

ATTOM detailed PROMs follow-up study (version 1.1)

General Information Questionnaire

Wherever options are provided with boxes, please put a '✓' in any box that applies.

1. Date of birth:	DD/MM/ YYYY	**2. Gender:**	Male ☐ Female ☐

3. What is your marital status?	
Married/Civil partnership or living with partner	☐
Widowed	☐
Divorced or separated	☐
Single	☐

4a. Are you in full-time education?

Yes ☐ Please specify: ……

No ☐

4b. What is the highest level of education you have obtained?

No formal qualifications	☐	NVQ level 4-5	☐
O level/GCSE or equivalent	☐	First Degree	☐
A Level or equivalent	☐	Higher degree	☐
National Vocational Qualification (NVQ) level 1-3	☐	Other qualification(s)	☐

If 'Other', please specify: ……

……

5. Please indicate your current employment status below:		
Working full-time		☐
Working part-time	due to kidney condition	☐
	due to other health problems	☐
	by choice	☐
Unable to work	due to kidney condition	☐
	due to other health problems	☐
Able to work	but cannot find work	☐
	but choose not to	☐
Retired	early due to kidney condition	☐
	early due to other health problems	☐
	early by choice	☐
	at the usual retirement age for my work	☐

6. Please indicate your ethnic group below:		
White	British	☐
	Irish	☐
	Scottish	☐
	Other, please state	☐ .....
Asian or Asian British	Indian	☐
	Pakistani	☐
	Bangladeshi	☐
	Chinese	☐
	Other, please state	☐ .....
Black or Black British	Caribbean	☐
	African	☐
	Other, please state	☐ .....

Continues on next page…

Mixed	White & Black Caribbean	☐
	White & Black African	☐
	White & Asian	☐
	Other, please state	☐.....
Other ethnic group	Any other ethnic group, please state	☐.....

7. Were you born in the UK?

Yes ☐ Please go to question 8a.

No ☐ For how long have you lived in the UK? ……years ……..months.

8a. Is English your first language?

Yes ☐ Please go to question 9.

No ☐ Please continue with question 8b & c.

8b. What is your first language?

……

8c. Please rate your fluency in English on the scale below by circling the <u>number</u> that applies to you:

Very basic **Very fluent**

1 2 3 4 5 6 7

9. We would like to calculate your body mass index (BMI).

What is your weight? ……

What is your height? …….....

10a. Are you receiving dialysis to treat your kidney condition?

No ☐ Please go to question 10b.

Yes ☐ Please indicate which type of dialysis:

Haemodialysis (hospital-based) ☐

Haemodialysis (home-based) ☐

Continuous ambulatory peritoneal dialysis ☐

Automated peritoneal dialysis (overnight machine) ☐

10b. Are you currently on the waiting list for a pancreas + kidney?

(also known as a simultaneous/combined/dual transplant)

Yes ☐ No ☐ Don't know ☐

10c. Are you currently on the waiting list for a kidney alone?

Yes ☐ No ☐ Don't know ☐

10d. When were you added to the transplant waiting list (approximately)?

DD/MM/YYYY | Not applicable ☐

11. Do you have a working transplant?

No ☐ Please go to question 12.

Yes ☐ Please indicate which type of transplant and transplant date below:

Pancreas + kidney transplant (combined/simultaneous/dual) ☐

Date of transplant: DD/MM/YYYY

Is the pancreas working now? Yes ☐ No ☐

Is the kidney working now? Yes ☐ No ☐

Deceased-donor kidney transplant ☐

Date of transplant: DD/MM/YYYY

Living-donor kidney transplant ☐

Date of transplant: DD/MM/YYYY

12. Have you <u>previously</u> had one or more kidney or pancreas + kidney transplant (other than any current working transplant)?

No ☐ Please go to question 13a.

Yes ☐ Please state the transplant type and provide the approximate date(s) of the transplant(s): …….

……

13a. Do you have a diagnosis of diabetes?

No ☐ Please go to question 14a.

Yes, type 1 ☐

Yes, type 2 ☐

Yes, other ☐ Please specify: ……..

13b. When was your diabetes diagnosed (approximately)?

DD/MM/YYYY

13c. What medications, including insulin(s), are you taking to treat your diabetes?

……

……

13d. If you are taking insulin, which type of regimen are you on?

Not applicable ☐ Please go to question 13e.

Two injections a day with mixed insulin ☐

Basal/bolus regimen with fixed doses at fixed meal times ☐

Basal/bolus regimen with flexible doses at fixed meal times ☐

Basal/bolus regimen with flexible doses and flexible timing of meals ☐

Continues on next page.

Insulin pump	☐
Other	☐

If other, please describe: ……..

……

13e. Have you experienced any recent or ongoing complications due to your diabetes?

No	☐ Please go to question 14a.
Yes	☐ Please tick and specify which complication(s):
Eye problems (e.g. cataracts, diabetic retinopathy)	☐ ……
Nerve problems (e.g. tingling, numbness, shooting pains)	☐ ……
Foot problems (e.g. ulcers, injuries)	☐ ……
Amputation	☐ ……
Diabetic ketoacidosis (risking or experiencing a high sugar coma)	☐ ……
Severe hypoglycaemia (requiring assistance from another person)	☐ ……
Other, please state	☐ ……

14a. If you <u>do not</u> have a functioning pancreas transplant please go to question 15a.

Since having your pancreas + kidney transplant, do you worry about your blood sugar levels being too high?

(Please circle whichever applies to you.)

always	often	sometimes	rarely	never
1	2	3	4	5

14b. Since having your pancreas + kidney transplant do you restrict your diet/avoid sugary foods and drinks?

always	often	sometimes	rarely	never
1	2	3	4	5

14c. Since having your pancreas + kidney transplant have you monitored your blood sugar levels?

No ☐

Yes ☐ How often have you measured your blood glucose in the past 4 weeks?

……

15a. Do you have any medical conditions other than your kidney condition?

No ☐ Please go to question 16.

Yes ☐ Please tick and specify if possible:

Anaemia	☐ ……
High blood pressure	☐ ……
Liver disease	☐ ……
Joint problems (e.g. rheumatoid arthritis)	☐ ……
Lung problems (e.g. asthma)	☐ ……
Cancer (e.g. lung, breast cancer)	☐ ……
Stroke or mini-stroke (TIA)	☐ ……
Heart problems (e.g. previous heart attack, angina, heart failure)	☐ ……
Circulatory problems (e.g. in legs causing pain when walking)	☐ ……
Chronic viral infection (e.g. HIV, hepatitis B or C)	☐ ……
Memory problems (e.g. dementia, Alzheimer's)	☐ ……
Mental health problems (e.g. depression, anxiety)	☐ ……
Other, please state:	☐ ……

15b. Did any of the above medical conditions develop within the past 6 years?

No ☐ Please go to question 16.

Yes ☐ Please specify: ……

16. Are you registered as (severely) visually impaired?

No ☐

Yes, visually impaired (previously termed “partially sighted”) ☐

Yes, severely visually impaired (previously termed “blind”) ☐

17a. Are you registered as disabled?

Yes ☐ No ☐ If ‘No’, please go to question 18.

17b. Are you disabled due to your kidney condition?

Yes ☐ No ☐

17c. Are you disabled due to other health problems?

Yes ☐ No ☐

If ‘Yes’, please specify:

……

17d. Please state what your disability is:

…….....
.

18. Since you last completed questionnaires for the ATTOM study (approx. 4 - 6 years ago) have you experienced any stressful major life events that may have impacted on your current health and well-being?

No ☐ Please go to question 19.

Yes ☐ Please describe:

19. How often do you need to have someone help you when you read instructions, pamphlets or other written material from your doctor or pharmacy? (Please circle whichever applies to you.)				
Never	**Rarely**	**Sometimes**	**Often**	**Always**
1	**2**	**3**	**4**	**5**

Date of completion of this questionnaire booklet: DD/MM/20YY

If you have any queries please contact:

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Royal Holloway, University of London,
Egham, Surrey,
TW20 0EX, UK.
Tel: 01784 443718
Email: katie.hann.2008@live.rhul.ac.uk

Thank you for taking the time to complete these questionnaires.

Appendix L.

RDQoL

RDQoL

This questionnaire asks about your quality of life – in other words how good or bad you feel your life to be.

Please put an "X" in the box that best indicates your response for each item.

What we would like to know is how you feel about your life now.

I) In general, my present quality of life is:

☐ excellent	☐ very good	☐ good	☐ neither good nor bad	☐ bad	☐ very bad	☐ extremely bad

Now we would like to know how your quality of life is affected by your renal condition, its management and any complications you may have.

II) If I did *not* have a renal condition, my quality of life would be:

☐ very much better	☐ much better	☐ a little better	☐ the same	☐ worse

Please respond to the more specific questions on the following pages. For each aspect of life described, you will find two parts:

For Part (a):	put an "X" in one box to show how your renal condition affects this aspect of your life;
For Part (b):	put an "X" in one box to show how important this aspect of your life is to your quality of life.

1	(a)	**If I did *not* have a renal condition, I would enjoy my leisure activities:**				
		☐ very much more	☐ much more	☐ a little more	☐ the same	☐ less
	(b)	**My leisure activities are:**				
		☐ very important	☐ important	☐ somewhat important	☐ not at all important	

2		**Are you currently working, looking for work or would you like to work?**				
		Yes ☐ If ***yes***, complete **(a)** and **(b)**.				
		No ☐ If ***no***, go straight to **3a**.				
	(a)	**If I did *not* have a renal condition, my working life would be:**				
		☐ very much better	☐ much better	☐ a little better	☐ the same	☐ worse
	(b)	**For me, having a working life is:**				
		☐ very important	☐ important	☐ somewhat important	☐ not at all important	

3	(a)	**If I did *not* have a renal condition, local or long distance journeys would be:**				
		☐ very much easier	☐ much easier	☐ a little easier	☐ the same	☐ more difficult
	(b)	**For me, local or long distance journeys are:**				
		☐ very important	☐ important	☐ somewhat important	☐ not at all important	

4	**Do you ever go on holiday or want to go on holiday?** **Yes** ☐ If ***yes***, complete **(a)** and **(b)**. **No** ☐ If ***no***, go straight to **5a**.
(a)	**If I did *not* have a renal condition, my holidays would be:** ☐ very much better ☐ much better ☐ a little better ☐ the same ☐ worse
(b)	**For me, holidays are:** ☐ very important ☐ important ☐ somewhat important ☐ not at all important

5	**(a)**	**If I did *not* have a renal condition, physically I could do:** ☐ very much more ☐ much more ☐ a little more ☐ the same ☐ less
	(b)	**For me, how much I can do physically is:** ☐ very important ☐ important ☐ somewhat important ☐ not at all important

6	**Do you have any family / relatives?** **Yes** ☐ If ***yes***, complete **(a)** and **(b)**. **No** ☐ If ***no***, go straight to **7a**.
(a)	**If I did *not* have a renal condition, my family life would be** ☐ very much better ☐ much better ☐ a little better ☐ the same ☐ worse
(b)	**My family life is:** ☐ very important ☐ important ☐ somewhat important ☐ not at all important

7	**(a)**	**If I did *not* have a renal condition, my friendships and social life would be:** ☐ very much better ☐ much better ☐ a little better ☐ the same ☐ worse
	(b)	**My friendships and social life are:** ☐ very important ☐ important ☐ somewhat important ☐ not at all important

8	**Do you have or would you like to have a close personal relationship (e.g. husband / wife, partner)?** Yes ☐ If ***yes***, complete **(a)** and **(b)**. No ☐ If ***no***, go straight to 9.
(a)	**If I did *not* have a renal condition, my closest personal relationship would be:** ☐ very much better ☐ much better ☐ a little better ☐ the same ☐ worse
(b)	**For me, having a close personal relationship is:** ☐ very important ☐ important ☐ somewhat important ☐ not at all important

9	**Do you have or would you like to have a sex life?** Yes ☐ If ***yes***, complete **(a)** and **(b)**. No ☐ If ***no***, go straight to **10a**.
(a)	**If I did *not* have a renal condition, my sex life would be:** ☐ very much better ☐ much better ☐ a little better ☐ the same ☐ worse
(b)	**For me, having a sex life is:** ☐ very important ☐ important ☐ somewhat important ☐ not at all important

10 (a)	**If I did *not* have a renal condition, my physical appearance would be:** ☐ very much better ☐ much better ☐ a little better ☐ the same ☐ worse
(b)	**My physical appearance is:** ☐ very important ☐ important ☐ somewhat important ☐ not at all important

11 (a)	**If I did *not* have a renal condition, my self-confidence would be:** ☐ very much better ☐ much better ☐ a little better ☐ the same ☐ worse
(b)	**My self-confidence is:** ☐ very important ☐ important ☐ somewhat important ☐ not at all important

12 (a)	**If I did *not* have a renal condition, my motivation would be:** ☐ very much better ☐ much better ☐ a little better ☐ the same ☐ worse
(b)	**My motivation is:** ☐ very important ☐ important ☐ somewhat important ☐ not at all important

13 (a)	**If I did *not* have a renal condition, the way people in general react to me would be:** ☐ very much better ☐ much better ☐ a little better ☐ the same ☐ worse
(b)	**The way people in general react to me is:** ☐ very important ☐ important ☐ somewhat important ☐ not at all important

14	**Do you have or would you like to have a spiritual or religious life?** **Yes** ☐ If ***yes***, complete **(a)** and **(b)**. **No** ☐ If ***no***, go straight to **15a**.
(a)	**If I did *not* have a renal condition, my spiritual or religious life would be:** ☐ very much better ☐ much better ☐ a little better ☐ the same ☐ worse
(b)	**My spiritual or religious life is:** ☐ very important ☐ important ☐ somewhat important ☐ not at all important

15 (a)	**If I did *not* have a renal condition, my feelings about the future (e.g. worries, hopes) would be:** ☐ very much better ☐ much better ☐ a little better ☐ the same ☐ worse
(b)	**My feelings about the future are:** ☐ very important ☐ important ☐ somewhat important ☐ not at all important

16 (a)	**If I did *not* have a renal condition, my financial situation would be:** ☐ very much better ☐ much better ☐ a little better ☐ the same ☐ worse
(b)	**My financial situation is:** ☐ very important ☐ important ☐ somewhat important ☐ not at all important

17 (a)	**If I did *not* have a renal condition, my living conditions would be:** ☐ very much better ☐ much better ☐ a little better ☐ the same ☐ worse
(b)	**My living conditions are:** ☐ very important ☐ important ☐ somewhat important ☐ not at all important

18 (a)	**If I did *not* have a renal condition, I would have to depend on others when I do not want to:** ☐ very much less ☐ much less ☐ a little less ☐ the same ☐ more
(b)	**For me, not having to depend on others is:** ☐ very important ☐ important ☐ somewhat important ☐ not at all important

19 (a)	**If I did *not* have a renal condition, people would fuss or worry about me (when I do not want them to):** ☐ very much less ☐ much less ☐ a little less ☐ the same ☐ more
(b)	**For me, not having others fussing or worrying about me is:** ☐ very important ☐ important ☐ somewhat important ☐ not at all important

20 (a)	**If I did *not* have a renal condition, my freedom to eat as I wish would be:** ☐ very much greater ☐ much greater ☐ a little greater ☐ the same ☐ less
(b)	**My freedom to eat as I wish is:** ☐ very important ☐ important ☐ somewhat important ☐ not at all important

21 (a)	**If I did *not* have a renal condition, my freedom to drink as I wish (e.g. water, fruit juice, wine, beer, hot and cold drinks) would be:**				
	☐ very much greater	☐ much greater	☐ a little greater	☐ the same	☐ less
(b)	**My freedom to drink as I wish is:**				
	☐ very important	☐ important	☐ somewhat important	☐ not at all important	

If there are any other ways in which your renal condition, its management and any complications affect your quality of life, please say what they are below:

Thank you for completing this questionnaire.

Date completed: .....

Appendix M.

ADDQoL

ADDQoL

This questionnaire asks about your quality of life – in other words how good or bad you feel your life to be.

Please put an "X" in the box that best indicates your response for each item.

We would like to know how your quality of life is affected by your diabetes, its management and any complications you may have.

l) If I did *not* have diabetes, my quality of life would be:	☐ very much better	☐ much better	☐ a little better	☐ the same	☐ worse

The following items are about different aspects of your life. Each item is divided into two parts:

For Part (a):	put an "X" in one box to show how diabetes affects this aspect of your life;
For Part (b):	put an "X" in one box to show how important this aspect of your life is to your quality of life.

1	(a)	**If I did *not* have diabetes, I would enjoy my leisure activities:**	☐ very much more	☐ much more	☐ a little more	☐ the same	☐ less
	(b)	**My leisure activities are:**	☐ very important	☐ important	☐ somewhat important	☐ not at all important	

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2	**Are you currently working, looking for work or would you like to work?** **Yes** ☐ If ***yes***, complete **(a)** and **(b)**. **No** ☐ If ***no***, go straight to 3a.
(a)	**If I did *not* have diabetes, my working life would be:** ☐ very much better ☐ much better ☐ a little better ☐ the same ☐ worse
(b)	**For me, having a working life is:** ☐ very important ☐ important ☐ somewhat important ☐ not at all important

3 **(a)**	**If I did *not* have diabetes, local or long distance journeys would be:** ☐ very much easier ☐ much easier ☐ a little easier ☐ the same ☐ more difficult
(b)	**For me, local or long distance journeys are:** ☐ very important ☐ important ☐ somewhat important ☐ not at all important

4	**Do you ever go on holiday or want to go on holiday?** **Yes** ☐ If ***yes***, complete **(a)** and **(b)**. **No** ☐ If ***no***, go straight to 5a.
(a)	**If I did *not* have diabetes, my holidays would be:** ☐ very much better ☐ much better ☐ a little better ☐ the same ☐ worse
(b)	**For me, holidays are:** ☐ very important ☐ important ☐ somewhat important ☐ not at all important

5 **(a)**	**If I did *not* have diabetes, physically I could do:** ☐ very much more ☐ much more ☐ a little more ☐ the same ☐ less
(b)	**For me, how much I can do physically is:** ☐ very important ☐ important ☐ somewhat important ☐ not at all important

6	**Do you have any family / relatives?** **Yes** ☐ If ***yes***, complete **(a)** and **(b)**. **No** ☐ If ***no***, go straight to **7a**.
(a)	**If I did *not* have diabetes, my family life would be** ☐ very much better ☐ much better ☐ a little better ☐ the same ☐ worse
(b)	**My family life is:** ☐ very important ☐ important ☐ somewhat important ☐ not at all important

7 **(a)**	**If I did *not* have diabetes, my friendships and social life would be:** ☐ very much better ☐ much better ☐ a little better ☐ the same ☐ worse
(b)	**My friendships and social life are:** ☐ very important ☐ important ☐ somewhat important ☐ not at all important

8	**Do you have or would you like to have a close personal relationship (e.g. husband / wife, partner)?** **Yes** ☐ If ***yes***, complete **(a)** and **(b)**. **No** ☐ If ***no***, go straight to 9.
(a)	**If I did *not* have diabetes, my closest personal relationship would be:** ☐ very much better ☐ much better ☐ a little better ☐ the same ☐ worse
(b)	**For me, having a close personal relationship is:** ☐ very important ☐ important ☐ somewhat important ☐ not at all important

9	**Do you have or would you like to have a sex life?** **Yes** ☐ If ***yes***, complete **(a)** and **(b)**. **No** ☐ If ***no***, go straight to **10a**.
(a)	**If I did *not* have diabetes, my sex life would be:** ☐ very much better ☐ much better ☐ a little better ☐ the same ☐ worse
(b)	**For me, having a sex life is:** ☐ very important ☐ important ☐ somewhat important ☐ not at all important

10 (a)	**If I did *not* have diabetes, my physical appearance would be:**				
	☐ very much better	☐ much better	☐ a little better	☐ the same	☐ worse
(b)	**My physical appearance is:**				
	☐ very important	☐ important	☐ somewhat important	☐ not at all important	

11 (a)	**If I did *not* have diabetes, my self-confidence would be:**				
	☐ very much better	☐ much better	☐ a little better	☐ the same	☐ worse
(b)	**My self-confidence is:**				
	☐ very important	☐ important	☐ somewhat important	☐ not at all important	

12 (a)	**If I did *not* have diabetes, my motivation would be:**				
	☐ very much better	☐ much better	☐ a little better	☐ the same	☐ worse
(b)	**My motivation is:**				
	☐ very important	☐ important	☐ somewhat important	☐ not at all important	

13 (a)	**If I did *not* have diabetes, the way people in general react to me would be:**				
	☐ very much better	☐ much better	☐ a little better	☐ the same	☐ worse
(b)	**The way people in general react to me is:**				
	☐ very important	☐ important	☐ somewhat important	☐ not at all important	

14 (a)	**If I did *not* have diabetes, my feelings about the future (e.g. worries, hopes) would be:**				
	☐ very much better	☐ much better	☐ a little better	☐ the same	☐ worse
(b)	**My feelings about the future are:**				
	☐ very important	☐ important	☐ somewhat important	☐ not at all important	

15 (a)	**If I did *not* have diabetes, my financial situation would be:**				
	☐ very much better	☐ much better	☐ a little better	☐ the same	☐ worse
(b)	**My financial situation is:**				
	☐ very important	☐ important	☐ somewhat important	☐ not at all important	

16 (a)	**If I did *not* have diabetes, my living conditions would be:**				
	☐ very much better	☐ much better	☐ a little better	☐ the same	☐ worse
(b)	**My living conditions are:**				
	☐ very important	☐ important	☐ somewhat important	☐ not at all important	

17 (a)	**If I did *not* have diabetes, I would have to depend on others when I do not want to:**				
	☐ very much less	☐ much less	☐ a little less	☐ the same	☐ more
(b)	**For me, not having to depend on others is:**				
	☐ very important	☐ important	☐ somewhat important	☐ not at all important	

18 (a)	**If I did *not* have diabetes, my freedom to eat as I wish would be:**				
	☐ very much greater	☐ much greater	☐ a little greater	☐ the same	☐ less
(b)	**My freedom to eat as I wish is:**				
	☐ very important	☐ important	☐ somewhat important	☐ not at all important	

19 (a)	**If I did *not* have diabetes, my freedom to drink as I wish (e.g. fruit juice, alcohol, sweetened hot and cold drinks) would be:**				
	☐ very much greater	☐ much greater	☐ a little greater	☐ the same	☐ less
(b)	**My freedom to drink as I wish is:**				
	☐ very important	☐ important	☐ somewhat important	☐ not at all important	

If there are any other ways in which diabetes, its management and any complications affect your quality of life, please say what they are below:

Thank you for completing this questionnaire.

