

Transplantation

Variation in Practice Patterns for Listing Patients for Renal Transplantation in the United Kingdom: a National Survey --Manuscript Draft--

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In submitting this form as corresponding author, I confirm that each author agrees with the points checked above and has participated sufficiently in the intellectual content, the analysis of data, if applicable, and the writing of the manuscript to take public responsibility for it. Each author has reviewed the manuscript, believes it represents valid work, and approves it for submission. Moreover, should the Editors request the data upon which the manuscript is based, the authors shall produce it.	Yes

Do you have color illustrations?	No
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All procedures and studies involving human subjects have been carried out according to the ethical guidelines outlined by The Transplantation Society http://www.tts.org/index.php?option=com_content&view=article&id=11&Itemid=14 and have involved no commercial transactions or other unethical practices in obtaining donor organs.	Yes
Reporting of all human and animal studies conforms to the following:	Not applicable
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<p>Other (Please list):</p> <p>as follow-up to ""Public Access Policy" Funding Disclosure</p> <p>Please disclose below if you have received funding for research on which your article is based from any of the following organizations:"</p>	<p>National Institute for Health Research (NIHR)</p>

Author Comments:	<p>Dear Editor,</p> <p>Many thanks for considering our revised manuscript for publication in your esteemed journal. Following the constructive feedback received from the editorial board and reviewers, this paper has been revised to address the issues raised. These changes have undoubtedly improved the quality of this manuscript, which we hope you will now deem suitable for publication.</p> <p>We appreciate your time and look forward to your response.</p> <p>Your Sincerely,</p> <p>Rishi Pruthi</p>	
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Abstract:	<p>Introduction: Despite the availability of guidelines for the evaluation of candidates for renal transplantation, variation in access to transplantation exists. This national survey investigates whether centre variation exists in the assessment of patients for renal transplantation in the UK.</p> <p>Methods: An online survey, informed by qualitative interviews, was distributed to all UK renal centres. This survey examined centre approaches to chronic kidney disease service provision, transplant recipient assessment, education provision and wait-listing decision making processes. Centre re-evaluation policies for patients already listed and priorities for future development were also examined.</p> <p>Results: All 71 renal centres responded. Of these, 83% reviewed pre-dialysis patients in a low clearance clinic. In 26% of centres transplantation was not discussed as a treatment option with all patients. Fourteen centres reported having a dedicated transplant assessment clinic whilst 28% did not have a formal assessment protocol. Age was an exclusion criterion for listing in three centres, all of which had a cut off at 75 years. 83% of centres excluded patients with a high BMI. Cardiac investigations were risk-stratified in 90% of centres. Surgical involvement varied with 11% of centres listing patients without formal surgical review. There was no formal protocol in place to</p>	

re-evaluate listed patients in 62% of centres.

Conclusions: There is wide variation in UK practice patterns for listing patients for renal transplantation, though its impact on access to transplantation is unclear. The extent to which centre-specific and patient-specific factors affect access to transplantation requires further analysis in a prospective cohort of patients.

Response to Decision Letter from Reviewers and Editors

Following the constructive feedback received from the editorial board and reviewers, this paper has been revised to address the issues raised and incorporate the minor amendments suggested. These changes have undoubtedly improved the quality of this manuscript, which we hope you will now deem suitable for publication.

Please find below a summary of the feedback points, and alongside a description of how they have been addressed.

Reviewer: 1

Content with changes and to accept.

No amendments requested.

Editor Comments:

I would encourage the authors to strengthen the current work by discussing the need to consider the relative costs of the various strategies.

Amendments:

- The discussion has been revised and now includes a section on the cost of changing practice patterns, and also re-emphasises how changes need to be driven by data proving their cost-effectiveness to validate the expenditure.

Variation in Practice Patterns for Listing Patients for Renal Transplantation in the United Kingdom: a National Survey

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All authors had full access to all of the data (including statistical reports and tables) in the study and can take responsibility for the integrity of the data and the accuracy of the data analyses.

Presented (as an abstract) at the *Joint British Transplantation Society and Nederlandse Transplantatie Vereniging Congress, Bournemouth, 2015; and at the American Society of Nephrology Kidney Week, Philadelphia, 2014*

Research idea and study design: RP, GL, CE, CT, AB, JLF, CB, JC, CD, CW, HD, RJ, WM, DF, RR, PJR; data acquisition: RP, STC, MC; data analysis/interpretation: RP, STC, GCO, RR, PJR; statistical analysis: RP; supervision or mentorship: RR, CE, GL, RR, PJR. Each author contributed important intellectual content during manuscript drafting or revision and accepts accountability for the overall work by ensuring that questions pertaining to the accuracy or integrity of any portion of the work are appropriately investigated and resolved. RP takes responsibility that this study has been reported honestly, accurately, and transparently; and that no important aspects of the study have been omitted.

Abbreviations

ATTOM	Access to Transplantation and Transplant Outcome Measures
BMI	Body mass index
CKD	Chronic kidney disease
eGFR	Estimated glomerular filtration rate
ESRF	End stage renal failure
LCC	Low clearance clinic
MDT	Multi-disciplinary team
PMP	Per million population
RRT	Renal replacement therapy
WTE	Whole-time equivalent

Abstract

Introduction: Despite the availability of guidelines for the evaluation of candidates for renal transplantation, variation in access to transplantation exists. This national survey investigates whether centre variation exists in the assessment of patients for renal transplantation in the UK.

Methods: An online survey, informed by qualitative interviews, was distributed to all UK renal centres. This survey examined centre approaches to chronic kidney disease service provision, transplant recipient assessment, education provision and wait-listing decision making processes. Centre re-evaluation policies for patients already listed and priorities for future development were also examined.

Results: All 71 renal centres responded. Of these, 83% reviewed pre-dialysis patients in a low clearance clinic. In 26% of centres transplantation was not discussed as a treatment option with all patients. Fourteen centres reported having a dedicated transplant assessment clinic whilst 28% did not have a formal assessment protocol. Age was an exclusion criterion for listing in three centres, all of which had a cut off at 75 years. 83% of centres excluded patients with a high BMI. Cardiac investigations were risk-stratified in 90% of centres. Surgical involvement varied with 11% of centres listing patients without formal surgical review. There was no formal protocol in place to re-evaluate listed patients in 62% of centres.

Conclusions: There is wide variation in UK practice patterns for listing patients for renal transplantation, though its impact on access to transplantation is unclear. The extent to which centre-specific and patient-specific factors affect access to transplantation requires further analysis in a prospective cohort of patients.

Introduction

It is widely regarded that for 'suitable' patients with end stage renal failure (ESRF), renal transplantation confers both better quality of life and life expectancy than dialysis and is the preferred modality of renal replacement therapy (RRT)¹⁻⁴. In light of these benefits, achieving prompt and timely activation on the transplant waiting list is important not least because increasing length of time on dialysis adversely affects graft and patient survival⁵, but also because organ allocation algorithms in many countries (including the UK) give priority to those who have spent greater time on the waiting list when allocating deceased donor kidneys⁶⁻⁷. Thus, centres that achieve earlier listing for transplantation may provide an advantage for their patients compared with centres that take longer.

Various guidelines on the timing of referral for renal transplantation are available from professional organisations across the world⁸⁻¹⁰. Guidelines from the United States Organ Procurement and Transplantation Network (OPTN) Minority Affairs Committee state that the goal for referral should be that all potential candidates are referred for transplant at an estimated glomerular filtration rate (eGFR) above 20 ml/min/1.73m² to favour early transplantation and avoid the development of comorbidities associated with dialysis as well as allowing patients to accrue waiting time that increases their chance of being allocated a donor organ⁸. In comparison the UK Renal Association guidelines recommend that patients with progressive deterioration in renal function suitable for transplantation should be placed on the national transplant list within six months of their anticipated dialysis start date and that pre-emptive transplantation should be the treatment of choice for all suitable patients whenever a living donor is available¹⁰.

1 The term 'suitable' used in these guidelines often poses a conundrum for clinicians
2 as objective criteria to confirm suitability for transplantation are not clearly defined
3 and hence are open to interpretation. To assist this process guidelines for the
4 evaluation of candidates for renal transplantation have been published by the
5 American Society of Transplantation¹¹, the European Renal Association and
6 European Society for Organ Transplantation¹², the UK Renal Association¹⁰, the
7 British Transplantation Society¹³ and Caring for Australasians with Renal
8 Impairment¹⁴. Despite the availability of clinical guidelines, significant variations in
9 the assessment practices among transplant centres have been reported in the
10 United States as well as Europe¹⁵⁻¹⁷.

11 To explore this further we undertook a national survey as part of the NIHR funded
12 Access to Transplantation and Transplant Outcome Measures (ATTOM) programme
13 to examine whether variation exists in the organisation of renal services in listing
14 patients, and to describe centre practices in the education and the evaluation of
15 potential transplant recipients as well as exploring how decisions are made in the
16 UK.