Date completed: .....

Appendix N.

ADDQoL for SPKT sample

ADDQoL (SPK)

This questionnaire asks about your quality of life – in other words how good or bad you feel your life to be.

Please put an "X" in the box that best indicates your response for each item.

We would like to know how your quality of life is affected by your having had diabetes, its management and any complications you may have.

l) If I had *never had* diabetes, my quality of life would be:					
☐ very much better	☐ much better	☐ a little better	☐ the same	☐ worse	

The following items are about different aspects of your life. Each item is divided into two parts:

For Part (a):	put an "X" in one box to show how diabetes has affected this aspect of your life;
For Part (b):	put an "X" in one box to show how important this aspect of your life is to your quality of life.

1	(a)	**If I had *never had* diabetes, I would enjoy my leisure activities:**				
		☐ very much more	☐ much more	☐ a little more	☐ the same	☐ less
	(b)	**My leisure activities are:**				
		☐ very important	☐ important	☐ somewhat important	☐ not at all important	

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Appendix O.

RTSQs

Renal Treatment Satisfaction Questionnaire: RTSQs

The following questions are concerned with the treatment for your renal condition (which may include a kidney transplant, some form of dialysis, medication, dietary and/or fluid requirements/restrictions) and your experience over the past few weeks. Please answer each question by circling a number on each of the scales.

1. How satisfied are you with your current renal treatment?
   very satisfied 6 5 4 3 2 1 0 very dissatisfied

2. How well controlled do you feel your renal condition is now?
   very well controlled 6 5 4 3 2 1 0 very poorly controlled

3. How satisfied are you with any side effects of your present renal treatment?
   very satisfied 6 5 4 3 2 1 0 very dissatisfied

4. How satisfied are you with the demands made by your current renal treatment?
   very satisfied 6 5 4 3 2 1 0 very dissatisfied

5. How convenient have you been finding your renal treatment to be recently?
   very convenient 6 5 4 3 2 1 0 very inconvenient

6. How flexible have you been finding your renal treatment to be recently?
   very flexible 6 5 4 3 2 1 0 very inflexible

7. How satisfied are you with the amount of freedom you have with your present renal treatment?
   very satisfied 6 5 4 3 2 1 0 very dissatisfied

8. How satisfied are you with your understanding of the treatment for your renal condition?
   very satisfied 6 5 4 3 2 1 0 very dissatisfied

9. How satisfied are you with the time taken by your present form of renal treatment?
   very satisfied 6 5 4 3 2 1 0 very dissatisfied

10. How satisfied are you with the amount of discomfort or pain involved with your present form of renal treatment?

very satisfied	6	5	4	3	2	1	0	very dissatisfied

11. How satisfied are you with the extent to which the renal treatment fits in with your lifestyle?

very satisfied	6	5	4	3	2	1	0	very dissatisfied

12. Would you recommend this form of renal treatment to someone else with your kind of renal condition?

Yes, I would definitely recommend the treatment	6	5	4	3	2	1	0	No, I would definitely not recommend the treatment

13. How satisfied would you be to continue with your present form of renal treatment?

very satisfied	6	5	4	3	2	1	0	very dissatisfied

The following question is specifically about medication for your renal condition.

14. How often have you taken the medication for your renal condition exactly as recommended?

all of the time	6	5	4	3	2	1	0	none of the time

Please make sure that you have circled one number on each of the scales.

Date completed: .....

Thank you

Health Psychology Research Unit, Orchard Building, Royal Holloway, University of London, Egham, Surrey, TW20 0EX, UK.

Appendix P.

DTSQs

Note. Original DTSQ given to participants prior to SPKT did not mention pancreas transplants in the instructions.

Diabetes Treatment Satisfaction Questionnaire: DTSQs (SPK)

The following questions are concerned with the treatment for your diabetes (including any pancreas transplant, medication and/or diet) and your experience over the past few weeks. Please answer each question by circling a number on each of the scales.

1. How satisfied are you with your current treatment for diabetes?

very satisfied	6	5	4	3	2	1	0	very dissatisfied

2. How often have you felt that your blood sugars have been unacceptably high recently?

most of the time	6	5	4	3	2	1	0	none of the time

3. How often have you felt that your blood sugars have been unacceptably low recently?

most of the time	6	5	4	3	2	1	0	none of the time

4. How convenient have you been finding your diabetes treatment to be recently?

very convenient	6	5	4	3	2	1	0	very inconvenient

5. How flexible have you been finding your diabetes treatment to be recently?

very flexible	6	5	4	3	2	1	0	very inflexible

6. How satisfied are you with your understanding of your treatment for diabetes?

very satisfied	6	5	4	3	2	1	0	very dissatisfied

7. Would you recommend this form of diabetes treatment to someone else with your kind of diabetes and renal condition?

Yes, I would definitely recommend the treatment	6	5	4	3	2	1	0	No, I would definitely not recommend the treatment

8. How satisfied would you be to continue with your present form of treatment for diabetes?

very satisfied	6	5	4	3	2	1	0	very dissatisfied

Please make sure that you have circled one number on each of the scales.

Date completed: .....

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Appendix Q.

EQ-5D-5L and EQ-VAS

(English version for the UK)

Under each heading, please tick the ONE box that best describes your health TODAY

MOBILITY

I have no problems in walking about ❑
I have slight problems in walking about ❑
I have moderate problems in walking about ❑
I have severe problems in walking about ❑
I am unable to walk about ❑

SELF-CARE

I have no problems washing or dressing myself ❑
I have slight problems washing or dressing myself ❑
I have moderate problems washing or dressing myself ❑
I have severe problems washing or dressing myself ❑
I am unable to wash or dress myself ❑

USUAL ACTIVITIES *(e.g. work, study, housework, family or leisure activities)*

I have no problems doing my usual activities ❑
I have slight problems doing my usual activities ❑
I have moderate problems doing my usual activities ❑
I have severe problems doing my usual activities ❑
I am unable to do my usual activities ❑

PAIN / DISCOMFORT

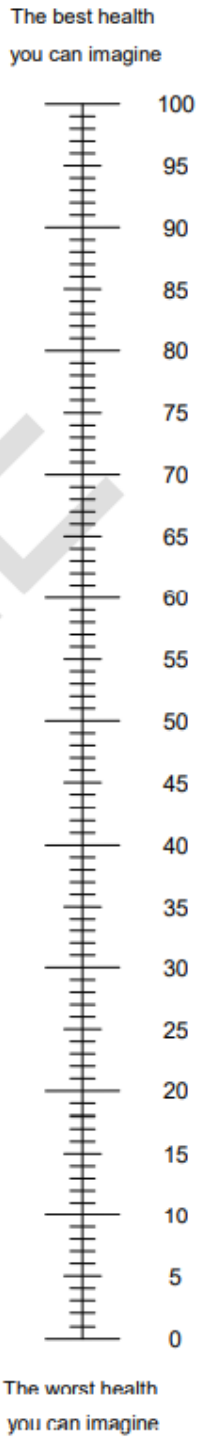
I have no pain or discomfort ❑
I have slight pain or discomfort ❑
I have moderate pain or discomfort ❑
I have severe pain or discomfort ❑
I have extreme pain or discomfort ❑

ANXIETY / DEPRESSION

I am not anxious or depressed ❑
I am slightly anxious or depressed ❑
I am moderately anxious or depressed ❑
I am severely anxious or depressed ❑
I am extremely anxious or depressed ❑

- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the best health you can imagine.
  0 means the worst health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY = ☐



Appendix R.

W-BQ12/16

Note. W-BQ12 includes the first 12 items of W-BQ16.

Well-being Questionnaire (W-BQ16)

Please circle one number on each scale, from 3 (all the time) to 0 (not at all), to indicate how often you feel each statement has applied to you in the past few weeks.

	all the time			not at all
1. I have crying spells or feel like it.....	3	2	1	0
2. I feel downhearted and blue	3	2	1	0
3. I feel afraid for no reason at all.....	3	2	1	0
4. I get upset easily or feel panicky	3	2	1	0
5. I feel energetic, active or vigorous.....	3	2	1	0
6. I feel dull or sluggish.....	3	2	1	0
7. I feel tired, worn out, used up or exhausted.....	3	2	1	0
8. I have been waking up feeling fresh and rested	3	2	1	0
9. I have been happy, satisfied or pleased with my personal life	3	2	1	0
10. I have lived the kind of life I wanted to	3	2	1	0
11. I have felt eager to tackle my daily tasks or make new decisions	3	2	1	0
12. I have felt I could easily handle or cope with any serious problem or major change in my life	3	2	1	0

Continued on the next page...

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To request use of this PROM, please contact: info@healthpsychologyresearch.com

		all the time			not at all
13.	I feel that too many demands are made on me	3	2	1	0
14.	I feel frustrated by obstacles which occur in my life	3	2	1	0
15.	I have too many problems to cope with	3	2	1	0
16.	I feel stressed	3	2	1	0

Please make sure that you have considered each of the 16 statements and have circled one number in response to each statement.

Appendix S.

RSSQ

Renal Service Satisfaction Questionnaire (RSSQ)

The following statements concern aspects of the care you receive for your renal condition at the dialysis centre and/or the hospital. Please circle a number from -2 to +2 on each scale to show how dissatisfied or satisfied you are with each aspect.

If a statement does not apply to you because you have no experience of that aspect of the service, please indicate by circling the 'n/a' beside that statement and note on the back of the page why it doesn't apply to you.

		Dissatisfied	Slightly dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied	
1.	The amount of time spent talking to the staff (including doctors, nurses and other staff)	-2	-1	0	1	2	n/a
2.	The value to you in talking to the staff	-2	-1	0	1	2	n/a
3.	Continuity of care, that is, whether or not you see the same doctor/nurse on each visit	-2	-1	0	1	2	n/a
4.	The extent to which you feel understood by the staff	-2	-1	0	1	2	n/a
5.	Discussing with staff any problems you may have	-2	-1	0	1	2	n/a
6.	Information given to you by the staff regarding your results (e.g. overall renal control)	-2	-1	0	1	2	n/a
7.	Information given to you by the staff regarding treatments and their effects (including unwanted effects)	-2	-1	0	1	2	n/a
8.	How you are treated as a person by the staff	-2	-1	0	1	2	n/a
9.	Ease in making or changing appointments	-2	-1	0	1	2	n/a
10.	The treatment for your renal condition (including medication, dialysis or transplant, and any diet/fluid recommendations)	-2	-1	0	1	2	n/a
11.	Surgical procedures (e.g. catheter insertion, fistula, or transplant)	-2	-1	0	1	2	n/a
12.	Timing of appointments	-2	-1	0	1	2	n/a
13.	Time spent waiting at the renal clinic/unit	-2	-1	0	1	2	n/a
14.	Privacy	-2	-1	0	1	2	n/a
15.	Comfort of the waiting areas	-2	-1	0	1	2	n/a
16.	Availability of refreshments	-2	-1	0	1	2	n/a

		Dissatisfied	Slightly dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied	
17.	Renal education (including books, pamphlets, videos)	-2	-1	0	1	2	n/a
18.	Dietary advice and support	-2	-1	0	1	2	n/a
19.	Psychological advice and support	-2	-1	0	1	2	n/a
20.	Social worker advice and support	-2	-1	0	1	2	n/a
21.	Ease of getting to the hospital/unit (including public transport and/or parking)	-2	-1	0	1	2	n/a
22.	The extent to which staff are caring and supportive	-2	-1	0	1	2	n/a
23.	Accessibility of staff	-2	-1	0	1	2	n/a
24.	Consistency of advice given by different members of staff	-2	-1	0	1	2	n/a
25.	Ease with which staff are able to access hospital notes and recent results	-2	-1	0	1	2	n/a
26.	Cleanliness of the clinic and other treatment areas in the hospital	-2	-1	0	1	2	n/a
27.	Care taken by staff over hygiene (e.g. washing hands before examining patients)	-2	-1	0	1	2	n/a
28.	Opportunities to talk with other patients who have renal failure	-2	-1	0	1	2	n/a
29.	The value to you in talking with other renal patients	-2	-1	0	1	2	n/a
30.	The extent to which renal services within the hospital (including transplant, dialysis, holidays etc) are allocated fairly	-2	-1	0	1	2	n/a
31.	Availability of resources (including preferred treatment, beds, etc)	-2	-1	0	1	2	n/a
32.	Arrangements for giving blood samples for routine measures of renal control (e.g. creatinine and haemoglobin)	-2	-1	0	1	2	n/a
33.	The extent to which computers are used to improve the quality of care you receive.	-2	-1	0	1	2	n/a
34.	Information about, and opportunities to use, new developments	-2	-1	0	1	2	n/a

Please make sure that you have circled one number on each of the scales.

Continued on next page....

In the space below please add sources of dissatisfaction or satisfaction not mentioned above. Comments and suggestions for improvements you may have will be helpful.

Additional problems, sources of dissatisfaction; comments and suggestions for improvement

_____

_____

_____

_____

_____

_____

Additional sources of satisfaction; comments on aspects of the service which you particularly value

_____

_____

_____

_____

_____

_____

Thank you for your help

Appendix T.

RMQ

Renal Medication Questionnaire: RMQ

This questionnaire asks about your kidney medication and your experience of this medication over the past few weeks. We would like you to tell us which immunosuppressant medications (sometimes referred to as anti-rejection medications) you are currently on to protect your transplant.

Examples of immunosuppressant medications include: mycophenolate mofetil/ mycophenolate sodium/ mycophenolic acid (also known as Cellcept, Myfortic, Ceptava, Myfenax); tacrolimus (also known as Prograf, Adoport, Advagraf, Envarsus); ciclosporin (also known as Neoral); sirolimus (also known as Rapamune); azathioprine and prednisolone.

For each different immunosuppressant medication prescribed for you by the doctors treating your kidney condition, please write in the name and prescribed dose in the boxes starting on the next page.

For each different immunosuppressant medication that you list below, please indicate in the boxes provided:

Part a)	Whether or not you take this medication. If you do not take the medication at all, please skip questions (b) to (e) about that medication and go on to the medication listed in the next box.
Part b)	How often you are meant to take this medication. If you have to vary the number of times you take it per day, please give the most usual number of times.
Part c)	When it is meant to be taken (please use BLOCK CAPITALS).
Parts d) and e):	Please circle a number from 0 (none of the time) to 6 (all of the time).

continued on the next page…

Name of medication #1: listed by nurse ☐ or patient ☐	**Prescribed dose**

1a) Do you take this medication?
Yes ☐ No ☐ If ***no***, go to box 2 below.

1b) How often are you meant to take this dose?
per day ☐ per week ☐ per month ☐ other ☐ don't know ☐

1c) When are you meant to take this medication? (e.g. morning ("a.m."), with breakfast, before food, anytime)

1d) How often have you taken this medication exactly as recommended?
none of the time 0 1 2 3 4 5 6 all of the time

1e) How often do you find it inconvenient or difficult to take this medication as recommended?
none of the time 0 1 2 3 4 5 6 all of the time

Name of medication #2: listed by nurse ☐ or patient ☐	**Prescribed dose**

2a) Do you take this medication?
Yes ☐ No ☐ If ***no***, go to box 3 below.

2b) How often are you meant to take this dose?
per day ☐ per week ☐ per month ☐ other ☐ don't know ☐

2c) When are you meant to take this medication? (e.g. morning ("a.m."), with breakfast, before food, anytime)

2d) How often have you taken this medication exactly as recommended?
none of the time 0 1 2 3 4 5 6 all of the time

2e) How often do you find it inconvenient or difficult to take this medication as recommended?
none of the time 0 1 2 3 4 5 6 all of the time

continued on the next page...

Name of medication #3: listed by nurse ☐ or patient ☐	**Prescribed dose**

3a) Do you take this medication?
Yes ☐ No ☐ If ***no***, go to box 4 below.

3b) How often are you meant to take this dose?
per day ☐ per week ☐ per month ☐ other ☐ don't know ☐

3c) When are you meant to take this medication? (e.g. morning ("a.m."), with breakfast, before food ,anytime)

3d) How often have you taken this medication exactly as recommended?
none of the time 0 1 2 3 4 5 6 all of the time

3e) How often do you find it inconvenient or difficult to take this medication as recommended?
none of the time 0 1 2 3 4 5 6 all of the time

Name of medication #4: listed by nurse ☐ or patient ☐	**Prescribed dose**

4a) Do you take this medication?
Yes ☐ No ☐ If ***no***, ignore this item.

4b) How often are you meant to take this dose?
per day ☐ per week ☐ per month ☐ other ☐ don't know ☐

4c) When are you meant to take this medication? (e.g. morning ("a.m."), with breakfast, before food ,anytime)

4d) How often have you taken this medication exactly as recommended?
none of the time 0 1 2 3 4 5 6 all of the time

4e) How often do you find it inconvenient or difficult to take this medication as recommended?
none of the time 0 1 2 3 4 5 6 all of the time

Thank you for completing this questionnaire.

Appendix U.

Study 1 Qualitative Interview Schedule for Kidney-only Transplant Recipients

Interview schedule

First, could you please tell me about your experience of having a kidney condition before you received a kidney transplant?

When and how did you first find out you were having kidney problems?

How did your kidney problems develop/progress?

What sort of symptoms did you experience, if any?

Can you tell me about your kidney treatment?

How well do you feel you understood your kidney problems?

How much control did you feel you had over your kidney condition before the transplant and in what way?

What impact did your kidney condition and treatment have on your life?

What impact did your kidney condition have on work/leisure activities/social life/family life?

What was the biggest impact of your kidney condition?

Can you tell me about the process you went through when you were added to the transplant waiting list?

What sort of information were you given about transplantation?

How did you feel about being on the waiting list?

Was the option of having a deceased-donor/living-donor transplant discussed with you and did you consider this option?

How did you feel about the idea of having a deceased-donor/living-donor kidney transplant?

Did you approach any family or friends about this?

Did you feel able to talk about it?

How differently do you think you would have felt about accepting a deceased-donor/living- donor transplant from someone you knew?

In what ways do you think the experience would have been more positive or negative, if at all?

Would you mind telling me about the time when you had your transplant?

What happened?

How did you feel during this time?

How did the kidney transplant impact on your life initially?

Now that it has been several years since your transplant, how has the transplant impacted your life?

In what ways do you think your life has been most impacted?

In the questionnaires that you completed recently, you reported that overall, your quality of life is excellent/very good/good/neither good nor bad/bad/very bad/extremely bad.

You said that your renal condition does not/does still have a negative impact on your quality of life.

From the questionnaire on quality of life that you recently completed, I can see that the aspect(s) of your life that appears to be most impacted by your renal condition are: List most impacted and important aspects of life from the participant's RDQoL questionnaire.

Can you tell me in what ways your kidney condition impacts on …….? (Discuss most impacted aspects of life one at a time.)

You also completed questionnaires about your treatment satisfaction and it appears that you are very satisfied/satisfied/not very satisfied with your kidney treatment.

Can you tell me about your treatment?

I can see that you appear to be most satisfied with… **Can you tell me about that?**

I can see that you are least satisfied with… **Can you tell me about that?**

Now I would like to discuss with you how you have adjusted and how you have coped with having a kidney transplant.

How have you adjusted since having the transplant?

Have you had any difficulties since the transplant and how did you deal with them?

What strategies have you use to help you cope with difficulties?

What sort of resources do you use, if any?

What support do you get, if any, from others in relation to your kidney condition?

Do you feel that you have control over you kidney condition/health and in what way?

When you were waiting for your kidney transplant what expectations did you have about life after the transplant, if any, and have they been met?

The closing

Now we are nearing the end of the interview. Thank you for sharing your experience with me, you have been very helpful in improving my understanding of the impact of having a kidney transplant.

Is there anything else you can think of that would be helpful for me to know to have an accurate record of your experience?

Thank you, I'm now going to turn off the recorder.

Appendix V.

Study 1 Qualitative Interview Schedule for SPKT Recipients

Interview schedule

First, could you please tell me about your experience of living with diabetes and a kidney condition before you received a pancreas and kidney transplant?

What sort of symptoms did you experience, if any?

Did you suffer from diabetes complications and what were they?

When and how did you first find out you were having kidney problems?

How did your kidney problems develop/progress?

Can you tell me about your diabetes treatments?

Can you tell me about your kidney treatment?

What impact did your diabetes have on your life?

What impact did your kidney condition have on your life?

How well do you feel you understood diabetes and your kidney problems?

How much control did you feel you had over your diabetes and kidney condition before the transplant?

Can you tell me about the process you went through when you were added to the transplant waiting list?

What options were discussed with you?

What sort of information were you given about transplantation?

How did you feel about being on the waiting list for a pancreas and kidney transplant?

Next, could you please tell me about the time when you received your pancreas and kidney transplant?

What happened?

How did you feel during this time?

How did the transplant impact on your life initially?

Now that it has been several years since your transplant, how has the transplant most impacted your life and quality of life?

In what ways do you think your life has been most impacted?

In the questionnaires that you completed recently, you reported that overall, your quality of life is excellent/very good/good/neither good nor bad/bad/very bad/extremely bad.
From the questionnaires I can see that having had **diabetes** appears to continue to negatively impact certain aspects of your quality of life including**:** List most impacted and important aspects of life from the participant's ADDQoL questionnaire.
Can you tell me in what ways having had diabetes impacts on…?
(Discuss most impacted aspects of life one at a time.)

The aspect(s) of your life that appear to continue to be negatively impacted by having had a **kidney condition** are**:** List most impacted and important aspects of life from the participant's RDQoL questionnaire.
Can you tell me in what ways your kidney condition impacts on…?
(Discuss most impacted aspects of life one at a time.)

You also completed questionnaires about your treatment satisfaction and it appears that you are very satisfied/satisfied/not very satisfied with your **diabetes** treatment.
Can you tell me a about your diabetes treatment?
I can see that you are most satisfied with**… Can you tell me about that?**
I can see that you are least satisfied with**… Can you tell me about that?**

From your responses to the questionnaire on your **kidney** treatment satisfaction it appears you are very satisfied/satisfied/not very satisfied.
I can see that you are most satisfied with... **Can you tell me about that?**
I can see that you are least satisfied with... **Can you tell me about that?**

Now I would like to discuss with you how you have adjusted to having a pancreas and kidney transplant.

How have you adjusted since having the pancreas and kidney transplant?

Have you had any difficulties since the transplant and how did you deal with them?

What strategies have you use to help you cope with any difficulties?

What sort of resources do you use, if any?

What support do you get, if any, from others in relation to your dealing with your transplant and treatment?

Do you feel that you have control over your health and in what way?

When you were waiting for your pancreas and kidney transplant, what expectations did you have about life after the transplant, if any, and have they been met?

The closing

Now we are nearing the end of the interview. Thank you for sharing your experience with me, you have been very helpful in improving my understanding of the impact of having a pancreas and kidney transplant.

Is there anything else you can think of that would be helpful for me to know to have an accurate record of your experience?

Thank you, I'm now going to turn off the recorder.

Appendix W.

Study 2 Recruitment Guide

Eligibility criteria

Patients are eligible to take part in the research if they are:
Aged 18 years or older.
On/being added to the waiting list for a pancreas + kidney (simultaneous/combined/dual) transplant.
Are fluent in English.
Have the capacity to consent to take part.

Face to face recruitment guide - introduction to research

Hello, I am …… [Introduce yourself, unless the patient already knows you].

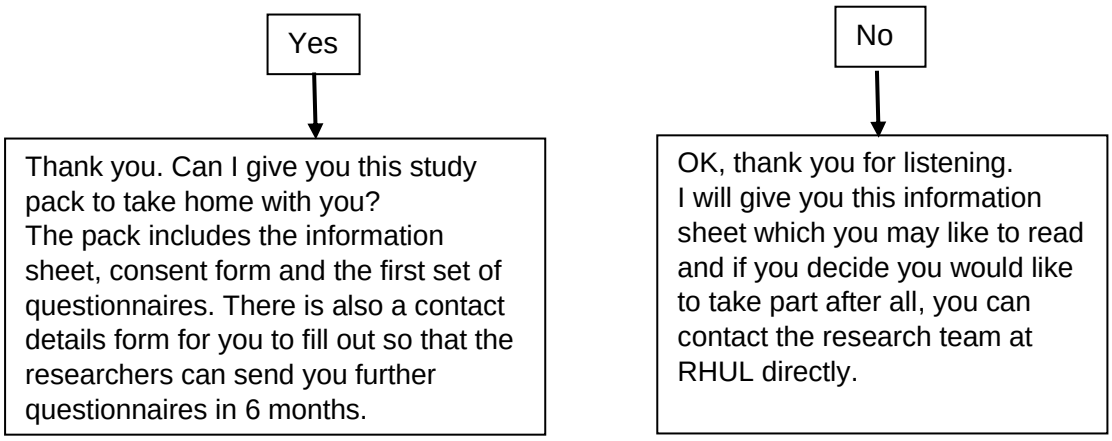
I am currently helping a research team from Royal Holloway, University of London to recruit patients who are on the pancreas and kidney transplant waiting. The questionnaire study is an investigation of quality of life and other patient-reported outcomes before and after transplantation. The research aims to gain a better understanding of the impact of having a pancreas and kidney transplant on patients' lives.

Taking part in the research is voluntary and your treatment will not be affected whether you decide to take part or not.

If you do take part in the research this will involve filling out the first pack of questionnaires as soon as possible and sending that back to the researchers at Royal Holloway in the stamped-addressed-envelope provided. You would then be sent further questionnaires in approximately 6 months and 12 months time if you are still on the transplant waiting list, or 12 months after you receive your transplant.

If you think you might be interested in taking part in the research I have an information sheet here for you that contains more information on the study and contact details for the research team at Royal Holloway so that you can contact them if you have any questions. If you decide to take part you will need to complete the consent form by initialling in each box and signing at the bottom to indicate that you agree to being involved in the research. If you consent to take part you can still decide to stop at any point in future.

Do you think you might be interested in taking part in the research?



Postal recruitment

Invitation letter – to be printed on headed paper and sent by each collaborating renal unit to patients already on the SPK waiting list. This may be edited by the renal units to fit their own style although the content will remain the same.

Patient name
Patient address
Patient address

Date

Dear [patient name],

At [hospital/renal unit name] we are currently collaborating with researchers from the Health Psychology Research Unit at Royal Holloway, University of London (RHUL) on a research study. The study is an investigation of quality of life and other patient-reported outcomes before and after a pancreas and kidney transplant (also referred to as a simultaneous, combined, or dual transplant). We would like to invite you to take part in this research.

Enclosed you will find a participant information sheet that explains the research study in detail. The contact details for the research team at RHUL are provided so that you can ask any questions you may have on the research. Participation in the study will involve completing the enclosed questionnaire pack which includes questionnaires asking you about your health, well-being, quality of life, treatment satisfaction and your perceptions of your diabetes and renal condition. A similar but much shorter questionnaire pack would then be sent to you approximately 6 months later and a further questionnaire pack would be sent to you in another 6 months or 12 months after you've had a transplant, depending on when you get a transplant. Some participants may also be invited to take part in an interview.

Participation in research is voluntary, whether you take part is up to you and your decision will not affect your healthcare treatment in anyway. If you decide you would like to take part you can always change your mind at a later date and stop without this having any impact on your treatment or rights. Taking part would not require you to attend any additional appointments and you would not need to travel anywhere.

If you think you would like to take part in the research, please read the information sheet provided. If you do decide to participate in the study you will need to provide consent by completing the enclosed consent form and sending it, along with the completed questionnaire pack and contact details form, to the research team at RHUL in the stamped addressed envelope provided.

Thank you for taking the time to read this invitation.

Yours faithfully,

[signed off by member of the renal unit]

Appendix X.

Study 2 Information Sheet

Cambridge University Hospitals NHS
NHS Foundation Trust

Guy's and St Thomas' NHS
NHS Foundation Trust

NHS
Lothian

Patient-reported outcomes of CKD and diabetes treatments (version 1.2)

Simultaneous pancreas and kidney transplantation: A longitudinal study of patient-reported outcomes

Invitation

You are being invited to take part in the above research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take some time to read the following information carefully and discuss it with friends, relatives and your renal team if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.
Thank you for reading this.

1. What is the purpose of the study?

This study forms part of a PhD research programme funded by Royal Holloway, University of London. The aim of this study is to investigate patient-reported outcomes such as quality of life of people who need a pancreas and kidney transplant. This type of transplant is also known as a simultaneous pancreas and kidney (SPK), a dual, or combined pancreas and kidney transplant. We would also like to interview people who need this type of transplant to explore their experiences of being on the waiting list and receiving a pancreas and kidney transplant.

Chronic medical conditions such as diabetes and kidney disease impact on families, as well as the person with the condition. So we would also like to speak with some partners of people who need or have received a transplant about their experiences.

This research will help us to understand how this type of transplant affects peoples' lives. Our findings may help future patients make decisions about their treatment.

2. Why have I been invited?

You have been invited to take part in this study because you have diabetes, a chronic kidney condition, and you are on the waiting list for a simultaneous pancreas and kidney transplant. We are interested in finding out about the impact of this type of transplant on patients' lives by exploring quality of life and other patient-reported outcomes.

3. Do I have to take part?

Participation in this study is voluntary, it is up to you to decide whether or not to take part. Your care will not be affected whether you decide to take part in the research or not. If you decide to take part you are still free to withdraw at any time and without giving a reason. If you do withdraw we will still use the data you provided up until that point, unless you specifically ask us to delete all of your data. Once reports have been written we will not be able to remove your data, however you will not be identifiable.

If you lose the capacity to consent to taking part in this research you will be withdrawn from the study and we will only use the data you provided to us whilst you were still able to give informed consent.

4. What will happen to me if I take part and what do I have to do?

If you agree to take part in this study, we would like you to complete a questionnaire pack a maximum of 4 times over approximately 24 months. We would like you to complete the first questionnaire pack as soon as possible. A shorter pack will then be sent to you 6 months later. If you are still waiting for a transplant 12 months from now you will receive a third questionnaire pack. If you receive a transplant during the study, we will send you the last questionnaire pack approximately 12 months later.

The questionnaire pack includes a general information questionnaire to tell us more about you (your gender, education, employment) and about your general health (your diabetes and any other medical conditions). A number of questionnaires are included in the pack. These ask questions about your quality of life, well-being, and treatment satisfaction. The first and last questionnaire packs we will send you could take around 45-60 minutes to complete. However, the questionnaire pack sent to you at 6 months should only take around 20 minutes to complete. Depending on if and when you receive a transplant during our study period, you may only complete 2 questionnaire packs, or 3 or all 4.

If you do decide to take part you should keep a copy of this information sheet. You will also need to complete the consent form. You can return the first questionnaire pack, along with the consent form, using the stamp-addressed envelope. If you would prefer to complete the measures over the telephone you can contact Ms Katie Hann, a PhD student sponsored by Royal Holloway, University of London (RHUL).

We would like to tell your renal clinician that you are taking part so that they can tell us if your treatment changes, for example if you receive a transplant. This is so that we know when to send you the next questionnaire pack. We will not share your completed questionnaires with your renal clinician without your permission.

We would also like you to agree to be contacted to take part in either a telephone interview or a face-to-face interview at Guy's Hospital with the PhD student, Katie Hann. Whether you take part in a telephone or face-to-face interview will be your choice. If you choose to take part in a face-to-face interview we will try to book a private room for the interview at a convenient time for you, for example on a day when you will already be attending an appointment at the hospital. If you decide to take part in the questionnaire study, you do not have to also take part in the interview. Not everyone who agrees to be contacted for an interview will be asked to take part. We intend to select participants for the interviews according to responses on the questionnaires and so that we have a group of men and women of different ages. The interview would last approximately one hour, but this would depend on how much you have to say about your experiences of diabetes, chronic kidney disease and treatment. We would like to audio-record the interview so that it can be analysed for our research. If you are invited to take part but no longer wish to be interviewed you are free to withdraw.

Lastly, we would like you to tell us if you have a long-term partner who may be interested in taking part in an interview. By long-term partner we mean someone that you have been in a relationship with for at least the past year. With your permission and the contact details you provide us with, we will contact your partner separately and invite them to take part in an interview. If you and your partner would both like to take part we will interview you individually. Anything that you say will be kept confidential and will not be shared or matched with your partner.

You will not be required to attend any extra clinics or have additional tests or receive extra drugs or medicines. Your standard renal and diabetes treatment will not be affected in any way by participating or not participating in the study.

5. Is there a drug or procedure being tested?

There are no drugs, medical devices or other treatments being tested in this study. There will be no change to your treatment or standard of care.

6. Are there any side effects from taking part?

There are no side effects of taking part in this study, because we are not testing any new medicines.

7. What are the possible disadvantages and risks of taking part?

There are no risks to your health or any changes to your treatment if you agree to take part in this study. You will be required to complete some questionnaires and this could take up to 3 hours 20 minutes of your time across approximately 24 months. If you or your partner are contacted for an interview this could also take up about an hour of your time or theirs.

Although unlikely, there is a small risk that you may become upset when completing the questionnaires or interview. Advice is available from Prof Clare Bradley, Professor of Health Psychology, Health Psychology Research Unit, Orchard Building, Royal Holloway, University of London: email c.bradley@rhul.ac.uk, telephone 01784 443708/01784 443714.

Information on kidney disease and support can be found on the Kidney Care UK and the National Kidney Federation (NKF) UK websites:
https://www.kidneycareuk.org/get-support/
http://www.kidney.org.uk/

A free helpline is also provided by the NKF on: 0800 1690936

8. What are the possible benefits of taking part?

There will be no direct benefit of taking part in this research for you personally. However, the information we get from this study may help healthcare professionals to advise and treat future patients with a kidney condition.

9. What happens when the research study stops?

At the end of the research your care continues as usual. You may be contacted to take part in future research but only if you consent to this.

10. What if something goes wrong?

Since the study is only asking you to fill in questionnaires or to be interviewed, it is very unlikely that something will go wrong. If you wish to complain about any aspect of this study, you can contact Prof Clare Bradley, Professor of Health Psychology, Health Psychology Research Unit, Orchard Building, Royal Holloway, University of London: email c.bradley@rhul.ac.uk, telephone 01784 443708/01784 443714.

11. Will my taking part in this study be kept confidential?

All information which is collected during the course of the study will be kept confidential. Only the research team has access to the information, and this will be stored safely. Your data will be anonymized using a participant identification code. Any identifying information about you will be removed from any reports or publications so that you cannot be recognized from it.

12. What will happen to the results of the research study?

The results of this study will be submitted for publication in national and international journals. You will not be identified in any reports or publications. At the end of the study a newsletter will be produced to provide details of our findings, this can be sent to you if you indicate an interest in receiving it (on the consent form below).

13. Who is organising and funding the research?

This study is part of a PhD studentship, supported by Royal Holloway, University of London.

14. Who has reviewed the study?

The study has been reviewed by an NHS Research Ethics Committee.

15. Contacts for Further Information

If you do require additional information on this research or if you wish to complete the measures over the telephone, please contact the PhD student, Katie Hann:

Miss Katie Hann
Orchard Building
Royal Holloway, University of London
Egham, Surrey
TW20 0EX
Tel: 01784 443718
Email: Katie.hann.2008@live.rhul.ac.uk

For independent advice you can contact your local Patient Advice and Liaison Service (PALS) by visiting www.nhs.uk and searching for 'Find Patient advice and liaison services (PALS)'.

Alternatively, you can contact the Guy's and St Thomas' office:
Patient Advice & Liaison Service
St Thomas' Hospital
Westminster Bridge Road
London
SE1 7EH
Tel: 020 7188 8801

Thank you for taking the time to read the study information. We hope you agree to take part in this study.

.

Appendix Y.

Study 2 Consent Form

Cambridge University Hospitals NHS
NHS Foundation Trust

Guy's and St Thomas' NHS
NHS Foundation Trust

NHS
Lothian

CONSENT FORM

Patient-reported outcomes in CKD and diabetes treatments (version 1.2)

Simultaneous pancreas and kidney transplantation: A longitudinal study of patient-reported outcomes

Name of Researcher: Katie Hann (Chief investigator – Prof. Clare Bradley)

Please read each statement carefully	**Please initial box**
1. I confirm that I have read and understand the information sheet dated 21/02/18 (version 1.2) for the above study. I have had the opportunity to ask questions and any questions that I have asked have been answered satisfactorily	☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason and without my medical care or legal rights being affected.	☐
3. I agree to my renal team being informed about my participation in this study and for them to update the research team on any changes to my treatment.	☐
4. I understand that I will be asked to complete up to 4 questionnaire packs including patient-reported outcome measures, and I agree to this.	☐
5. I understand that I may be asked to participate in an interview with the PhD student and I give my permission to be contacted to arrange an interview. (If you prefer not to do an interview leave this box and the one below blank.)	☐
6. I agree with the audio-recording of the interview if invited.	☐
7. I would like to be sent a newsletter detailing the findings at the end of the study.	☐

8. I would be interested in being involved in other research in future and I consent to being contacted for this. (If you prefer not to be invited to take part in other future research please leave this box blank.) ☐

9. Do you have a long-term partner? (Please circle response below)

Yes No

If yes, may we contact them to invite them to take part in an interview?

Yes No

I understand that you may contact my partner to invite them to take part in an interview if I provide their contact details ☐

.....	.....	.....
Name of Patient	Date	Signature

.....	.....	.....
Researcher	Date	Signature

Please keep one copy and send one copy to the researchers with the questionnaire pack.

Appendix Z.

Study 2 Contact Details Form for Participants and Partners

Your contact details

Thank you for completing the first questionnaire pack. If you are willing to continue to take part in this study and receive further questionnaires or you would like to take part in the interview, please write down your contact details below.

Name _____

Telephone _____

Postal address _____

_____

_____

_____

Email address _____

If you are willing to be contacted about taking part in an interview, how would you prefer to be interviewed?

☐ No preference

☐ Face-to-face (in person)

☐ Over the telephone

(*Note. This was only included for participants recruited through Guy's Hospital)*

Your partner's contact details

As part of the PhD research project, we would also like to explore the experiences of the partners of patients awaiting or already having undergone a simultaneous pancreas and kidney transplant. If you have a partner who may like to be invited to complete a questionnaire and take part in a telephone interview, please provide their contact details below.

Name _____

Telephone _____

Postal address _____

_____

_____

Email address _____

If you are willing to be contacted about taking part in an interview, how would you prefer to be interviewed?

☐ No preference

☐ Face-to-face (in person)

☐ Over the telephone

(*Note. This was only included for participants recruited through Guy's Hospital)*

For more information or to ask questions please contact the research team:

Ms Katie Hann, PhD Researcher
Dr Andrea Gibbons, Research Fellow
Prof Clare Bradley, Professor of Health Psychology
Health Psychology Research Unit,
Royal Holloway, University of London,
Egham, TW20 0EX.
Telephone: 01784 443718 or 01784 443714

Appendix AA.

Study 2 Recruitment Reminder Letter Template and Response form

Patient name
Patient address
Patient address

Date

Dear [patient name],

At [hospital/renal unit name] we are currently collaborating with researchers from the Health Psychology Research Unit at Royal Holloway, University of London (RHUL) on a research study. The study is an investigation of quality of life and other patient-reported outcomes before and after a pancreas and kidney transplant (also known as a simultaneous, combined, or dual transplant).

Participation in the study will involve completing questionnaires about your quality of life, health, well-being, treatment satisfaction and your perceptions of your diabetes and renal condition. The researchers would then ask you to complete a similar but shorter questionnaire pack approximately 6 months later and a further questionnaire pack in another 6 months or 12 months after you've had a transplant, depending on when you get a transplant. You may also be invited to take part in an in-depth telephone interview if you consent to be contacted about this.

We are contacting you to check that you received the first questionnaire pack previously sent to you in the post and to remind you that you can complete the questionnaires over the telephone with the PhD student, Katie Hann, if you would prefer. If you have not received the questionnaire pack, have mislaid it, or if you would like to complete the questionnaires over the telephone please return the enclosed reply slip directly to the research team in the stamped addressed envelope provided. It would also be useful for the researchers to know your reasons if you decide not to take part, so that they can understand patient participation in research and improve future research.

Research participation is voluntary, whether you take part is up to you and your decision will not affect your healthcare treatment in any way. If you decide you would like to take part you can always change your mind at a later date and stop without this having any impact on your treatment or rights. Taking part would not involve any additional appointments or travel.

Thank you for taking the time to consider this study.

Yours sincerely,

[signed off by member of the renal unit]

For more information or to ask questions please contact the research team:

Ms Katie Hann, PhD Researcher
Dr Andrea Gibbons, Research Fellow
Prof Clare Bradley, Professor of Health Psychology

Health Psychology Research Unit,
Royal Holloway, University of London,
Egham,
TW20 0EX.

Telephone: 01784 443718 or 01784 443714
Email: katie.hann.2008@live.rhul.ac.uk

Simultaneous pancreas and kidney transplantation: A longitudinal study of patient-reported outcomes

Thank you for taking the time to consider this research.

Please indicate below whether or not you are interested in taking part in this study:

☐ No, I am not interested in taking part because… (it will be helpful to know your reason(s) but you are of course free to leave this section blank)

……

……..

☐ Yes, I am interested in taking part but I have not received or I have misplaced the first questionnaire pack.

☐ Yes, I am interested in taking part but I would like to complete the questionnaires over the telephone.

If you are interested in taking part please provide your contact details below so that the research team from Royal Holloway can respond if needed.

Name…….

Telephone…….

Postal address……..

……..

Email……

Please return this page to: Ms Katie Hann, Health Psychology Research Unit, Royal Holloway, University of London, Egham, Surrey, TW20 0EX, in the stamped, addressed envelope provided.

Appendix BB.

Study 2 General Information/Demographic Questionnaire

Patient-reported outcomes of CKD and diabetes treatments (version 1.2)

Simultaneous pancreas and kidney transplantation: A longitudinal study of patient-reported outcomes

General Information Questionnaire

Wherever options are provided with boxes, please put a '✓' in any box that applies.

1. Date of birth:	DD/MM/YYYY	**2. Gender:**	Male ☐ Female ☐

3. What is your marital status?	
Married/Civil partnership or living with partner	☐
Widowed	☐
Divorced or separated	☐
Single	☐

4a. Are you in full-time education?

Yes ☐ Please specify: ……

No ☐

4b. What is the highest level of education you have obtained?