17 **Materials and Methods**

18 A structured online and paper-based survey consisting of 96 questions was
19 developed using the results of two qualitative studies carried out within the ATTOM
20 programme^{18,19}. Qualitative studies included 53 patients and 42 healthcare
21 professionals, and explored patients' views and experiences of joining the transplant
22 waiting list and staff members' experiences of listing patients for transplantation.
23 Staff and patients were recruited from a purposive maximum variation sample of nine
24 renal units in the UK. Existing published literature was also reviewed and feedback

sought and incorporated from a group of experts on the ATTOM steering group. Pilot face-to-face interviews with 4 clinicians were conducted using the first draft survey to guide revision to improve instrument face and content validity and usability prior to distribution.

The questionnaire was designed to establish the practice patterns of the unit relating to listing patients aged <75 years for transplantation. Once finalised, both versions (online and paper-based) of the survey were sent to the lead physicians and surgeons of all 71 adult renal centres in the UK in January 2014. Clinicians were invited either to complete the survey personally or to nominate a representative within the unit to respond. It was specified that the respondent's answers should reflect current practice in the unit rather than individual preference.

Statistical analyses were performed using SAS version 9.3. Results for each question were expressed as a percentage of the total number of centres responding to the question. We identified several factors a priori as 'exposure' variables and tested for associations of these categorical variables with care processes using Chi squared test or Mann Whitney test. Given the potential for multiple testing and false positives we only report associations that were significant at $p < 0.01$. In order to measure how much time renal staff were involved in transplantation listing, Whole-time equivalent (WTE) time was asked. An WTE of 1.0 indicates that a person is equivalent to a Whole-time worker, or 2 persons working half-time.

Results

A completed survey was received from all 71 (100%) adult centres in the UK, of which 23 were transplanting and 48 were non-transplanting renal centres. The reported roles of respondents were: Clinical Director (42.3%), Consultant Nephrologist (49.3%), Consultant Transplant Surgeon (2.8%) and 'Other health professional' (5.6%). Forty centres (56.3%) completed the web-based version and 31 centres (43.7%) the paper version of the survey. The responding centres had a total of 6699 patients active on the UK transplant waiting list at the end of 2012 and reported a national workforce involved in listing patients for transplantation which comprised of 488 WTE Consultant Nephrologists, 113 WTE Transplant Surgeons, 57 WTE Associate Specialists, 73 WTE Transplant Co-ordinators and 75 WTE Live Kidney Donor Nurses. The median number of Consultant Nephrologists was significantly greater at transplanting centres (8.5; IQR 8-11) compared with non-transplanting centres (4.5; IQR 3-6), $p<0.001$).

Chronic Kidney Disease Workforce and Organisation

Almost 48% (47.9%, $n=34$) of centres reported seeing all pre-dialysis patients in a dedicated low-clearance clinic (LCC), whilst 33.8% ($n=24$) of centres used a LCC for some of their patients. The remaining 18.3% ($n=13$) of centres did not have a designated LCC service. There was no significant difference between non-transplanting and transplanting centres in terms of the pattern of LCC utilisation. LCCs were mostly joint (consultant with nurse, 48.3%) or consultant-led (43.1%), with only 8.6% of centres having a nurse-led service. When LCCs were present, 30% of non-transplanting centres did not have a specified protocol for referral for transplantation compared with 11.1% of transplanting centres ($p<0.001$).

Transplantation Education

Transplantation was discussed as a treatment option with all patients under the age of 75 in 51 (71.8%) of centres, with other centres reporting a more selective policy. The decision not to discuss was made mostly by a consultant led multi-disciplinary team (MDT) (55%) or solely by a consultant nephrologist (40%). Discussions regarding transplantation were led most often by a consultant nephrologist (64.8%), with nurses leading the discussion in 19.7%, transplant surgeons in 2.8% and 'other' healthcare professionals in 12.6% of centres. Despite reporting a wide range of educational delivery tools, education almost always took the form of a one-to-one consultation (98.6%) where patients were given literature to take home to read (91.5%).