No formal qualifications	☐	NVQ level 4-5	☐
O level/GCSE or equivalent	☐	First Degree	☐
A Level or equivalent	☐	Higher degree	☐
National Vocational Qualification (NVQ) level 1-3	☐	Other qualification(s)	☐

If 'Other', please specify: ……

……

5. Please indicate your current employment status below:		
Working full-time		☐
Working part-time	due to kidney condition	☐
	due to other health problems	☐
	by choice	☐
Unable to work	due to kidney condition	☐
	due to other health problems	☐
Able to work	but cannot find work	☐
	but choose not to	☐
Retired	early due to kidney condition	☐
	early due to other health problems	☐
	early by choice	☐
	at the usual retirement age for my work	☐

6. Please indicate your ethnic group below:		
White	British	☐
	Irish	☐
	Scottish	☐
	Other, please state	☐ .....
Asian or Asian British	Indian	☐
	Pakistani	☐
	Bangladeshi	☐
	Chinese	☐
	Other, please state	☐ .....
Black or Black British	Caribbean	☐
	African	☐
	Other, please state	☐ .....

Continues on next page.

Mixed	White & Black Caribbean	☐
	White & Black African	☐
	White & Asian	☐
	Other, please state	☐ .....
Other ethnic group	Any other ethnic group, please state	☐.....

7. Were you born in the UK?

Yes ☐ Please go to question 8a.

No ☐ For how long have you lived in the UK? ……years ……..months.

8a. Is English your first language?

Yes ☐ Please go to question 9.

No ☐ Please continue with question 8b & c.

8b. What is your first language?

……

8c. Please rate your fluency in English on the scale below by circling the <u>number</u> that applies to you:

Very basic **Very fluent**

1 2 3 4 5 6 7

9. We would like to calculate your body mass index (BMI).

What is your weight? ……

What is your height? …….....

10. What treatment are you <u>currently</u> receiving or <u>most recently</u> received for your kidney condition?

None ☐

Haemodialysis (hospital-based) ☐

Haemodialysis (home-based) ☐

Continues on next page.

Continuous ambulatory peritoneal dialysis	☐
Automated peritoneal dialysis (overnight machine)	☐
Other, please specify	☐ ……

11. When were you added to the waiting list for a (simultaneous/combined/dual) pancreas + kidney transplant (approximately)?	DD/MM/YYYY

12. Have you <u>previously</u> had one or more kidney or pancreas + kidney transplant (other than any current working transplant)?

No ☐ Please go to question 13a.

Yes ☐ Please provide the approximate date(s) of the transplant(s): ……

……..

13a. What type of diabetes are you diagnosed with?

Type 1 ☐ Type 2 ☐ Other ☐ Not sure ☐

If 'Other', please specify: …….

13b. When was your diabetes diagnosed (approximately)?

DD/MM/YYYY

13c. What medications, including insulin(s), are you taking to treat your diabetes?

…….

…….

…….

13d. If you are taking insulin, which type of regimen are you on?

Not applicable	☐ Please go to question 13e.
Two injections a day with mixed insulin	☐
Basal/bolus regimen with fixed doses at fixed meal times	☐
Basal/bolus regimen with flexible doses at fixed meal times	☐ Continues on next page.

Basal/bolus regimen with flexible doses and flexible timing of meals	☐
Insulin pump	☐
Other	☐

If other, please describe: …….....

……..

13e. Do you worry about your blood sugar levels being too high?
(Please circle whichever applies to you.)

always	often	sometimes	rarely	never
1	2	3	4	5

13f. Do you restrict your diet / avoid sugary foods and drinks?

always	often	sometimes	rarely	never
1	2	3	4	5

14a. Have you experienced any recent or ongoing complications due to your diabetes?

No ☐ Please go to question 15a.

Yes ☐ Please tick and specify which complication(s):

Eye problems (e.g. cataracts, diabetic retinopathy)	☐ ……
Nerve problems (e.g. tingling, numbness, shooting pains)	☐ ……
Foot problems (e.g. ulcers, injuries)	☐ ……
Amputation	☐ ……
Diabetic ketoacidosis (risking or experiencing a high sugar coma)	☐ ……
Severe hypoglycaemia (requiring assistance from another person)	☐ ……
Other, please specify	☐ ……

15a. Do you have any medical conditions other than your kidney condition and diabetes?

No ☐ Please go to question 16.

Yes ☐ Please tick and specify as needed:

Anaemia	☐	.....
High blood pressure	☐	.....
Liver disease	☐	.....
Joint problems (e.g. rheumatoid arthritis)	☐	.....
Lung problems (e.g. asthma)	☐	.....
Cancer (e.g. lung, breast cancer)	☐	.....
Stroke or mini-stroke (TIA)	☐	.....
Heart problems (e.g. previous heart attack, angina, heart failure)	☐	.....
Circulatory problems (e.g. in legs causing pain when walking)	☐	.....
Chronic viral infection (e.g. HIV, hepatitis B or C)	☐	.....
Memory problems (e.g. dementia, Alzheimer's)	☐	.....
Mental health problems (e.g. depression, anxiety)	☐	.....
Other, please state:	☐	.....

16. Are you registered as (severely) visually impaired?

No ☐

Yes, visually impaired (previously termed "partially sighted") ☐

Yes, severely impaired (previously termed "blind") ☐

17a. Are you registered as disabled?

Yes ☐ No ☐ If 'No', please go to question 18.

17b. Are you disabled due to your kidney condition?

Yes ☐ No ☐

17c. Are you disabled due to other health problems?

Yes ☐ No ☐

If 'Yes', please specify:

……

17d. Please state what your disability is:

……..
.

18. In the past year have you experienced any stressful major life events that may have impacted on your current health and well-being?

No ☐ Please go to question 19.

Yes ☐ Please describe:

19. How often do you need to have someone help you when you read instructions, pamphlets or other written material from your doctor or pharmacy? (Please circle whichever applies to you.)

Never	Rarely	Sometimes	Often	Always
1	2	3	4	5

Date of completion of this questionnaire booklet: DD/MM/20YY

If you have any queries please contact:

Katie Hann, BSc, MSc.
Orchard Building
Royal Holloway, University of London
Egham, Surrey
TW20 0EX
Tel: 01784 443718
Email: katie.hann.2008@live.rhul.ac.uk

Thank you for taking the time to complete these questionnaires.

Appendix CC.

Brief IPQ (renal)

The Brief Illness Perceptions Questionnaire (renal)

For the following questions, please circle the number that best refers to your views:

1. How much does your renal condition affect your life?											
No affect at all	0	1	2	3	4	5	6	7	8	9	10	Severely affects my life
2. How long do you think your renal condition will last?											
A very short time	0	1	2	3	4	5	6	7	8	9	10	Forever
3. How much do you feel that you have control over your renal condition?											
Absolutely no control	0	1	2	3	4	5	6	7	8	9	10	Extreme amount of control
4. How much do you think your treatment (including medications) can help your renal condition?											
Not at all	0	1	2	3	4	5	6	7	8	9	10	Extremely helpful
5. How much do you experience symptoms from your renal treatment (including medications)?											
No symptoms at all	0	1	2	3	4	5	6	7	8	9	10	Many severe symptoms
6. How much do you experience symptoms from your renal condition and any complications of your renal condition?											
No symptoms at all	0	1	2	3	4	5	6	7	8	9	10	Many severe symptoms
7. How concerned are you about your renal condition?											
Not at all concerned	0	1	2	3	4	5	6	7	8	9	10	Extremely concerned
8. How well do you feel you understand your renal condition?											
Don't understand at all	0	1	2	3	4	5	6	7	8	9	10	Understand very clearly
9. How much does your renal condition affect you emotionally?											
Not at all affected emotionally	0	1	2	3	4	5	6	7	8	9	10	Extremely affected emotionally

10. Please list in rank-order the three most important factors that you believe caused your renal condition.

The most important causes for me are:

1.

2.

3.

Adapted from the Brief IPQ: Broadbent, E., Petrie, K.J., Main, J., & Weinman, J. (2006). The Brief Illness Perception Questionnaire (BIPQ). *Journal of Psychosomatic Research, 60,* 631-637

Appendix DD.

Brief IPQ (diabetes)

The Brief Illness Perceptions Questionnaire (diabetes)

For the following questions, please circle the number that best refers to your views:

1. How much does your diabetes affect your life?											
No affect at all	0	1	2	3	4	5	6	7	8	9	10	Severely affects my life
2. How long do you think your diabetes will last?											
A very short time	0	1	2	3	4	5	6	7	8	9	10	Forever
3. How much do you feel that you have control over your diabetes?											
Absolutely no control	0	1	2	3	4	5	6	7	8	9	10	Extreme amount of control
4. How much do you think your treatment (including medications) can help your diabetes?											
Not at all	0	1	2	3	4	5	6	7	8	9	10	Extremely helpful
5. How much do you experience symptoms from your diabetes treatment (including medications)?											
No symptoms at all	0	1	2	3	4	5	6	7	8	9	10	Many severe symptoms
6. How much do you experience symptoms from your diabetes and any complications of diabetes?											
No symptoms at all	0	1	2	3	4	5	6	7	8	9	10	Many severe symptoms
7. How concerned are you about your diabetes?											
Not at all concerned	0	1	2	3	4	5	6	7	8	9	10	Extremely concerned
8. How well do you feel you understand your diabetes?											
Don't understand at all	0	1	2	3	4	5	6	7	8	9	10	Understand very clearly
9. How much does your diabetes affect you emotionally?											
Not at all affected emotionally	0	1	2	3	4	5	6	7	8	9	10	Extremely affected emotionally
10. Please list in rank-order the three most important factors that you believe caused your diabetes.											
The most important causes for me are:											
1.											
2.											
3.											

Adapted from the Brief IPQ: Broadbent, E., Petrie, K.J., Main, J., & Weinman, J. (2006). The Brief Illness Perception Questionnaire (BIPQ). *Journal of Psychosomatic Research, 60,* 631-637

Appendix EE.

RTSQ change version

Note: Instructions were slightly different on the RTSQc for participants who were still wait-listed at follow-up.

Renal Treatment Satisfaction Questionnaire (change): RTSQc

Approximately 12 months ago you had a transplant whilst taking part in a study about your renal treatment. Today we would like to know about your experience of your current renal treatment (which may include a kidney transplant, some form of dialysis, medication, dietary and/or fluid requirements/restrictions). Please compare it with your experience of renal treatment before you had the transplant 12 months ago. Please answer each question by circling a number on each of the scales. If you have experienced no change in your satisfaction with treatment, please circle '0'.

1. How satisfied are you with your current renal treatment?

much more satisfied now	3	2	1	0	-1	-2	-3	much less satisfied now

2. How well controlled do you feel your renal condition is now?

much better controlled now	3	2	1	0	-1	-2	-3	much less well controlled now

3. How satisfied are you with any side effects of your present renal treatment?

much more satisfied now	3	2	1	0	-1	-2	-3	much less satisfied now

4. How satisfied are you with the demands made by your current renal treatment?

much more satisfied now	3	2	1	0	-1	-2	-3	much less satisfied now

5. How convenient have you been finding your renal treatment to be recently?

much more convenient now	3	2	1	0	-1	-2	-3	much less convenient now

6. How flexible have you been finding your renal treatment to be recently?

much more flexible now	3	2	1	0	-1	-2	-3	much less flexible now

7. How satisfied are you with the amount of freedom you have with your present renal treatment?

much more satisfied now	3	2	1	0	-1	-2	-3	much less satisfied now

Please note that the Health Psychology Research Unit has moved to 188 High Street, Egham, Surrey, TW20 9ED. www.healthpsychologyresearch.com
To request use of this PROM, please contact: info@healthpsychologyresearch.com

Appendix FF.

DTSQ change version

Note. Instructions were slightly different for the DTSQc for participants who were still wait-listed at follow-up.

Diabetes Treatment Satisfaction Questionnaire (change): DTSQc (SPK)

Approximately 12 months ago you had a transplant whilst taking part in a study about your diabetes treatment. Today we would like to know about your experience of your current diabetes treatment (including any pancreas transplant, medication and/or diet). Please compare it with your experience of treatment for diabetes before you had the transplant 12 months ago. Please answer each question by circling a number on each of the scales. If you have experienced no change in your satisfaction with treatment, please circle '0'.

1. How satisfied are you with your current treatment for diabetes?

much more satisfied now	3	2	1	0	-1	-2	-3	much less satisfied now

2. How often have you felt that your blood sugars have been unacceptably high recently?

much more of the time now	3	2	1	0	-1	-2	-3	much less of the time now

3. How often have you felt that your blood sugars have been unacceptably low recently?

much more of the time now	3	2	1	0	-1	-2	-3	much less of the time now

4. How convenient have you been finding your diabetes treatment to be recently?

much more convenient now	3	2	1	0	-1	-2	-3	much less convenient now

5. How flexible have you been finding your diabetes treatment to be recently?

much more flexible now	3	2	1	0	-1	-2	-3	much less flexible now

6. How satisfied are you with your understanding of your treatment for diabetes?

much more satisfied now	3	2	1	0	-1	-2	-3	much less satisfied now

7. How likely would you be to recommend your present diabetes treatment to someone else with your kind of diabetes and renal condition?

much more likely to recommend the treatment now	3	2	1	0	-1	-2	-3	much less likely to recommend the treatment now

8. How satisfied would you be to continue with your present form of treatment for diabetes?

much more satisfied now	3	2	1	0	-1	-2	-3	much less satisfied now

Please make sure that you have circled one number on each of the scales.

Date completed: .....

Please note that the Health Psychology Research Unit has moved to 188 High Street, Egham, Surrey, TW20 9ED. www.healthpsychologyresearch.com
To request use of this PROM, please contact: info@healthpsychologyresearch.com

Appendix GG.

Study 2 Qualitative Interview Schedule Pre and Post-SPKT

Interview schedule - Patients on SPKT waiting list

First, could you please tell me about your experience of living with diabetes?

What sort of symptoms have you experienced, if any?

(In the questionnaires you said that you have had diabetes complications, can you tell me about that?)

Can you tell me about your diabetes treatment?

How well do you feel you understand diabetes and its treatment?

Could you tell me about when you were first diagnosed with chronic kidney disease and your experience of living with kidney problems?

When and how did you first find out you were having kidney problems?

How did the kidney problems develop/progress?

What sort of symptoms did you get, if any? Do you get symptoms now?

Can you tell me about your kidney treatment?

How well do you feel you understand your kidney condition and its treatment?

Can you tell me about the process you went through when you were added to the transplant waiting list?

What options were discussed with you?

What sort of information were you given about transplantation?

How do you feel about being on the waiting list for a pancreas and kidney transplant?

In the questionnaires that you completed recently, you reported that overall, your quality of life is excellent/very good/good/neither good nor bad/bad/very bad/extremely bad.

From the questionnaire I can see that that your diabetes does not/does have a negative impact on your quality of life.

Some of the aspect(s) of your life appeared to be most negatively impacted by your **diabetes** included: List most impacted and important aspects of life from the participant's ADDQoL questionnaire.

Can you tell me in what ways your diabetes impacts on…?

(Discuss most impacted aspects of life one at a time.)

You also indicated that your renal condition does not/does negative impact on your quality of life.
The aspect(s) of your life that appeared to be most negatively impacted by your **renal condition** included: List most impacted and important aspects of life from the participant's RDQoL questionnaire.
Can you tell me in what ways your renal condition impacts on…?
(Discuss most impacted aspects of life one at a time.)

You also completed questionnaires about your treatment satisfaction and it appears that you are very satisfied/satisfied/not very satisfied with your diabetes treatment.
Can you tell me about that?
I can see that you are most satisfied with... **Can you tell me about that?**
I can see that you are least satisfied with... **Can you tell me about that?**

From your responses to the questionnaire on your renal treatment satisfaction and it appears that you are very satisfied/satisfied/not very satisfied with your kidney treatment. **Can you tell me about that?**
I can see that you are most satisfied with... **Can you tell me about that?**
I can see that you are least satisfied with... **Can you tell me about that?**

Now I would like to discuss with you how you have adjusted and how you cope with your diabetes and renal condition.

What adjustments have you made or strategies do you use to help you to live with your diabetes and kidney condition?

What strategies have you use to help you cope with any difficulties?
What sort of resources do you use, if any?
What sort of support do you get, if any, and from whom?
Do you feel that you have control over your diabetes and in what way?
Do you feel you have control over your renal condition and in what way?

Lastly, what expectations, if any, do you have about how a pancreas and kidney transplant might impact on you and your quality of life?

The closing

Thank you for sharing your experience with me, you have been very helpful in improving my understanding of the experience of living with diabetes and kidney disease.

Now we are nearing the end of the interview. Is there anything else you can think of that would be helpful for me to know to have an accurate record of your experience?

Thank you, I'm now going to turn off the recorder.

Interview schedule - patients approximately 12 months post-SPKT

First, could you please tell me about your experience of living with diabetes and a kidney condition before you received a pancreas and kidney transplant?

What was your experience with diabetes before you developed kidney problems?
What sort of symptoms did you experience, if any?
Did you have any diabetes complications and what were they?
When and how did you first find out you were having kidney problems?
How did your kidney problems develop/progress?
Can you tell me about your diabetes treatments?
Can you tell me about your kidney treatment?
What impact did your diabetes have on your life?
What impact did your kidney condition have on your life?
How well do you feel you understood diabetes and your kidney problems?
How much control did you feel you had over your diabetes and kidney condition before the transplant and in what way?

Can you tell me about the process you went through when you were added to the transplant waiting list?

What options were discussed with you?
How did you feel about being on the waiting list for a pancreas and kidney transplant?

Next, could you please tell me about the time when you received your pancreas and kidney transplant?

What happened?

How did you feel during this time?

In the questionnaires that you completed recently, you reported that overall, your quality of life is excellent/very good/good/neither good nor bad/bad/very bad/extremely bad.

It appears that your quality of life has improved/remained stable/worsened since you received a pancreas and kidney transplant.

Can you tell me about how your quality of life has improved since the transplant?

From the questionnaire I can see that that your **diabetes** does not/does have a negative impact on your quality of life.

The aspect(s) of your life that appear to continue to be most negatively impacted by having had diabetes are: List most impacted and important aspects of life from the participant's ADDQoL questionnaire.

Can you tell me in what ways having had diabetes impacts on…?

(Discuss most impacted aspects of life one at a time.)

From the questionnaire I can see that that your kidney condition does not/does have a negative impact on your quality of life.

The aspect(s) of your life that appear to continue to be most negatively impacted by having a kidney condition are: List most impacted and important aspects of life from the participant's RDQoL questionnaire.

Can you tell me in what ways having a kidney condition impacts on…?

(Discuss most impacted aspects of life one at a time.)

From your responses to the questionnaire on treatment satisfaction it appears that you are very satisfied/satisfied/not very satisfied with your diabetes treatment. **Can you tell me about that?**

I can see that you are most satisfied with... **Can you tell me about that?**

I can see that you are least satisfied with... **Can you tell me about that?**

You also completed questionnaires about your renal treatment satisfaction and it appears that you are very satisfied/satisfied/not very satisfied with your kidney treatment.
I can see that you are most satisfied with... **Can you tell me about that?**
I can see that you are least satisfied with... **Can you tell me about that?**

Now I would like to discuss with you how you have adjusted to having a pancreas and kidney transplant.

How have you adjusted since having the pancreas and kidney transplant?

Have you had any difficulties since the transplant and how did you deal with them?

What strategies have you used to help you cope with difficulties?

What sort of resources do you use, if any?

What support do you get, if any, from others in relation to your dealing with your transplant and treatment?

Do you feel that you have control over your health, your diabetes and kidney disease and in what way?

When you were waiting for your pancreas and kidney transplant what expectations did you have about life after the transplant, if any, and have they been met?

The closing

Thank you for sharing your experience with me, you have been very helpful in improving my understanding of the experience of living with diabetes and kidney disease.

Now we are nearing the end of the interview. Is there anything else you can think of that would be helpful for me to know to have an accurate record of your experience?

Thank you, I'm now going to turn off the recorder.

Appendix HH.

Study 3 Information Sheet

Simultaneous pancreas and kidney transplantation: Partners' experiences

Invitation

You are being invited to take part in the above research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take some time to read the following information carefully and discuss it with friends and/or family if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.
Thank you for reading this.

1. What is the purpose of the study?

This study forms part of a PhD research programme funded by Royal Holloway, University of London. The aim of this research is to explore, through telephone interviews, the experiences of the partners of people who need a pancreas and kidney transplant. This type of transplant is also known as a simultaneous pancreas-kidney (SPK), combined or dual transplant. Chronic medical conditions and transplantation impact the families, as well as the person with the condition. So we would like to know what it has been like for you and what has been helpful and unhelpful.

This study will help to provide us with a 'bigger picture' of how these conditions and treatments affect patients and their partners. The research findings may help future patients and their families make decisions about their treatment.

2. Why have I been invited?

You have been invited to take part in this study because you are the long-term partner of someone who has received a simultaneous pancreas and kidney transplant. By long-term partner, we mean someone who has been in a relationship with the person needing a transplant for at least the past 12 months. We are interested in finding out about the experiences of partners to help us understand the effect that wait-listing and this type of transplant has on you and your partner.

3. Do I have to take part?

Participation in the study is voluntary, it is up to you to decide whether or not to take part. Whether you decide to participate or not will not affect your partner's

care in any way. If you decide to take part you are still free to withdraw at any time, without giving a reason and without it having any negative consequences for you or your partner. If you withdraw from the study your data will be deleted. If your data have already been included in reports or publications they cannot be removed from these. You will not be identifiable from any of the reports.

4. What will happen to me if I take part and what do I have to do?

If you agree to take part in this study you will need to complete the consent form. You should keep one copy of the consent form and send the other copy to the research team at Royal Holloway, University of London. If you prefer, you can give consent over the telephone, this will be recorded and stored safely. You will be sent a copy of the consent form completed by phone.

We would like you to complete a short general information questionnaire and measures of health status and well-being. You would then take part in a telephone interview with Katie Hann, a PhD student at Royal Holloway, at a convenient time for you. During the interview you will be asked about your experiences as a partner of someone who has received a pancreas and kidney transplant. The interview will last about 1 hour, but this depends on how much you would like to say. We would like to audio-record the interview so that it can be analysed for our research. If you and your partner would both like to take part we will interview you individually. Anything that you say will be kept confidential and will not be shared or matched with your partner.

Your participation in this study will **not** require your partner to travel to attend any extra clinics or have additional tests or receive extra drugs or medicines. You will also not need to travel anywhere to take part in the interview as this can be done over the telephone.

5. Is there a drug or procedure being tested?

There are no drugs, medical devices or other treatments being tested in this study. There will be no change to your partner's treatment or standard of care as a result of taking part.

6. Are there any side effects from taking part?

There are no side effects of taking part in this study because we are not testing any new medicines or procedures.

7. What are the possible disadvantages and risks of taking part?

There are no risks to your health if you agree to take part in this study. You will be required to complete some questionnaires (which would take about 10-15 minutes) and an interview (which would take about one hour of your time).

Although unlikely, there is a small risk that you may become upset when completing the questionnaires or interview. Advice is available from Prof Clare Bradley, Professor of Health Psychology, Health Psychology Research Unit, Orchard Building, Royal Holloway, University of London: email c.bradley@rhul.ac.uk, telephone 01784 443708/01784 443714.

Information on kidney disease and support can be found on the Kidney Care UK and the National Kidney Federation (NKF) UK websites:
https://www.kidneycareuk.org/get-support/
http://www.kidney.org.uk/

A free helpline is also provided by the NKF on: 0800 1690936.

8. What are the possible benefits of taking part?

There will be no direct benefit of taking part in this study for you personally. However, the information we get from this study will help us to understand the experiences of those closest to people going through the process of receiving a SPK transplant and what impact this has.

9. What happens when the research study stops?

If you would like to find out about the results of the study a newsletter can be sent to you at the end of the study.

10. What if something goes wrong?

Since the study is only asking you to fill in questionnaires and be interviewed, it is very unlikely that anything will go wrong. If you wish to complain about any aspect of the study, you can contact Prof Clare Bradley, Professor of Health Psychology, Health Psychology Research Unit, Orchard Building, Royal Holloway, University of London: email c.bradley@rhul.ac.uk, telephone 01784 443708/01784 443714.

11. Will my taking part in this study be kept confidential?

Royal Holloway, University of London is the sponsor for this study based in the United Kingdom. We will be using information provided by you in order to undertake this study and we will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly.

Royal Holloway will use your name and contact details to contact you about the research study and to oversee the quality of the study. Individuals from Royal Holloway and regulatory organisations may look at your research records to check the accuracy of the research study. The only people at Royal Holloway who will have access to information that identifies you will be people who need to contact you to follow-up or invite you to take part in an interview, or to audit the data collection process.

Royal Holloway will keep identifiable information about you from this study for 5 years after the study has finished/ until 2025. You can find out more about how we use your information by contacting the PhD student, Katie Hann, on the details provided below.

12. What will happen to the results of the research study?

The results of this study will be submitted for publication in national and

international journals. You will not be identified in any reports or publications. At the end of the study a newsletter will be produced to provide details of our findings, this can be sent to you if you indicate an interest in receiving it (on the consent form).

13. Who is organising and funding the research?

This study is part of a PhD studentship, funded by Royal Holloway, University of London.

14. Who has reviewed the study?

The study has been reviewed by an NHS Research Ethics Committee.

15. Contacts for Further Information

If you do require additional information on this research, please contact the PhD student, Katie Hann:

Katie Hann
Orchard Building
Royal Holloway, University of London
Egham, Surrey
TW20 0EX
Tel: 01784 443718
Email: Katie.hann.2008@live.rhul.ac.uk

For independent advice you can contact your local Patient Advice and Liaison Service (PALS) by visiting www.nhs.uk and searching for 'Find Patient advice and liaison service (PALS) services' then entering your postcode.

Alternatively, you can contact the Cambridge office:

Patient Advice & Liaison Service
Cambridge University Hospitals NHS Foundation Trust
Addenbrooke's Hospital
Hills Road
Cambridge
CB2 2QQ
Tel: 01223 216756

Thank you for taking the time to read/listen to the study information. We hope you agree to take part in this study.

Please keep a copy of this information sheet and a signed consent form for your records

Appendix II.

Study 3 Consent Form

CONSENT FORM

Simultaneous pancreas and kidney transplantation: Partners' experiences

Name of Researcher: Katie Hann (Chief Investigator: Prof. Clare Bradley)

Please read each statement carefully	**Please initial box**
1. I confirm that I have read (or have been read) and understand the information sheet dated 10.10.18 (version 1.2) for the above study. I have had the opportunity to ask questions and any questions that I have asked have been answered satisfactorily.	☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.	☐
3. I understand that I have been asked to complete a general information questionnaire and measures of health status and well-being, and I agree to this.	☐
4. I understand that I have been asked to participate in an interview with the PhD student and I give my permission to be contacted to do the interview.	☐
5. I agree with the audio-recording of the interview.	☐
6. I would like to be sent a newsletter detailing the findings at the end of the study.	☐
7. I would be interested in being involved in other research in future and I consent to being contacted for this. (If you do not want to be invited to take part in other future research, please leave this box blank.)	☐

.....	.....	.....
Name of Patient	Date	Signature
.....	.....	.....
Researcher	Date	Signature

Please keep one copy and send one copy to the researchers.

Project ID: 240896. Version 1.3 08/10/2020
Project ID: 242848. Version 1.2. 10.10.18

Appendix JJ.

Study 3 General Information/Demographics Questionnaire

Simultaneous pancreas and kidney transplantation: Partners' experiences

General Information Questionnaire

Wherever options are provided with boxes, please put a '✓' in any box that applies.

1. Date of birth:	DD/MM/**19**YY	**2. Gender:**	Male ☐ Female ☐

3. For how many years have you been together with your partner (approximately)?	……

4. Do you consider yourself to be your partner's carer?

No ☐ Please go to question 5a.

Yes ☐ How many hours each week do you spend caring for your partner (approximately)?
……..

5a. Are you in full-time education?

No ☐

Yes ☐ Please specify: ……

5b. What is the highest level of education you have obtained?

No formal qualifications	☐	NVQ level 4-5	☐
O level/GCSE or equivalent	☐	First Degree	☐
A Level or equivalent	☐	Higher degree	☐
National Vocational Qualification (NVQ) level 1-3	☐	Other qualification(s)	☐

If 'Other', please specify: ……

……

Project ID: 240896. Version 1.1. 18/12/17
Project ID: 242848. Version 1.1 14.05.18

6. Please indicate your current employment status below:

Working full-time	☐	Full-time carer	☐
Working part-time	☐	Retired	☐
Unable to work due to illness/disability	☐	Unemployed	☐

7. Were you born in the UK?

Yes ☐ Please go to question 8a.

No ☐ For how long have you lived in the UK? …….years ……..months.

8a. Is English your first language?

Yes ☐ Please go to question 9.

No ☐ Please continue with question 8b & c.

8b. What is your first language?

……

8c. Please rate your fluency in English on the scale below by circling the number that applies to you:

Very basic Very fluent

1 2 3 4 5 6 7

9. Please indicate your ethnic group below:

White	British	☐	
	Irish	☐	
	Scottish	☐	
	Other, please state	☐	……
Asian or Asian British	Indian	☐	
	Pakistani	☐	
	Bangladeshi	☐	
	Chinese	☐	
	Other, please state	☐	……

Black or Black British	Caribbean	☐
	African	☐
	Other, please state	☐ .....
Mixed	White & Black Caribbean	☐
	White & Black African	☐
	White & Asian	☐
	Other, please state	☐.....
Other ethnic group	Any other ethnic group, please state	☐ .....

10. Do you have any medical conditions?

No ☐ Please go to question 11.

Yes ☐ Please tick and specify as needed:

Diabetes	☐.....
Anaemia	☐.....
High blood pressure	☐.....
Liver disease	☐.....
Kidney problems (e.g. chronic kidney disease)	☐.....
Joint problems (e.g. rheumatoid arthritis)	☐.....
Lung problems (e.g. asthma)	☐.....
Cancer (e.g. lung, breast cancer)	☐.....
Stroke or mini-stroke (TIA)	☐.....
Heart problems (e.g. previous heart attack, angina, heart failure)	☐.....
Circulatory problems (e.g. in legs causing pain when walking)	☐.....
Chronic viral infection (e.g. HIV, hepatitis B or C)	☐.....
Memory problems (e.g. dementia, Alzheimer's)	☐.....

Continues on next page.

Mental health problems (e.g. depression, anxiety)	☐.....
Other, please state:	☐.....

11. In the past year have you experienced any stressful major life events that may have impacted on your current health and well-being?

No ☐ Please go to question 12.

Yes ☐ Please describe:

12. How often do you need to have someone help you when you read instructions, pamphlets or other written material from your doctor or pharmacy? (Please circle whichever applies to you.)

Never	Rarely	Sometimes	Often	Always
1	2	3	4	5

13. In general, my present health is:

excellent	very good	good	neither good nor bad	bad	very bad	extremely bad
☐	☐	☐	☐	☐	☐	☐

The next question asks about your quality of life – in other words how good or bad you feel your life to be.

We would like to know how you feel about your life now.

14. In general, my present quality of life is:

excellent	very good	good	neither good nor bad	bad	very bad	extremely bad
☐	☐	☐	☐	☐	☐	☐

Date of completion: DD/MM/20YY

If you have any queries, please contact:

Katie Hann, BSc, MSc.
Orchard Building
Royal Holloway, University of London
Egham, Surrey
TW20 0EX
Tel: 01784 443718
Email: Katie.hann.2008@live.rhul.ac.uk

Thank you for taking the time to complete this questionnaire

Appendix KK.

Study 3 Qualitative Interview Schedule

Simultaneous Pancreas and Kidney Transplantation: Partners' Experiences Interview schedule

First, could you please tell me about your experience before your partner received a pancreas and kidney transplant?

What was your experience when your partner just had diabetes, before the kidney problems?

Did you need to support your partner with their diabetes and in what sort of ways?

When and how did you discover that your partner was having kidney problems?

How did the kidney disease develop?

Did you need to support your partner because of the kidney disease and in what ways?

How well did you feel that you understood your partner's health conditions and the treatment?

What sort of impact, if any, did your partner's diabetes and treatment have on you and your quality of life?

What sort of impact, if any, did your partner's kidney condition and treatment have on you and your quality of life?

Work/social life/leisure activities/role around the house/other family/ holidays/ dietary?

Did your partner's diabetes and kidney disease impact on your relationship and in what way?

What sort of changes, if any, did you need to make due to your partner's health conditions?

What was the process like when your partner was added to the transplant waiting list?

How did you feel about your partner being on the waiting list for a pancreas and kidney transplant?

What sort of strategies did you use to help you cope before the transplant?

Next, could you please tell me about the time when your partner received their pancreas and kidney transplant?

What happened?

What was the recovery period like?

How did you feel during this time?

How has the transplant impacted your quality of life?

Work/social life/partner relationship/leisure activities/role around the house/other family/holidays?

What has been most impacted or improved for you?

Are there ways in which your partner's health conditions are still impacting on your life and in what way?

In what ways, if any, do you still support your partner now in relation to having had these conditions?

Now I would like to discuss with you how you have adjusted and how you cope with your partner having a pancreas and kidney transplant.

How have you adjusted to your partner having the pancreas and kidney transplant?

Have there been any changes that you have had to adjust to and in what way?

Have you experienced any changes in your relationship and in what way?

Is there anything you think might have helped you both cope throughout the process?

What sort of resources have you used to help you cope throughout the process, if any?

Have there been any difficulties or issues since the transplant and how have you coped with them?

When your partner was waiting for the pancreas and kidney transplant what expectations did you have about life for you both after the transplant, if any, and have they been met?

The closing

Thank you for sharing your experience with me, you have been very helpful in improving my understanding of the wider impact that transplantation can have on patients and their families.

Now we are nearing the end of the interview. Is there anything else you can think of that would be helpful for me to know to have an accurate record of your experience? Thank you, I'm now going to turn off the recorder.

Appendix LL.

Distress Protocol.

Prior to the interview starting

Participants will be informed that the interviews will be about their quality of life and experiences of chronic kidney disease, diabetes, waiting for a transplant and receiving a transplant. Because the interview will be about their experiences this may include things that have happened to them, how they have felt, and what they have done to adjust/cope.

Participants will be reminded at the start of their interview that if they do not want to answer a question they do not have to, they can say they wish to skip questions or end the interview at any time.

During the interview

Throughout the interview the interviewer will listen out for signs that a participant may be getting upset including:
what they are saying
prolonged pauses
changes in tone
sobbing/crying

If the interviewer feels that a participant may be getting upset they will check how they are doing (if they are OK) and whether they feel they would like to take a break or to end the interview.

If the participant says that they would like to continue with the interview the interviewer will continue. However, if the participant shows further signs of distress/upset the interviewer will end the interview.

If the interview is ended or paused the interviewer will turn off the audio recorder (and tell the interviewee they have done so) and speak with the participant about their concerns (if they wish). The interviewer will enquire whether they feel that they often become upset and distressed because of their condition and what sort of

support they already have. The interviewer will ask whether the participant feels that they need more support and what sort of support.

If the participant would like further support:
Participants will be offered the option of speaking with Professor Clare Bradley, Health Psychologist (HCPC registered) to discuss their concerns.
Participants will be reminded of the organisations that offer information and support to kidney patients and their families and of the free helpline that is available.
Partners or patients who would like to make their own arrangements for further support will be advised to speak with their GP or renal clinician about their options.

The interviewer will ask the participant if there is another person at home who could support them at the time and once the call has ended. If the participant is particularly distressed the interviewer will ask to speak to the individual to ensure that the person will be kept safe. If the participant is home alone the interviewer will discuss with them what they think they might do after the interview and whether they are going to be OK. If the participant is unsure what to do the interviewer will ask them about the sorts of things they usually do when they feel upset to help themselves feel better (e.g. listening to favourite music, watching television, reading, going for a short walk, taking a nap) and suggest whether doing one of these activities may help them. The interviewer will also ask for permission to call the participant the next day to follow up and check that they are OK.

Participants who become upset during the interview but do not feel that they need further support will also be reminded of the two UK kidney disease organisations for which details have been provided on the Patient Information Sheet, including the number for a helpline. All participants will also be reminded that they can contact Professor Clare Bradley, whose contact details are available on the Patient Information Sheet, to discuss the research or for advice.

If participants would still like to continue the interview after taking a break they will be offered a second call at a time that suits them.

Only in a very extreme situation when a participant has no other support and reports plans to harm themselves in the immediate future will an ambulance will be called for the participant.

Debriefing

After each interview the interviewer will turn off the audio recorder and thank the participant for giving up their time to take part. The interviewer will also check whether the participant is feeling OK and how they felt about the interview. Participants will be reminded that they will not be identifiable from the reports and that their information will be kept confidential.

Appendix MM.

Study 1 Additional Data

Table MM1

Study 1 - HD Participants' Demographic Characteristics and PROs at Follow-up

Variable	**HD patients (*n* = 14)**
Age in years *M* (*SD)*	57.71 (11.02)
BMI *M* (*SD)*	27.18 (6.08)
Sex: male *n* (%)	7.00 (50.00)
Ethnicity: white *n* (%)	13.00 (92.86)
Marital status *n* (%)	
Married/civil partnership/ living with partner	9.00 (64.29)
Separated/divorced	2.00 (14.29)
Single	3.00 (21.42)
Education *n* (%)	
No formal qualifications	1.00 (7.14)
Basic	8.00 (57.14)
Higher	4.00 (28.58)
Missing	1.00 (7.14)
Employment status *n* (%)	
Full-time	2.00 (14.29)
Part-time	1.00 (7.14)
Retired	6.00 (42.86)
Unemployed	5.00 (35.71)
Number of comorbidities *M* (*SD)*	2.71 (1.86)
Comorbidity *n* (%)	13.00 (92.86)
Diabetes type 1	2.00 (14.29)
Diabetes type 2	2.00 (14.29)
Anaemia	5.00 (35.71)
High blood pressure	4.00 (28.57)
Joint problems	7.00 (50.00)
Lung problems	2.00 (14.29)
Stroke	2.00 (14.29)
Heart problems	5.00 (35.71)
Circulatory problems	4.00 (28.57)
Memory problems	1.00 (7.14)
Mental health problems	4.00 (28.57)
Other	3.00 (21.43)
Previous other transplant *n* (%)	9.00 (64.29)
Number of previous transplants *n* (%)	1.14 (1.10)

Variable	HD patients
Registered as disabled *n* (%)	9.00 (64.29)
Registered as visually impaired *n* (%)	1.00 (7.14)
Generic QoL *M* (*SD)*	0.25 (1.22)
Renal-Dependent QoL Overview *M* (*SD)*	-2.25 (1.06)
RDQoL AWI *M* (*SD)*	-3.75 (1.71)
RTSQs *M* (*SD)*	55.33 (17.67)
EQ-VAS *M* (*SD)*	54.38 (20.27)
EQ-5D-5L Utility *M* (*SD)*	0.53 (0.32)
W-BQ12 *M* (*SD)*	19.50 (7.99)
Positive Well-Being *M* (*SD)*	5.69 (3.47)
Negative Well-Being *M* (*SD)*	3.54 (3.43)
Energy *M* (*SD)*	4.42 (2.50)

Note. M: mean; *SD*: standard deviation; Energy: Energy subscale of W-BQ16 (0-12, higher scores indicate better energy); EQ-5D-5L utility: EuroQoL-5 Dimension-5 Level utility score (-0.28- +1, state worse than death to optimal health state); EQ-VAS: EuroQol Visual Analogue scale (0-100, higher scores indicate better perceived health); Generic QoL: Generic Quality of Life (-3- +3, extremely bad to excellent quality of life); Negative W-B: Negative Well-Being subscale (0-12, higher scores indicate worse negative well-being); Positive W-B: Positive Well-Being subscale (0-12, higher scores indicate better positive well-being); RDQoL AWI: Renal Dependent Quality of Life average weighted impact score (-9- +3, indicates maximum negative impact/importance to maximum positive impact/importance); RTSQs: Renal Treatment Satisfaction Questionnaire status version (0-78, higher scores indicate better satisfaction); W-BQ12: Well-Being Questionnaire 12 item version (0-36, higher scores indicate better general well-being).

Table MM2

Study 1 – Comparisons of ATTOM detailed PROMs Follow-up Study Non-responders' and Responders' Baseline Demographic Characteristics

Variable	**Non-responder** (*n* = 160)	**Responder** (*n* = 127)	***p***
Age *M (SD)*	46.26 (12.83)	48.91 (11.36)	.069
BMI* *M (SD)*	25.60 (4.62)	26.33 (5.01)	.218
Gender male *n (%)*	98.00 (61.25)	71.00 (55.91)	.361
Ethnicity: white *n (%)*	124.00 (78.5)	115.00 (92.0)	**.003**
Marital status *n (%)*			.826
Married/civil partnership/living with a partner	91.00 (56.87)	80.00 (62.99)	
Divorced/separated	21.00 (13.13)	18.00 (14.17)	
Widowed	5.00 (3.13)	4.00 (3.14)	
Single	41.00 (25.63)	24.00 (18.90)	
Missing	2.00 (1.25)	1.00 (0.79)	
Education *n (%)*			**.019**
No formal qualification	18.00 (11.25)	13.00 (10.23)	
Basic qualification	**62.00 (38.75)**	**30.00 (23.62)**	
Higher qualification	**25.00 (15.62)**	**34.00 (26.77)**	
Other	53.00 (33.13)	49.00 (38.58)	
Missing	2.00 (1.25)	1.00 (0.79)	
Employment *n (%)*			**.010**
Full-time	**38.00 (23.75)**	**55.00 (44.31)**	
Part-time	19.00 (11.88)	8.00 (6.30)	
Unemployed	24.00 (15.00)	12.00 (9.45)	
Retired	24.00 (15.00)	21.00 (16.54)	
Long-term sick/Disabled	47.00 (29.38)	29.00 (22.83)	
Student	**5.00 (3.13)**	**0.00**	
Missing	3.00 (1.88)	2.00 (1.57)	
Participant group *n (%)*			.291
Matched control	45.00 (28.13)	37.00 (29.13)	
Incidence dialysis	34.00 (21.25)	18.00 (14.17)	
Transplant	81.00 (50.63)	72.00 (56.69)	

Note. M: mean; *SD*: standard deviation; BMI: body mass index.
*Missing BMI data for 12 non-responders and 16 responders.

Table MM3

Study 1 - t-test and Bootstrapped t-test Comparisons of ATTOM detailed PROMs Follow-up Study Non-Responders' and Responders' Baseline PROs

Measures	**Non-responder**	**Responder**					
	M (SE)	***M (SE)***	**Mean difference 95% CI**	***t***	***df***	***p***	***r***
RDQoL AWI (*n* = 234)	-3.93 (0.19)	-3.41 (0.19)	-0.52 -1.05, 0.01	-1.94	232	.054	.13
EQ-VAS (*n* = 275)	65.66 (1.62)	67.17 (1.75)	-1.51 -6.21, 3.20	-0.63	273	.529	.04
W-BQ12 (*n* = 274)	22.19 (0.56)	23.38 (0.64)	-1.18 -2.86, 0.49	-1.39	272	.166	.08
Positive W-B (*n* = 274)	7.20 (0.26)	7.65 (0.27)	-0.44 -1.17, 0.28	-1.20	272	.231	.07
Energy (*n* = 274)	5.54 (0.23)	5.80 (0.29)	-0.26 -0.98, 0.45	0.72	272	.470	.04
	M (SE)	***M (SE)***	**Mean difference BCa 95% CI**	***t***	***df***	***p***	***r***
Generic QoL (*n* = 235)	0.81 (0.11)	1.09 (0.10)	-0.28 -0.57, 0.02	-1.94	233	**.048**	**.13**
Renal-Dependent QoL Overview (*n* = 235)	-1.92 (0.09)	-1.96 (0.09)	0.05 -0.19, 0.29	0.41	233	.685	.03
RTSQs (*n* = 232)	61.27 (1.13)	61.75 (1.18)	-0.28 -3.76, 3.22	-0.17	230	.863	.01
EQ-5D-5L utility (*n* = 276)	0.76 (0.02)	0.80 (0.02)	-0.03 -0.08, 0.02	-1.38	274	.165	.08
Negative W-B (*n* = 274)	2.57 (0.22)	2.07 (0.21)	0.50 -0.15, 1.13	1.67	272	.108	.10

Note. M: mean; *SE*: standard error, *r*: effect size; 95% CI: 95% confidence intervals; BCa 95% CI: Bias corrected and accelerated 95% confidence intervals using 1000 bootstraps; *r*: effect size. Energy: Energy subscale of W-BQ12 (0-12, higher scores indicate better energy); EQ-5D-5L utility: EuroQoL-5 Dimension-5 Level utility score (-0.28- +1, state worse than death to optimal health state); EQ-VAS: EuroQol Visual Analogue scale (0-100, higher scores indicate better perceived health); Generic QoL: Generic Quality of Life (-3- +3, extremely bad to excellent quality of life); Negative W-B: Negative Well-Being subscale (0-12, higher scores indicate worse negative well-being); Positive W-B: Positive Well-Being subscale (0-12, higher scores indicate better positive well-being); RDQoL AWI: Renal Dependent Quality of Life average weighted impact score (-9- +3, indicates maximum negative impact/importance to maximum positive impact/importance); RTSQs: Renal Treatment Satisfaction Questionnaire status version (0-78, higher scores indicate better satisfaction); W-BQ12: Well-Being Questionnaire 12 item version (0-36, higher scores indicate better general well-being).

Table MM4

Study 1 - T-test and Bootstrapped t-test Comparisons of ATTOM detailed PROMs Follow-up study Non-Responders' and Responders' 12-month PROs

Measures	**Non-responder**	**Responder**					
	M (SE)	***M (SE)***	**Mean difference 95% CI**	***t***	***df***	***p***	***r***
Energy (*n* = 286)	6.13 (0.24)	6.74 (0.26)	-0.61 -1.31, 0.09	-1.71	284	.089	.10
	M (SE)	***M (SE)***	**Mean difference BCa 95% CI**	***t***	***df***	***p***	***r***
Generic QoL (*n* = 287)	0.94 (0.10)	1.35 (0.11)	-0.41 -0.70, -0.14	-2.73	285	**.006**	.16
Renal-Dependent QoL Overview (*n* = 284)	-1.77 (0.08)	-1.54 (0.10)	-0.23 -0.50, 0.00	-1.67	282	.094	.10
RDQoL AWI (*n* = 286)	-3.44 (0.18)	-2.63 (0.18)	-0.80 -1.32, -0.32	-3.22	284	**.004**	.19
RTSQs (*n* = 287)	65.13 (0.95)	66.90 (1.01)	-1.77 -4.65, 1,23	-1.27	285	.199	.07
EQ-5D-5L utility (*n* = 279)	0.75 (0.02)	0.84 (0.2)	-0.09 -0.14, -0.03	-3.23	276.87	**.003**	.19
EQ-VAS (*n* = 283)	71.29 (1.63)	77.12 (1.52)	-5.83 -10.65, -1.20	-2.54	280.99	**.010**	.15
W-BQ12 (*n* = 286)	22.26 (0.64)	25.07 (0.64)	-2.81 -4.67, -1.00	-3.08	284	**.003**	.18
Positive W-B (*n* = 286)	7.08 (0.23)	8.34 (0.25)	-1.26 -1.94, -1.62	-3.61	284	**.001**	.21
Negative W-B (*n* = 286)	2.74 (0.23)	2.02 (0.23)	0.72 0.09, 1.34	2.26	281.43	**.026**	.13

Note. M: mean; *SE*: standard error, *r*: effect size; 95% CI: 95% confidence intervals; BCa 95% CI: Bias corrected and accelerated 95% confidence intervals using 1000 bootstraps; *r*: effect size. Energy: Energy subscale of W-BQ12 (0-12, higher scores indicate better energy); EQ-5D-5L utility: EuroQoL-5 Dimension-5 Level utility score (-0.28- +1, state worse than death to optimal health state); EQ-VAS: EuroQol Visual Analogue scale (0-100, higher scores indicate better perceived health); Generic Quality of Life (-3- +3, extremely bad to excellent quality of life); Negative W-B: Negative Well-Being subscale (0-12, higher scores indicate worse negative well-being); Positive W-B: Positive Well-Being subscale (0-12, higher scores indicate better positive well-being); RDQoL AWI: Renal Dependent Quality of Life average weighted impact score (-9- +3, indicates maximum negative impact/importance to maximum positive impact/importance); RTSQs: Renal Treatment Satisfaction Questionnaire status version (0-78, higher scores indicate better satisfaction); W-BQ12: Well-Being Questionnaire 12 item version (0-36, higher scores indicate better general well-being).

Table MM5

Study 1 - Demographic Characteristics at Follow-up for DDKT and LDKT Recipients with Pre- and Post-Transplant PROMs Data

Variable	**Total sub-sample** (*n* = 39)	**DDKT** (*n* = 24)	**LDKT** (*n* = 15)	***p***
Age in years *M* (*SD)*	57.74 (10.59)	59.20 (10.12)	55.40 (11.24)	.280
BMI *M* (*SD)*	26.59 (4.23)	26.82 (3.87)	26.25 (4.85)	.497
Months since transplant *M* (*SD)*	55.04 (20.28)	51.69 (20.03)	60.40 (20.18)	.198
Sex: male *n* (%)	23.00 (59.00)	16.00 (66.67)	7.00 (46.67)	.217
Ethnicity: white *n* (%)	36.00 (92.31)	21.00 (87.50)	15.00 (100.00)	.271
Marital status *n* (%)				.054
Married/civil partnership/ living with partner	26.00 (66.67)	12.00 (50.00)	14.00 (93.33)	
Separated/divorced	7.00 (17.95)	6.00 (25.00)	1.00 (6.67)	
Single	4.00 (10.26)	4.00 (16.67)	0.00	
Widowed	2.00 (5.13)	2.00 (8.33)	0.00	
Education *n* (%)				.678
No formal qualifications	7.00 (17.95)	5.00 (20.83)	2.00 (13.33)	
Basic	9.00 (23.08)	4.00 (16.67)	5.00 (33.33)	
Higher	22.00 (56.41)	14.00 (58.33)	8.00 (53.33)	
Missing	1.00 (2.56)	1.00 (4.17)	0.00	
Employment status *n* (%)				.483
Full-time	12.00 (30.77)	7.00 (29.16)	5.00 (33.33)	
Part-time	6.00 (15.38)	2.00 (8.33)	4.00 (26.67)	
Retired	17.00 (43.59)	12.00 (50.00)	5.00 (33.33)	
Unemployed	4.00 (10.26)	3.00 (12.50)	1.00 (6.67)	
Number of comorbidities *M* (*SD)*	2.59 (1.96)	2.54 (1.53)	2.67 (2.55)	.849
Comorbidity n (%)	34.00 (87.18)	22.00 (91.67)	12.00 (80.00)	1.00
Diabetes	11.00 (28.21)	7.00 (29.16)	4.00 (26.67)	.866
Anaemia	6.00 (15.38)	3.00 (12.50)	3.00 (20.00)	.658
High blood pressure	24.00 (61.54)	17.00 (70.83)	7.00 (46.67)	.182
Liver disease	2.00 (5.13)	2.00 (8.33)	0.00	.522
Joint problems	9.00 (23.08)	4.00 (16.67)	5.00 (33.33)	.266
Lung problems	1.00 (2.56)	1.00 (4.16)	0.00	1.00
Cancer	2 (5.13)	0.00	2.00 (13.33)	.142
Stroke	4.00 (10.26)	1 (4.16)	3.00 (20.00)	.279
Heart problems	11.00 (28.21)	7.00 (29.16)	4.00 (26.67)	1.00

Variable	Total sub-sample	DDKT	LDKT	*p*
Circulatory problems	6.00 (15.38)	5.00 (20.83)	1.00 (6.67)	.376
Chronic viral infection	1.00 (2.56)	1.00 (4.16)	0.00	1.00
Memory problems	2.00 (5.13)	1.00 (4.16)	1.00 (6.67)	1.00
Mental health problems	8.00 (20.51)	6.00 (25.00)	2.00 (13.33)	.450
Other	11 (28.21)	5.00 (20.83)	6.00 (40.00)	.277
Previous transplant *n* (%)	12.00 (30.77)	5.00 (20.83)	7.00 (46.66)	.089
Transplanted pre-dialysis *n* (%)	3.00 (7.69)	3.00 (12.50)	0.00	.271
Registered as disabled *n* (%)	10.00 (25.64)	8.00 (33.33)	2.00 (13.33)	.263
Registered as visually impaired *n* (%)	2.00 (5.13)	0.00	2.00 (13.33)	.142

Note. M: mean; *SD*: standard deviation; DDKT: deceased-donor kidney transplant; LDKT: Living-donor kidney transplant; BMI: body mass index.

Table MM6

Study 1 - SPKT Recipients' Self-reported Adherence and Inconvenience/Difficulty of Taking Anti-Rejection Medications as Recommended

Medication	***n***		**0** *n* (%)	**1** *n* (%)	**2** *n* (%)	**3** *n* (%)	**4** *n* (%)	**5** *n* (%)	**6** *n* (%)	**missing** *n* (%)
Azathioprine	3	**Adherence**[1]	-	-	-	-	-	-	2 (67)	1 (33)
		Inconvenience[2]	2 (67)	-	-	-	-	-	-	1 (33)
Mycophenolic acid	13	**Adherence**	-	-	-	-	-	6 (46)	7 (54)	-
		Inconvenience	7 (54)	5 (38)	-	-	-	-	1 (8)	-
Prednisolone	4	**Adherence**	-	-	-	-	-	-	4 (100)	-
		Inconvenience	4	-	-	-	-	-	-	-
Tacrolimus	17	**Adherence**	-	-	-	-	-	5 (29)	11 (65)	1 (6)
		Inconvenience	10 (59)	4 (24)	1 (6)	-	-	1 (6)	-	1 (6)

Note. [1]Adherence (how often have you taken this medication exactly as recommended?): scored 0 (none of the time) to 6 (all of the time).
[2]Inconvenience (how often do you find it inconvenient or difficult to take this medication exactly as recommended?): scores 0 (none of the time) to 6 (all of the time).

Table MM7

Study 1 – SPKT Recipients' Highest and Lowest Rated Renal Service Satisfaction Items of the RSSQ

Highest rated items	***M (SD)***	**Range**	**Slightly dissatisfied/ dissatisfied** *n* (%)	**Neither satisfied nor dissatisfied** *n* (%)	**Very satisfied/ satisfied** *n* (%)
The treatment for your renal condition (including medication, dialysis or transplant and any diet/fluid recommendations). (*n* = 15)	1.87 (0.35)	1.00, 2.00	-	-	15.00 (100.00)
Care taken by staff over hygiene (e.g. washing hands before examining patients). (*n* = 15)	1.80 (0.41)	1.00, 2.00	-	-	15.00 (100.00)
Surgical procedures (e.g. catheter insertion, fistula or transplant). (*n* = 14)	1.79 (0.43)	1.00, 2.00	-	-	14.00 (100.00)
Privacy. (*n* = 16)	1.69 (0.70)	0.00, 2.00	-	2.00 (12.50)	14.00 (87.50)
Ease in making or changing appointments. (*n* = 15)	1.67 (0.49)	1.00, 2.00	-	-	15.00 (100.00)
Discussing with staff any problems you may have. (*n* = 15)	1.67 (0.49)	1.00, 2.00	-	-	15.00 (100.00)

Lowest rated items	***M (SD)***	**Range**	**Slightly dissatisfied/ dissatisfied** *n* (%)	**Neither satisfied nor dissatisfied** *n* (%)	**Very satisfied/ satisfied** *n* (%)
Social worker advice and support. (*n* = 5)	0.00 (1.22)	-1.00, 2.00	2.00 (40.00)	2.00 (40.00)	1.00 (20.00)
Psychological advice and support. (*n* = 11)	0.18 (1.40)	-2.00, 2.00	4.00 (36.36)	3.00 (27.27)	4.00 (36.36)
Ease of getting to the hospital/unit (including public transport and/or parking). (*n* = 15)	0.27 (1.33)	-2.00, 2.00	5.00 (33.33)	4.00 (26.67)	6.00 (40)
Time spent waiting at the renal clinic/unit. (*n* = 15)	0.33 (1.05)	-1.00, 2.00	5.00 (33.33)	1.00 (6.67)	9.00 (60.00)
Availability of resources (including preferred treatment, beds etc.). (*n* = 13)	0.54 (0.97)	-1.00, 2.00	2.00 (15.38)	4.00 (30.77)	7.00 (53.85)

Note. M: mean; *SD*: standard deviation; *n*: number of participants who indicated that the item was applicable and gave a response; RSSQ: Renal Service Satisfaction Questionnaire (-2- +2, indicates dissatisfied to very satisfied with 0 being neither satisfied nor dissatisfied. Participants can mark each item as not applicable.).

Table MM8

Study 1 – Kidney-only Transplant Recipients' Self-reported Adherence and Inconvenience/Difficulty of Taking Anti-Rejection Medications as Recommended

Medication	***n***		**0** *n* (%)	**1** *n* (%)	**2** *n* (%)	**3** *n* (%)	**4** *n* (%)	**5** *n* (%)	**6** *n* (%)	**Missing** *n* (%)
Azathioprine	11	**Adherence[1]**	-	-	-	-	-	5 (45)	5 (45)	1 (9)
		Inconvenience[2]	6 (55)	1 (9)	-	-	1 (9)	2 (18)	-	1 (9)
Cyclosporine	2	**Adherence**	-	-	-	-	-	1 (50)	1 (50)	-
		Inconvenience	-	1 (50)	-	-	-	1 (50)	-	-
Mycophenolic acid	50	**Adherence**	-	-	-	-	-	15 (30)	35 (70)	-
		Inconvenience	32 (64)	6 (12)	1 (2)	2 (4)	2 (4)	7 (14)	-	-
Prednisolone	51	**Adherence**	-	-	-	-	-	7 (14)	38 (74)	6 (12)
		Inconvenience	35 (68)	4 (8)	2 (4)	-	-	3 (6)	1 (2)	6 (12)
Sirolimus	4	**Adherence**	-	-	-	-	-	1 (25)	3 (75)	-
		Inconvenience	2 (50)	1 (25)	-	-	-	1 (25)	-	-
Tacrolimus	77	**Adherence**	1 (1)	-	-	-	1 (1)	18 (23)	54 (70)	4 (5)
		Inconvenience	43 (56)	10 (13)	2 (3)	2 (3)	5 (6)	7 (9)	4 (5)	4 (5)

Note. [1]Adherence (how often have you taken this medication exactly as recommended?): scored 0 (none of the time) to 6 (all of the time).
[2]Inconvenience (how often do you find it inconvenient or difficult to take this medication exactly as recommended?): scores 0 (none of the time) to 6 (all of the time).

Table MM9

Study 1 – Kidney-only Transplant Recipients' Highest and Lowest Rated Renal Service Satisfaction Items of the RSSQ

Highest rated items	***M (SD)***	**Range**	**Slightly dissatisfied/ dissatisfied** *n* (%)	**Neither satisfied nor dissatisfied** *n* (%)	**Very satisfied/ satisfied** *n* (%)
How you are treated as a person by the staff. (*n* = 86)	1.79 (0.49)	-1.00, 2.00	1.00 (1.16)	-	85.00 (98.84)
Information given to you by the staff regarding your results. (*n* = 86)	1.77 (0.42)	1.00, 2.00	-	-	86.00 (100.00)
The extent to which staff are caring and supportive (*n* = 86)	1.69 (0.47)	1.00, 2.00	-	-	86.00 (100.00)
The treatment for your renal condition (including medication, dialysis or transplant and any diet/fluid recommendations). (*n* = 86)	1.67 (0.58)	-1.00, 2.00	1.00 (1.16)	2.00 (2.33)	83.00 (96.51)
The value to you in talking to staff. (*n* = 86)	1.63 (0.60)	-1.00, 2.00	1.00 (1.16)	2.00 (2.33)	83.00 (96.51)

Lowest rated items	***M (SD)***	**Range**	**Slightly dissatisfied/ dissatisfied** *n* (%)	**Neither satisfied nor dissatisfied** *n* (%)	**Very satisfied/ satisfied** *n* (%)
Social worker advice and support. (*n* = 45)	0.31 (1.02)	-2.00, 2.00	8.00 (17.78)	19.00 (42.22)	18.00 (40.00)
Ease of getting to the hospital/unit (including public transport and/or parking). (*n* = 83)	0.55 (1.27)	-2.00, 2.00	21.00 (25.30)	9.00 (10.84)	53.00 (63.86)
Psychological advice and support. (*n* = 67)	0.69 (1.08)	-2.00, 2.00	9.00 (13.43)	19.00 (28.36)	39.00 (58.21)
Information about and opportunities to use new developments. (*n* = 72)	0.83 (0.90)	-2.00, 2.00	3.00 (4.17)	21.00 (29.16)	48.00 (66.67)
Time spent waiting at the renal clinic/unit. (*n* = 85)	0.86 (1.26)	-2.00, 2.00	15.00 (17.64)	4.00 (4.70)	66.00 (77.65)

Note. M: mean; *SD*: standard deviation; *n*: number of participants who indicated that the item was applicable and gave a response; RSSQ: Renal Service Satisfaction Questionnaire (-2- +2, indicates dissatisfied to very satisfied with 0 being neither satisfied nor dissatisfied. Participants can mark each item as not applicable.).

Table MM10

Study 1 - Pearson's r and Kendal's tau (τ) *Correlations Between Kidney Transplant Recipients' Follow-up PROMs and Demographic/Clinical variables*

Measure	Age	Time since transplant τ	BMI τ	Gender	Ethnicity	Previous transplant	Pre-transplant treatment	Has a partner	Education	Mental health	Number of Comorbidities τ
EQ-VAS τ (n = 87)	-.00	**.17***	**-.18***	-.01	-.04	-.15	-.01	**.26***	.10	**-.24***	**-.38****
Utility τ (n = 86)	-.03	**.16***	-.09	-.11	-.01	-.11	.02	**.20***	.04	**-.33****	**-.43****
W-BQ12 total (n = 88)	.16	.11	-.13	-.04	-.07	-.06	-.01	**.29****	.03	**-.52****	**-.31***
Positive W-B (n = 89)	.06	**.15***	-.10	.05	-.10	-.08	-.12	**.30****	.11	**-.38****	-.13
Negative W-B τ (n = 88)	**-.24****	-.09	.16	.14	.13	.13	-.04	**-.23***	.02	**.36****	**.21****
Energy (n = 86)	.12	.05	-.11	.00	-.02	.02	.04	.10	-.06	**-.45****	**-.37****
Generic QoL (n = 89)	-.02	**.19***	**.18***	.07	.03	-.13	-.11	**.22***	.00	-.21	**-.38****

Measure	Age	Time since transplant τ	BMI τ	Gender	Ethnicity	Previous failed transplant	Pre-transplant treatment	Has a partner	Education	Mental health	Number of Comorbidities τ
Renal-Dependent QoL Overview τ (*n* = 88)	.10	.15	-.05	-.14	**-.24***	**-.26***	-.17	.08	.10	-.15	-.13
RDQoL AWI τ (*n* = 88)	.10	.14	-.04	-.14	**-.24****	**-.20***	-.15	.15	.06	**-.20***	-.09
RTSQ τ (*n* = 88)	**.21****	.12	-.03	.04	-.14	-.06	-.04	.04	-.14	-.13	-.09

Note. Pearson's *r* unless stated otherwise. Time since transplant: time since transplant in months; BMI: Body Mass Index.
Categorical variables have been dichotomised: male or female; white ethnicity or other ethnic minority group; previous failed transplant or no failed transplants; pre-dialysis or dialysis; partner or no partner; no formal education or formal education; self-reported mental health problems or no reported mental health problems.
Energy: Energy subscale of W-BQ12; EQ-5D-5L utility: EuroQoL-5 Dimension-5 Level utility score; EQ-VAS: EuroQol Visual Analogue scale of health status; Generic QoL: Generic Quality of Life; Negative W-B: Negative Well-Being subscale of W-BQ12; Positive W-B: Positive Well-Being subscale of W-BQ12; RDQoL AWI: Renal Dependent Quality of Life average weighted impact score; RTSQs: Renal Treatment Satisfaction Questionnaire status version; W-BQ12: Well-Being Questionnaire 12 item version.
*significant $p < .05$; **significant $p < .01$.

Table MM11

Study 1 - t-test and Bootstrapped t-test Comparisons of DDKT and LDKT Recipients' Pre-Transplant PROs at Recruitment/3-months

Measures	**DDKT**	**LDKT**					
	M (SE)	***M (SE)***	**Mean difference (95% CI)**	***t***	***df***	***p***	***r***
Generic QoL (*n* = 35)	0.82 (0.26)	0.54 (0.31)	0.28 (-0.57, 1.12)	0.67	33	.505	.12
EQ-VAS (*n* = 39)	60.42 (3.94)	71.00 (4.69)	-10.58 (-23.15, 1.99)	-1.71	37	.097	.18
W-BQ12 (*n* = 39)	22.25 (1.38)	22.53 (1.26)	-0.28 (-4.37, 3.80)	-0.14	37	.889	.02
Positive W-B (*n* = 39)	7.21 (0.55)	7.53 (0.61)	-0.33 (-2.05, 1.40)	-0.38	37	.705	.06
	M (SE)	***M (SE)***	**Mean difference (95% BCa CI)**	***t***	***df***	***p***	***r***
Renal-Dependent QoL Overview (*n* =35)	-1.91 (0.21)	-2.77 (0.67)	0.86 (0.34, 1.35)	3.21	32.99	**.004**	**.49**
RDQol AWI (*n* = 35)	-2.98 (0.45)	-4.45 (0.56)	1.47 (0.03, 2.90)	2.05	33	.060	.34
RTSQs total (*n* = 35)	57.19 (2.94)	50.92 (3.83)	6.27 (-3.54, 16.08)	1.30	33	.202	.22
EQ-5D-5L Utility (*n* =37)	0.76 (0.06)	0.85 (0.03)	-0.09 (-0.23, 0.03)	-1.40	34.94	.167	.23
Negative W-B (*n* = 39)	2.21 (0.47)	2.20 (0.68)	0.01 (-1.87, 1.69)	0.01	37	.992	.00
Energy (*n* = 39)	5.25 (0.60)	5.20 (0.26)	0.05 (-1.55, 1.56)	0.07	36.92	.946	.01

Note. M: adjusted means; *SE*: standard error; 95% CI: 95% confidence intervals; BCa 95% CI: Bias-corrected and accelerated 95% confidence intervals; *r*: effect size. Energy: Energy subscale of W-BQ12 (0-12, higher scores indicate better energy); EQ-5D-5L utility: EuroQoL-5 Dimension-5 Level utility score (-0.28- +1, state worse than death to optimal health state); EQ-VAS: EuroQol Visual Analogue scale (0-100, higher scores indicate better perceived health); Generic Quality of Life (-3- +3, extremely bad to excellent quality of life); Negative W-B: Negative Well-Being subscale (0-12, higher scores indicate worse negative well-being); Positive W-B: Positive Well-Being subscale (0-12, higher scores indicate better positive well-being); RDQoL AWI: Renal Dependent Quality of Life average weighted impact score (-9- +3, indicates maximum negative impact/importance to maximum positive impact/importance); RTSQs: Renal Treatment Satisfaction Questionnaire status version (0-78, higher scores indicate better satisfaction); W-BQ12: Well-Being Questionnaire 12 item version (0-36, higher scores indicate better general well-being).

Table MM12

Study 1 - t-test and Bootstrapped t-test Comparisons of DDKT and LDKT Recipients' PROs at 6/7-year Follow-up (participants with pre-transplant data)

Measure	**DDKT**	**LDKT**					
	M (SE)	***M (SE)***	**Mean difference (95% CI)**	***t***	***df***	***p***	***r***
Generic QoL (*n* = 38)	0.87 (0.21)	1.27 (0.27)	-0.40 (-1.08, 0.29)	-1.17	36	.249	.19
Renal-Dependent QoL Overview (*n* = 38)	-1.57 (0.23)	-2.07 (0.33)	0.50 (-0.30, 1.30)	1.28	36	.211	.21
W-BQ12 (*n* = 38)	21.09 (1.42)	23.93 (1.30)	-2.85 (-6.99, 1.30)	-1.39	36	.173	.23
Energy (*n* = 38)	5.17 (0.63)	6.13 (0.74)	-0.96 (-2.95, 1.03)	-0.98	36	.335	.16
	M (SE)	***M (SE)***	**Mean difference (95% BCa CI)**	***t***	***df***	***p***	***r***
RDQol AWI (*n* = 38)	-2.60 (0.39)	-2.42 (0.59)	-0.18 (-1.45, 1.28)	-0.25	36	.806	.04
RTSQs total (*n* = 38)	66.79 (1.65)	71.67 (1.92)	-4.88 (-9.65, -0.35)	-1.92	36	.068	.30
EQ-VAS (*n* = 38)	68.13 (4.28)	75.00 (5.22)	-6.87 (-20.10, 7.09)	-1.00	36	.312	.16
EQ-5D-5L Utility (*n* = 37)	0.72 (0.06)	0.85 (0.06)	-0.13 (-0.28, 0.02)	-1.58	35	.120	.26
Positive W-B (*n* = 38)	6.43 (0.66)	7.33 (0.74)	-0.90 (-2.73, 1.19)	-0.92	36	.393	.15
Negative W-B (*n* = 38)	2.52 (0.54)	1.53 (0.49)	-0.99 (-0.50, 2.39)	1.37	36	.200	.22

M: adjusted means; *SE*: standard error; 95% CI: 95% confidence intervals; BCa 95% CI: Bias-corrected and accelerated 95% confidence intervals; *r*: effect size. Energy: Energy subscale of W-BQ12 (0-12, higher scores indicate better energy); EQ-5D-5L utility: EuroQoL-5 Dimension-5 Level utility score (-0.28- +1, state worse than death to optimal health state); EQ-VAS: EuroQol Visual Analogue Scale of health status (0-100, higher scores indicate better perceived health); Generic Quality of Life (-3- +3, extremely bad to excellent quality of life); Negative W-B: Negative Well-Being subscale of W-BQ12 (0-12, higher scores indicate worse negative well-being); Positive W-B: Positive Well-Being subscale (0-12, higher scores indicate better positive well-being); RDQoL AWI: Renal Dependent Quality of Life average weighted impact score (-9- +3, indicates maximum negative impact/importance to maximum positive impact/importance); RTSQs: Renal Treatment Satisfaction Questionnaire status version (0-78, higher scores indicate better satisfaction); W-BQ12: Well-Being Questionnaire 12 item version (0-36, higher scores indicate better general well-being).

Table MM13

Study 1 - Pearson's r and Kendal's tau (τ) *Correlations between Kidney Transplant Recipients' Follow-up PROMs and Demographic/Clinical variables (participants with pre-transplant data)*

Measure	Age	BMI τ	Time since transplant	Gender	Ethnicity	Previous failed transplant	Pre-transplant treatment	Has a partner	Education	Mental health	Number of Comorbidities τ
EQ-VAS τ (n = 38)	-.07	-.21	.12	.04	-.02	-.16	-.18	.26	.13	-.18	**-.44***
Utility τ (n = 37)	-.06	-.09	.11	-.10	.07	-.07	-.06	**.38***	.11	**-.33***	**-.57****
W-BQ12 total (n = 38)	.13	-.15	.06	-.06	-.04	.00	-.09	**.50****	.14	**-.58****	**-.36****
Positive W-B (n = 38)	.21	-.13	-.02	-.02	-.04	.05	-.05	**.41****	.12	**-.39***	-.08
Negative W-B τ (n = 38)	-.22	.16	-.15	.03	.17	.09	.05	**-.37***	-.17	**.31***	.15
Energy (n = 38)	-.09	-.08	-.02	-.10	.08	.01	-.08	**.32***	.02	**-.60****	**-.48****
QoL overview τ (n = 34)	.01	-.03	.06	-.02	-.12	-.15	-.21	.28	-.01	-.10	**-.41****

Measure	Age	BMI τ	Time since transplant	Gender	Ethnicity	Previous failed transplant	Pre-transplant treatment	Has a partner	Education	Mental health	Number of Comorbidities τ
Renal-Dependent QoL Overview τ (n = 34)	**.29***	.00	-.14	-.27	-.12	-.27	-.26	-.04	.07	-.12	-.08
RDQoL AWI (n = 34)	.31	-.04	.08	-.33	-.15	-.29	-.22	.02	.04	-.26	-.16
RTSQs τ (n = 33)	.21	-.02	-.04	-.06	-.11	-.13	-.04	.18	.14	-.27	-.24

Note. Pearson's *r* unless stated otherwise. Time since transplant: time since transplant in months; BMI: Body Mass Index..

Categorical variables have been dichotomised: male or female; white ethnicity or other ethnic minority group; previous failed transplant or no failed transplants; pre-dialysis or dialysis; partner or no partner; no formal education or formal education; self-reported mental health problems or no reported mental health problems.

Energy: Energy subscale of W-BQ12; EQ-5D-5L utility: EuroQoL-5 Dimension-5 Level utility score; EQ-VAS: EuroQol Visual Analogue scale of health status; Generic QoL: Generic Quality of Life; Negative W-B: Negative Well-Being subscale of W-BQ12; Positive W-B: Positive Well-Being subscale of W-BQ12; RDQoL AWI: Renal Dependent Quality of Life average weighted impact score; RTSQs: Renal Treatment Satisfaction Questionnaire status version; W-BQ12: Well-Being Questionnaire 12 item version.

*significant $p < .05$; **significant $p < .01$.

Appendix NN.

Study 2 Additional Data

Table NN1

Study 2 - Comparisons of Follow-up Non-responders and Responders' Baseline Demographic Data

Variable	**Non-responder** (*n* = 12)	**Responder** (*n* = 20)	***p***
Age *M (SD)*	36.58 (8.05)	38.20 (7.50)	.570
BMI* *M (SD)*	24.57 (4.35)	24.05 (3.24)	.712
Months on waiting list *Mdn (IQR)*	1.75 (17.13)	4.00 (11.63)	.632
Gender male *n (%)*	4.00 (33.33)	7.00 (35.00)	1.000
Ethnicity *n (%)*			.485
White British/European	10.00 (83.33)	18.00 (90.00)	
African	1.00 (8.33)	0.00	
Indian	0.00	1.00 (5.00)	
Pakistani	1.00 (8.33)	0.00	
White and Asian	0.0	1.00 (5.00)	
Marital status *n (%)*			.436
Married/civil partnership/living with a partner	6.00 (50.00)	13.00 (65.00)	
Divorced/separated	1.00 (8.33)	0.00	
Single	5.00 (41.67)	7.00 (35.00)	
Education *n (%)*			.678
No formal qualification	0.00	1.00 (5.00)	
Basic qualification	8.00 (66.67)	10.00 (50.00)	
Higher qualification	4.00 (33.33)	9.00 (45.00)	
Employment *n (%)*			.314
Unemployed	5.00 (41.67)	11.00 (55.00)	
Part-time	2.00 (16.67)	6.00 (30.00)	
Full-time	4.00 (33.33)	3.00 (15.00)	
Retired	1.00 (8.33)	0.00	
Renal treatment *n (%)*			.090
Pre-dialysis	5.00 (41.67)	10.00 (50.00)	
Hospital HD	5.00 (41.67)	5.00 (25.00)	
Home HD	1.00 (8.33)	0.00	
CAPD	1.00 (8.33)	0.00	
APD	0.00	5.00 (25.00)	
Diabetes treatment *n (%)*			.303
Two injections mixed insulin	0.00	2.00 (10.00)	

Variable	Non-responder	Responder	*p*
Basal/bolus, fixed doses, fixed meals	0.00	1.00 (5.00)	
Basal/bolus, flexible doses, fixed meal	2.00 (16.67)	2.00 (10.00)	
Basal/bolus, flexible doses, flexible meals	6.00 (50.00)	10.00 (50.00)	
Insulin pump	1.00 (8.33)	5.00 (25.00)	
Other**	2.00 (16.67)	0.00	
Number of comorbidities *Mdn (IQR)*	2.00 (1.75)	2.00 (1.75)	.366
Number of complications *M (SD)*	1.83 (1.03)	2.60 (1.64)	.156
Visually impairment *n (%)*			.779
Visually impaired	1.00 (8.33)	1.00 (5.00)	
Severely visually impaired	0.00	2.00 (10.00)	
Registered disabled* *n (%)*	2.00 (16.67)	9.00 (45.00)	.241

Note. M: mean; *SD*: standard deviation; HD: haemodialysis; CAPD: continuous ambulatory peritoneal dialysis; APD: automated peritoneal dialysis. *Missing data for 2 participants.
** other: DAFNE; 5x insulin injections per day before meals/snacks; Basal/Bolus but flexibility of regimen unclear.

Table NN2

Study 2 -T-test and Mann-Whitney U test Comparisons of Baseline PROMs Data Between Follow-up Non-responders and Responders

Measures	**Non-responder**	**Responder**					
	M (SE)	***M (SE)***	**Mean difference 95% CI**	***t***	***df***	***p***	***r***
Generic QoL (*n* = 32)	-0.58 (0.40)	-0.30 (0.38)	-0.28 -1.48, 0.91	-0.48	30	.632	.10
ADDQoL AWI (*n* = 32)	-4.88 (0.51)	-4.23 (0.45)	-0.65 -2.09, 0.78	-0.93	30	.361	.17
RDQoL AWI (*n* = 32)	-5.65 (0.70)	-4.71 (0.48)	-0.94 -2.62, 0.75	-1.13	30	.266	.20
RTSQs (*n* = 32)	46.54 (5.16)	54.28 (2.58)	-7.73 -19.93, 4.46	-1.34	16.60	.198	.31
W-BQ16 (*n* = 31)	20.83 (2.52)	21.45 (2.49)	-0.61 -8.22, 6.99	-0.17	29	.870	.03
W-BQ12 (*n* = 32)	15.33 (1.79)	14.98 (1.77)	0.36 -5.12, 5.83	0.13	30	.895	.02
Negative W-B (*n* = 32)	5.17 (0.86)	4.55 (0.64)	0.62 -1.55, 2.78	0.58	30	.565	.11
Positive W-B (*n* = 32)	5.50 (0.74)	4.85 (0.78)	0.65 -1.73, 3.03	0.56	30	.581	.10
Energy (*n* = 32)	3.00 (0.73)	2.68 (0.58)	0.33 -1.59, 2.24	0.35	30	.731	.06

Measures	Non-responder	Responder					
	M (SE)	*M (SE)*	**Mean difference 95% CI**	*t*	*df*	*p*	*r*
Stress (*n* = 31)	6.50 (1.13)	6.00 (0.82)	0.50 -2.30, 3.30	0.37	29	.718	.07
EQ-VAS (*n* = 30)	49.17 (7.01)	50.28 (5.49)	-1.11 -19.20, 16.97	-0.13	28	.901	.02
	Mdn (IQR)	***Mdn (IQR)***		***U***		***p***	***r***
Renal-Dependent QoL Overview (*n* = 32)	-2.50 (1.75)	-3.00 (1.00)		105.00		.578	-.11
DTSQs (*n* = 31)	28.00 (13.25)	29.00 (11.00)		98.00		.535	-.12
EQ-5D-5L utility (*n* = 30)	0.83 (0.38)	0.78 (0.42)		93.50		.545	-.11

Note. M: mean; *SE*: standard error; *Mdn*: median; *IQR*: interquartile range; *r*: effect size; ADDQoL AWI: Audit of Diabetes Dependent Quality of Life average weighted impact score (-9- +3, indicates maximum negative impact/importance to maximum positive impact/importance); DTSQs: Diabetes Treatment Satisfaction Questionnaire status version (0-36, higher scores indicate better satisfaction); Energy: Energy subscale of W-BQ16 (0-12, higher scores indicate better energy); EQ-5D-5L utility: EuroQoL-5 Dimension-5 Level utility score (-0.28- +1, state worse than death to optimal health state); EQ-VAS: EuroQol Visual Analogue scale (0-100, higher scores indicate better perceived health); Generic Quality of Life (-3- +3, extremely bad to excellent quality of life); Negative W-B: Negative Well-Being subscale (0-12, higher scores indicate worse negative well-being); Positive W-B: Positive Well-Being subscale (0-12, higher scores indicate better positive well-being); RDQoL AWI: Renal Dependent Quality of Life average weighted impact score (-9- +3, indicates maximum negative impact/importance to maximum positive impact/importance); RTSQs: Renal Treatment Satisfaction Questionnaire status version (0-78, higher scores indicate better satisfaction); Stress: Stress subscale of W-BQ16 (0-12, higher scores indicate worse stress); W-BQ12: Well-Being Questionnaire 12 item version (0-36, higher scores indicate better general well-being); W-BQ16: Well-Being Questionnaire 16 item version (0-48, higher scores indicate better general well-being).

Table NN3

Study 2 – Pre-dialysis Participants' Highest and Lowest Rated Renal Service Satisfaction Items of the RSSQ at Baseline

Highest rated items	***Mean (SD)***	***Range***	**Slightly dissatisfied/ dissatisfied** *n* (%)	**Neither satisfied nor dissatisfied** *n* (%)	**Very satisfied/ satisfied** *n* (%)
Continuity of care, that is, whether or not you see the same doctor/ nurse on each visit. (*n* = 16)	1.69 (0.60)	0.00, 2.00	-	1.00 (6.25)	15.00 (93.75)
Discussing with staff any problems you may have. (*n* = 16)	1.63 (0.81)	-1.00, 2.00	1.00 (6.25)	-	15.00 (93.75)
Information given to you by the staff regarding your results. (*n* = 16)	1.56 (0.63)	0.00, 2.00	-	1.00 (6.25)	15.00 (93.75)
Cleanliness of the clinic and other treatment areas in the hospital. (*n* = 16)	1.56 (0.63)	0.00, 2.00	-	1.00 (6.25)	15.00 (93.75)
Care taken by staff over hygiene (e.g. washing hands before examining patients). (*n* = 16)	1.56 (0.63)	0.00, 2.00	-	1.00 (6.25)	15.00 (93.75)

Lowest rated items	***Mean (SD)***	***Range***	**Slightly dissatisfied/ dissatisfied** *n* (%)	**Neither satisfied nor dissatisfied** *n* (%)	**Very satisfied/ satisfied** *n* (%)
Availability of refreshments. (*n* = 13)	0.31 (1.18)	-2.00, 2.00	2.00 (15.38)	4.00 (30.77)	7.00 (53.85)
Social worker advice and support. (*n* = 8)	0.63 (0.92)	-1.00, 2.00	1.00 (12.50)	2.00 (25.00)	5.00 (62.50)
Surgical procedures (e.g. catheter insertion, fistula or transplant). (*n* = 6)	0.67 (1.63)	-2.00, 2.00	1.00 (16.67)	2.00 (33.33)	3.00 (50.00)
Psychological advice and support. (*n* = 11)	0.73 (1.27)	-2.00, 2.00	2.00 (18.18)	1.00 (9.09)	8.00 (72.73)
Ease with which staff are able to access hospital notes and recent results. (*n* = 16)	0.94 (0.99)	-1.00, 2.00	2.00 (12.50)	2.00 (12.50)	12.00 (75.00)

Note. M: mean; *SD*: standard deviation; *n*: number of participants who indicated that the item was applicable and gave a response; RSSQ: Renal Service Satisfaction Questionnaire (-2- +2, indicates dissatisfied to very satisfied with 0 being neither satisfied nor dissatisfied. Participants can mark each item as not applicable.).

Table NN4

Study 2 – Dialysis Patients' Highest and Lowest Rated Renal Service Satisfaction Items of the RSSQ at Baseline

Highest rated items	***Mean (SD)***	***Range***	**Slightly dissatisfied/ dissatisfied** *n* (%)	**Neither satisfied nor dissatisfied** *n* (%)	**Very satisfied/ satisfied** *n* (%)
Care taken by staff over hygiene (e.g. washing hands before examining patients). (*n* = 18)	1.39 (1.33)	-2.00, 2.00	2.00 (11.11)	1.00 (5.56)	15.00 (83.33)
How you are treated as a person by the staff. (*n* = 18)	1.33 (1.19)	-2.00, 2.00	2.00 (11.11)	1.00 (5.56)	15.00 (83.33)
The value to you in talking to staff. (*n* = 18)	1.28 (1.18)	-2.00, 2.00	2.00 (11.11)	1.00 (5.56)	15.00 (83.33)
The extent to which computers are used to improve the quality of care you receive. (*n* = 16)	1.25 (1.13)	-2.00, 2.00	1.00 (6.25)	2.00 (12.50)	13.00 (81.25)
Cleanliness of the clinic and other treatment areas in the hospital. (*n* = 17)	1.24 (1.35)	-2.00, 2.00	2.00 (11.76)	1.00 (5.88)	14.00 (82.35)

Lowest rated items	***Mean (SD)***	***Range***	**Slightly dissatisfied/ dissatisfied** *n* (%)	**Neither satisfied nor dissatisfied** *n* (%)	**Very satisfied/ satisfied** *n* (%)
Social worker advice and support. (*n* = 14)	-0.14 (1.29)	-2.00, 2.00	6.00 (42.86)	4.00 (28.57)	4.00 (28.57)
Psychological advice and support. (*n* = 14)	0.21 (1.37)	-2.00, 2.00	4.00 (28.57)	4.00 (28.57)	6.00 (42.86)
Ease of getting to the hospital/unit (including public transport and/or parking). (*n* = 16)	0.31 (1.35)	-2.00, 2.00	4.00 (25.00)	5.00 (31.25)	7.00 (43.75)
Availability of refreshments. (*n* = 16)	0.38 (1.20)	-2.00, 2.00	4.00 (25.00)	4.00 (25.00)	8.00 (50.00)
Comfort of the waiting areas. (*n* = 17)	0.41 (1.46)	-2.00, 2.00	4.00 (23.53)	4.00 (23.53)	9.00 (52.94)

Note. M: mean; *SD*: standard deviation; *n*: number of participants who indicated that the item was applicable and gave a response; RSSQ: Renal Service Satisfaction Questionnaire (-2- +2, indicates dissatisfied to very satisfied with 0 being neither satisfied nor dissatisfied. Participants can mark each item as not applicable.).

Table NN5

Study 2 - t-test and Wilcoxon Signed Rank test Comparisons of PROs Pre- and Post-SPKT, using the Most Recent Pre-transplant Data

Measures	**Baseline**		**12-months post-SPKT**					
	M (SE)	***Range***	***M (SE)***	***Range***	***t***	***df***	***p***	***r***
Generic QoL (*n* = 11)	-0.18 (0.44)	-3.00, 2.00	1.73 (0.19)	1.00, 3.00	-5.19	10	**<.001**	**.85**
Renal-Dependent QoL Overview (*n* = 11)	-2.36 (0.31)	-3.00, 0.00	-2.00 (0.43)	-3.00, 0.00	-0.84	10	.420	.26
RDQoL AWI (*n* = 11)	-5.19 (0.61)	-8.65, -2.24	-3.59 (0.73)	-7.81, 0.00	-2.00	10	.073	.53
Single item DTSQs (*n* = 11)	4.73 (0.33)	3.00, 6.00	6.00 (0.00)	6.00, 6.00	-3.83	10	**.003**	**.77**
Single item RTSQs (*n* = 11)	4.82 (0.42)	2.00, 6.00	5.91 (0.09)	5.00, 6.00	-2.78	10	**.019**	**.66**
DTSQs total (*n* = 11)	27.82 (1.88)	15.00, 36.00,	35.27 (0.51)	31.00, 36.00	-3.66	10	**.004**	**.76**
RTSQs total (*n* = 11)	54.36 (3.32)	36.00, 72.00	70.59 (1.94)	59.00, 78.00	-4.98	10	**.001**	**.84**
EQ-VAS (*n* = 10)	49.00 (7.14)	15.00, 90.00	69.50 (4.50)	40.00, 90.00	-3.57	9	**.006**	**.77**
EQ-5D-5L utility (*n* = 10)	0.66 (0.08)	0.19, 1.00	0.73 (0.06)	0.48, 1.00	-1.76	9	.112	.51

Measures	Baseline		12-months post-SPKT					
	M (SE)	***Range***	***M (SE)***	***Range***	***t***	***df***	***p***	***r***
Negative W-B (*n* = 11)	4.36 (0.82)	1.00, 8.00	3.36 (0.73)	0.00, 7.00	1.00	10	.341	.30
Positive W-B (*n* = 11)	5.18 (0.88)	0.00, 10.00	6.55 (0.79)	3.00, 12.00	-2.19	10	.053	.57
Energy (*n* = 11)	2.64 (0.68)	0.00, 7.00	5.82 (0.91)	0.00, 9.00	-2.78	10	**.019**	**.66**
Stress (*n* = 11)	7.36 (0.82)	1.00, 12.00	5.27 (0.95)	0.00, 10.00	2.81	10	**.018**	**.66**
	Mdn (IQR)	***Range***	***Mdn (IQR)***	***Range***	***T***		***p***	***r***
Diabetes-Dependent QoL Overview (*n* = 8)	-3.00 (0.00)	-3.00, -2.00	-3.00 (0.75)	-3.00, -2.00	4.00		.564	.14
W-BQ16 (*n* = 11)	22.00 (13.00)	4.00, 33.00	27.50 (13.00)	14.00, 44.00	57.50		**.029**	**.47**
W-BQ12 (*n* = 11)	18.00 (13.00)	4.00, 22.00	21.00 (10.00)	12.00, 32.00	57.50		**.029**	**.47**

Note. M: mean; *SE*: standard error; *Mdn*: median; *IQR*: interquartile range; *r*: effect size; ADDQoL AWI: Audit of Diabetes Dependent Quality of Life average weighted impact score (-9-3, indicates maximum negative impact/importance to maximum positive impact/importance); DTSQs: Diabetes Treatment Satisfaction Questionnaire status version calculated by multiplying the single item by 6 (0-36, higher scores indicate better satisfaction); Energy: Energy subscale of W-BQ16 (0-12, higher scores indicate better energy); EQ-5D-5L utility: EuroQoL-5 Dimension-5 Level utility score (-0.28- +1, state worse than death to optimal health state); EQ-VAS: EuroQol Visual Analogue scale (0-100, higher scores indicate better perceived health); Generic Quality of Life (-3- +3, extremely bad to excellent quality of life);Negative W-B: Negative Well-Being subscale (0-12, higher scores indicate worse negative well-being); Positive W-B: Positive Well-Being subscale (0-12, higher scores indicate better positive well-being); RDQoL AWI: Renal Dependent Quality of Life average weighted impact score (-9- +3, indicates maximum negative impact/importance to maximum positive impact/importance); RTSQs: Renal Treatment Satisfaction Questionnaire status version calculated by multiplying the single item by 13 (0-78, higher scores indicate better satisfaction); Stress: Stress subscale of W-BQ16 (0 to 12, higher scores indicate worse stress); W-BQ12: Well-Being Questionnaire 12 item version (0-36, higher scores indicate better general well-being); W-BQ16: Well-Being Questionnaire 16 item version (0-48, higher scores indicate better general well-being).

Table NN6

Study 2 - t-test and Mann Whitney U test Comparisons of Wait-listed Participants' and SPKT Recipients' Baseline PROs.

Measures	**Waitlisted**	**SPKT**					
	M (SE)	***M (SE)***	***Mean difference (95% CI)***	***t***	***df***	***p***	***r***
ADDQoL AWI (*n* = 20)	-3.41 (0.67)	-4.81 (0.51)	1.41 -0.33, 3.14	1.70	18	.106	.37
RDQoL AWI (*n* = 20)	-4.02 (0.70)	-5.08 (0.60)	1.05 -0.88, 2.99	1.15	18	.267	.26
DTSQs (*n* = 19)	27.35 (2.50)	27.25 (1.77)	0.10 -6.18, 6.37	0.03	17	.975	.01
DTSQs-item 2 (*n* = 19)	3.13 (0.61)	3.18 (0.50)	-0.06 -1.71, 1.60	-0.07	17	.943	.02
DTSQs-item 3 (*n* = 19)	2.50 (0.63)	3.00 (0.40)	-0.50 -2.00, 1.00	-0.70	17	.492	.17
RTSQs (*n* = 20)	57.67 (3.96)	52.50 (3.19)	5.17 -5.39, 15.72	1.03	18	.318	.24
EQ-VAS (*n* = 20)	55.00 (8.78)	52.50 (5.59)	2.50 -19.86, 24.86	0.24	13.79	.814	.05
EQ-5D-5L utility (*n* = 19)	0.73 (0.08)	0.72 (0.07)	0.01 -0.22, 0.24	0.11	17	.916	.03
W-BQ16 (*n* = 19)	24.33 (3.54)	20.00 (2.58)	4.33 -4.77, 13.44	1.00	17	.329	.24

Measures	Wait-listed	SPKT					
	M (SE)	***M (SE)***	***Mean difference (95% CI)***	***t***	***df***	***p***	***r***
W-BQ12 (*n* = 20)	17.56 (2.45)	13.82 (1.95)	3.74 -2.88, 10.35	1.19	18	.251	.27
Negative W-B (*n* = 20)	4.33 (0.78)	4.64 (0.81)	-0.30 -2.71, 2.10	-0.27	18	.794	.06
Positive W-B (*n* = 20)	5.89 (1.05)	4.26 (0.94)	1.53 -1.42, 4.47	1.09	18	.291	.25
Energy (*n* = 20)	4.00 (0.93)	2.09 (0.68)	1.91 -0.46, 4.27	1.70	18	.107	.37
Stress (*n* = 19)	5.22 (1.18)	6.60 (0.95)	-1.38 -4.53, 1.78	-0.92	17	.370	.22
	Mdn (IQR)	***Mdn (IQR)***		***U***		***p***	***r***
Generic QoL (*n* = 20)	0.00 (2.50)	0.00 (2.00)		53.50		.766	.07
Renal-Dependent QoL Overview item (*n* = 20)	-2.00 (1.00)	-3.00 (1.00)		32.00		.201	-.33

Note. M: mean; *SE*: standard error; *Mdn*: median; *IQR*: interquartile range; ADDQoL AWI: Audit of Diabetes Dependent Quality of Life average weighted impact score (-9- +3, indicates maximum negative impact/importance to maximum positive impact/importance); DTSQs: Diabetes Treatment Satisfaction Questionnaire status version (0-36, higher scores indicate better satisfaction); Energy: Energy subscale of W-BQ16 (0-12, higher scores indicate better energy); EQ-5D-5L utility: EuroQoL-5 Dimension-5 Level utility score (-0.28- +1, state worse than death to optimal health state); EQ-VAS: EuroQol Visual Analogue scale (0-100, higher scores indicate better perceived health); Negative W-B: Negative Well-Being subscale (0 to 12, higher scores indicate worse negative well-being); Positive W-B: Positive Well-Being subscale (0-12, higher scores indicate better positive well-being); RDQoL AWI: Renal Dependent Quality of Life average weighted impact score (-9- +3, indicates maximum negative impact/importance to maximum positive impact/importance); RTSQs: Renal Treatment Satisfaction Questionnaire status version (0-78, higher scores indicate better satisfaction); Stress: Stress subscale of W-BQ16 (0-12, higher scores indicate worse stress); W-BQ12: Well-Being Questionnaire 12 item version (0-36, higher scores indicate better general well-being); W-BQ16: Well-Being Questionnaire 16 item version (0-48, higher scores indicate better general well-being)

Table NN7

Study 2 – Wait-listed Participants' Highest and Lowest Rated Renal Service Satisfaction Items of the RSSQ at Follow-up

Highest rated items	***M** (SD)*	***Range***	**Slightly dissatisfied/ dissatisfied** *n* (%)	**Neither satisfied nor dissatisfied** *n* (%)	**Very satisfied/ satisfied** *n* (%)
How you are treated as a person by the staff. (*n* = 9)	1.78 (0.44)	1.00, 2.00	-	-	9.00 (100.00)
The extent to which staff are caring and supportive. (*n* = 9)	1.78 (0.44)	1.00, 2.00	-	-	9.00 (100.00)
Cleanliness of the clinic and other treatment areas in the hospital. (*n* = 9)	1.78 (0.44)	1.00, 2.00	-	-	9.00 (100.00)
Care taken by staff over hygiene (e.g. washing hands before examining patients). (*n* = 9)	1.78 (0.44)	1.00, 2.00	-	-	9.00 (100.00)
Arrangement of giving blood samples for routine measures of renal control (e.g. creatinine and haemoglobin) (*n* = 9)	1.67 (0.50)	1.00, 2.00	-	-	9.00 (100.00)

Lowest rated items	***M (SD)***	***Range***	**Slightly dissatisfied/ dissatisfied** *n* (%)	**Neither satisfied nor dissatisfied** *n* (%)	**Very satisfied/ satisfied** *n* (%)
Availability of refreshments. (*n* = 6)	0.00 (1.26)	-2.00, 1.00	2.00 (33.33)	1.00 (16.67)	3.00 (50.00)
Social worker advice and support. (*n* = 6)	0.00 (1.26)	-2.00, 2.00	1.00 (16.67)	4.00 (66.67)	1.00 (16.67)
Psychological advice and support. (*n* = 9)	0.33 (1.22)	-2.00, 2.00	1.00 (11.11)	5.00 (55.56)	3.00 (33.33)
Comfort of the waiting areas. (*n* = 9)	0.78 (1.30)	-2.00, 2.00	1.00 (11.11)	2.00 (22.22)	6.00 (66.67)
Opportunities to talk with other patients who have renal failure. (*n* = 8)	0.88 (1.36)	-1.00, 2.00	2.00 (25.00)	1.00 (12.50)	5.00 (62.50)

Note. M: mean; *SD*: standard deviation; *n*: number of participants who indicated that the item was applicable and gave a response; RSSQ: Renal Service Satisfaction Questionnaire (-2- +2, indicates dissatisfied to very satisfied with 0 being neither satisfied nor dissatisfied. Participants can mark each item as not applicable.).

Table NN8

Study 2 – SPKT Recipients' Highest and Lowest Rated Renal Service Satisfaction Items of the RSSQ at Follow-up

Highest rated items	***M (SD)***	***Range***	**Slightly dissatisfied/ dissatisfied** *n* (%)	**Neither satisfied nor dissatisfied** *n* (%)	**Very satisfied/ satisfied** *n* (%)
The value to you in talking to staff. (*n* =11)	1.82 (0.40)	1.00, 2.00	-	-	11.00 (100.00)
Discussing with staff any problems you may have. (*n* = 11)	1.82 (0.40)	1.00, 2.00	-	-	11.00 (100.00)
Surgical procedures (e.g. catheter insertion, fistula or transplant). (*n* = 11)	1.82 (0.40)	1.00, 2.00	-	-	11.00 (100.00)
Privacy. (*n* = 11)	1.82 (0.40)	1.00, 2.00	-	-	11.00 (100.00)
The extent to which you feel understood by the staff. (*n* = 11)	1.77 (0.41)	1.00, 2.00	-	1.00 (9.09)	10.00 (90.91)

Lowest rated items	***M (SD)***	***Range***	**Slightly dissatisfied/ dissatisfied** *n* (%)	**Neither satisfied nor dissatisfied** *n* (%)	**Very satisfied/ satisfied** *n* (%)
Social worker advice and support. (*n* = 7)	0.43 (0.98)	-1.00, 2.00	1.00 (14.28)	3.00 (42.86)	3.00 (42.86)
Opportunities to talk with other patients who have renal failure. (*n* = 11)	0.55 (1.13)	-1.00, 2.00	2.00 (18.18)	4.00 (36.36)	5.00 (45.45)
Psychological advice and support. (*n* = 9)	0.56 (1.13)	-1.00, 2.00	2.00 (22.22)	2.00 (22.22)	5.00 (55.56)
Ease of getting to the hospital/ unit (including public transport and/or parking). (*n* = 11)	0.73 (1.01)	-1.00, 2.00	1.00 (9.09)	4.00 (36.36)	6.00 (54.55)
Availability of refreshments. (*n* = 11)	0.73 (1.27)	-2.00, 2.00	1.00 (9.09)	4.00 (36.36)	6.00 (54.55)

Note. M: mean; *SD*: standard deviation; *n*: number of participants who indicated that the item was applicable and gave a response; RSSQ: Renal Service Satisfaction Questionnaire (-2- +2, indicates dissatisfied to very satisfied with 0 being neither satisfied nor dissatisfied. Participants can mark each item as not applicable.).

Table NN9

Study 2 - Brief IPQ - Most Important Causes of Diabetes in Rank Order (n = 34)

First most important cause	***n*** (%)	**Second most important cause**	***n* (%)**	**Third most important cause**	***n* (%)**
Genetics or family history.	9 (26)	Genetics or family history.	2 (6)	Genetics or family history.	3 (9)
Autoimmune.	2 (6)	A virus.	2 (6)	Lifestyle/diet.	2 (6)
Pancreas failed/ stopped working.	2 (6)	Stress/tension.	2 (6)	Stress.	1 (3)
		Lifestyle/diet.	2 (6)	Environment.	1 (3)
		Weight.	1 (3)	Infection.	1 (3)
Stress.	2 (6)	Autoimmune.	1 (3)	Heat.	1 (3)
Another illness.	2 (6)	Tiredness.	1 (3)		
Weight.	2 (6)	E-numbers.	1 (3)		
Lifestyle.	1 (3)				
Pregnancy.	1 (3)				
Missing/ don't know/ uninterpretable.	13 (38)	Missing/ repeated answer/ uninterpretable.	22 (64)	Missing/ repeated answer/ uninterpretable.	25 (73)

Brief IPQ: Brief Illness Perceptions Questionnaire for diabetes.

Table NN10

Study 2 - Brief IPQ - Most Important Causes of the Renal Condition in Rank Order (*n* = 34)

First most important cause	***n* (%)**	**Second most important cause**	***n* (%)**	**Third most important cause**	***n* (%)**
Diabetes.	28 (82)	Hypertension.	5 (14)	Hypertension.	3 (9)
Poor diabetes control.	3 (9)	Pregnancy or having children.	3 (9)	Genetics or family history.	3 (9)
Weight.	1 (3)	Lifestyle/diet.	3 (9)	Diet or lifestyle.	1 (3)
Poor diabetes control when younger.	1 (3)	Poor diabetes control.	2 (6)	Stress/ hormones /mental health.	1 (3)
		Poor diabetes control when younger.	2 (6)	Autoimmune.	1 (3)
		Lack of knowledge about diabetes.	1 (3)	Virus.	1 (3)
		Family history of diabetes.	1 (3)	Inflammation.	1 (3)
		Stress.	1 (3)	Poor diabetes control.	1 (3)
		Infection.	1 (3)	Heat.	1 (3)
		Bad luck.	1 (3)		
		Environment.	1 (3)		
Missing.	1 (3)	Missing/ repeated/ uninterpretable.	13 (38)	Missing/ repeated/ uninterpretable.	21 (61)

Note. Brief IPQ: Brief Illness Perceptions Questionnaire for the renal condition.

Table NN11

Study 2 - Independent t-test and Mann Whitney U test Comparisons of Pre-dialysis and Dialysis Participants' Renal Condition Illness Perceptions (n = 34)

Brief IPQ Renal	**Pre-dialysis** ***M (SE)***	**Dialysis** ***M (SE)***	***Mean difference (95% CI)***	***t***	***df***	***p***	***r***
Renal treatment identity	5.25 (0.84)	6.83 (0.54)	-1.58 (-3.64, 0.47)	-1.58	25.89	.126	.30
	Mdn (IQR)	***Mdn (IQR)***		***U***		***p***	***r***
Consequences	8.00 (2.75)	9.00 (2.00)		172.50		.330	.18
Timeline	9.00 (4.75)	9.00 (3.00)		152.00		.798	.05
Personal control	3.00 (6.00)	5.50 (2.50)		177.00		.266	.20
Renal treatment control	8.00 (5.25)	8.00 (3.25)		165.00		.484	.13
Renal identity	7.00 (4.00)	7.50 (2.00)		168.50		.403	.15
Concern	10.00 (2.00)	9.50 (2.25)		122.50		.463	-.14
Understanding	9.00 (2.00)	9.00 (2.25)		125.00		.528	-.12
Emotional representation	8.00 (3.75)	8.00 (3.25)		143.00		.986	-.01

Note M: mean; *SE*: standard error; *Mdn*: median; *IQR*: interquartile range; *r*: effect size. Brief IPQ: Brief Illness Perception Questionnaire for the renal condition (0-10, where 0 indicates a less negative perception e.g. acute timeline or less concern).

Table NN12

Study 2 - t-test and Wilcoxon Signed Rank Test Comparisons of Wait-listed Participants' Diabetes Illness Perceptions from Baseline to 12-months Follow-up. (n = 9)

Brief IPQ Diabetes	**Baseline** ***M (SE)***	***Range***	**12 months post-SPKT** ***M (SE)***	***Range***	***t***	***df***	***p***	***r***
Consequences	7.44 (0.90)	2.00, 10.00	6.61 (0.96)	2.00, 10.00	2.04	8	.076	.59
Timeline*	8.00 (0.85)	4.00, 10.00	8.38 (0.91)	3.00, 10.00	-0.57	7	.584	.21
Diabetes treatment control	8.89 (0.59)	5.00, 10.00	8.56 (0.44)	6.00, 10.00	1.00	8	.347	.33
Diabetes treatment identity	5.00 (1.11)	0.00, 9.00	4.89 (0.89)	0.00, 8.00	0.10	8	.927	.03
Concern	7.22 (1.01)	1.00, 10.00	6.33 (1.13)	0.00, 10.00	1.84	8	.104	.54
Emotional representation	6.56 (1.18)	1.00, 10.00	6.11 (1.21)	0.00, 10.00	1.00	8	.347	.33
	Mdn (IQR)	***Range***	***Mdn (IQR)***	***Range***	***T***		***p***	***r***
Personal control	7.00 (4.00)	3.00, 10.00	8.00 (3.00)	5.00, 10.00	15.00		.335	.23
Diabetes identity	8.00 (3.50)	2.00, 10.00	6.00 (2.00)	5.00, 10.00	8.50		.343	-.22
Understanding	10.00 (2.00)	1.00, 10.00	10.00 (3.00)	2.00, 10.00	4.00		.705	-.09

Note. M: mean; SE: standard error; Mdn: median; IQR: interquartile range; r: effect size. Brief IPQ: Brief Illness Perception Questionnaire for diabetes (each item scored 0 to 10, where 0 represents a less negative perception e.g. acute timeline or less concern). *Missing data for 1 participant.

Table NN13

Study 2 - t-test and Wilcoxon Signed Rank Test Comparisons of Wait-listed Participants' Renal Condition Illness Perceptions from Baseline to 12-months Follow-up (n = 9)

Brief IPQ	**Baseline**		**12-months post-SPKT**					
Renal	***M (SE)***	***Range***	***M (SE)***	***Range***	***t***	***df***	***p***	***r***
Consequences	8.00 (0.69)	3.00, 10.00	8.11 (0.51)	6.00, 10.00	-0.18	8	.860	.06
Timeline	9.00 (0.47)	6.00, 10.00	8.11 (0.56)	6.00, 10.00	1.46	8	.160	.46
Personal control	6.00 (0.93)	3.00, 10.00	6.00 (0.75)	2.00, 10.00	0.00	8	1.00	.00
	Mdn (IQR)	***Range***	***Mdn (IQR)***	***Range***	***T***		***p***	***r***
Renal treatment control	8.00 (3.00)	4.00, 10.00	9.00 (3.50)	2.00, 10.00	3.00		1.00	.00
Renal treatment identity*	8.00 (6.00)	0.00, 9.00	7.00 (3.50)	0.00, 10.00	7.00		.892	-.03
Renal identity	8.00 (3.50)	3.00, 10.00	7.00 (3.50)	2.00, 8.00	1.50		.197	-.30
Concern	10.00 (2.00)	7.00, 10.00	9.00 (2.00)	2.00, 10.00	2.50		.157	-.33
Understanding	9.00 (3.00)	5.00, 10.00	9.00 (3.50)	5.00, 10.00	1.50		.414	-.19
Emotional representation	8.00 (3.50)	4.00, 10.00	8.00 (4.00)	2.00, 10.00	1.00		.285	-.25

Note. M: mean; *SD*: standard deviation; *Mdn*: median; *IQR*: interquartile range; *r*: effect size. Brief IPQ: Brief Illness Perception Questionnaire for the renal condition (0-10, where 0 represents a less negative perception e.g. acute timeline or less concern).
*Missing data for one participant.