Transplant Listing Pathway and Role of Transplant Surgeons

The clinical setting for transplant assessment varied, with 36.4% of centres utilising a LCC, 21.2% seeing patients in their usual CKD clinic and 19.7% utilising a specific transplant assessment clinic. The remaining 22.7% of centres reported a mix of 'other' clinical settings. The use of specific transplant assessment clinics was similar in non-transplanting centres and transplanting centres, though the frequency varied widely, with clinics occurring monthly or less frequently in 55% of non-transplanting centres, as compared with 100% of transplanting centres running these clinics fortnightly or more frequently, $p < 0.001$. Overall 88.2% ($n=63$) of centres required all patients to be seen by a Transplant Surgeon prior to being listed; of the remaining 8 centres that did not require direct surgical review, 4 centres (1 transplanting and 3 non-transplanting) reported that all patients were discussed with a Transplant

1 Surgeon, whilst 4 centres reported no surgical involvement in the decision to list for
2 transplantation.
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7 The Assessment Process

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9 Nationally 30% (n=21) of centres did not have a written transplant work-up protocol
10 for recipient assessment, which included 3 transplant centres. Figure 1 shows the
11 frequency with which different investigations were used for the routine assessment of
12 potential renal transplant recipients amongst the 71 centres. Three non-transplanting
13 centres reported having an upper age limit of 75 years (above which patients were
14 only considered in exceptional circumstances for transplantation) whilst all other
15 centres (n=68, 95.6%) did not report any age restrictions. In comparison, Body Mass
16 Index (BMI) was widely used as an exclusion criterion for listing patients, with 81.7%
17 (n=58) of centres excluding patients for transplantation based on BMI. The overall
18 median upper BMI cut off, in these centres was 35 (IQR: 33.25-35), with 36 centres
19 reporting an upper limit of 35, and 5 centres an upper limit of 40 whilst the remaining
20 17 centres stated a BMI limit between 33-30. The reasons stated for using BMI as an
21 exclusion criterion are summarised in Table 1. These did not differ between centres
22 other than perceived increased cardiovascular risk, which appeared to be more of an
23 issue for non-transplanting (52.5%) than transplanting centres (33.3%), $p<0.01$.
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25 All transplanting centres, and 87.5% (n=65) of non-transplanting centres reported
26 stratifying patients by risk when deciding which cardiac investigations to perform.
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28 Age (median 50 years; IQR: 50-55)(88%), diabetes (97%), previous cardiovascular
29 disease (91%), and an abnormal ECG (89%) were used to determine risk. Thirty-one
30 centres (44%) conducted some form of 'cardiac stress testing' even in low risk
31 patients whilst significant variation was seen in the first-line investigation of choice
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1 for the assessment of coronary artery disease in high risk patients (Table 2). If a
2 coronary angiogram was deemed necessary for listing a low clearance patient, 5.6%
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4 (n=4) of centres reported they would refrain from performing the test until patients
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6 were on dialysis to avoid precipitating the need for dialysis, with a further 74.6%
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8 stating they would 'sometimes' refrain from proceeding. Only 19.7% reported always
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10 proceeding.
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13 Variation was also seen in screening for malignancies with 38% of centres reporting
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15 that screening for cancer such as breast, prostate, bladder and colorectal was part of
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17 the routine work-up of transplant recipients, in addition to national screening
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19 programmes. In contrast, formal psychological or cognitive assessment of all
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21 potential recipients was only performed in 7.0% and 5.6% of centres respectively,
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23 with 13.1% of centres reporting no access to psychologist or counsellor services.
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31 Decision Making

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33 Overall 76.1% (n=54) of centres utilised an MDT approach when listing patients for
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35 transplantation. This proportion was greater amongst transplanting centres where all
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37 but one centre (95.7%) used an MDT, compared to 66.7% (n=54) in non-
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39 transplanting centres. MDTs occurred more frequently in transplanting centres with a
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41 median of 4 meetings a month (IQR 1.25-4) as compared to 2 a month (IQR 1-4;p=
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43 0.001) in non-transplanting centres.
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48 If a patient was not deemed suitable for listing for deceased donor transplantation,
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50 76.1% of centres said that they would consider listing them for living donor
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52 transplantation if a suitable donor was available. Living donor availability was
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54 generally seen as a positive driver for listing, alongside patient enthusiasm, whilst
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56 the majority of centres did not perceive socioeconomic factors, including employment
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status or level of patient education, as important when deciding whether to list patients for transplantation (Figure 2). Once a decision regarding listing was made, 50.7% of centres reported informing all patients on dialysis, or with CKD stage 5 under 75 years, of the decision, with 78.6% of centres recording all decisions made on transplant suitability on their electronic patient record (EPR). Once recorded on their EPR, only 61.8% of centres performed regular audit of this information. After listing, only 38% of centres reported having a protocol in place to monitor patients activated on the transplant list with the majority of centres (53.5%) reviewing patient suitability annually. Significant variation existed in how centres undertook on-going surveillance for cardiac disease in asymptomatic patients once listed as shown (Table 3). This was also highlighted in centres' responses to questions on improving listing, with 53 centres (74.6%) either agreeing or strongly agreeing with the need for having a national consensus on cardiac work up, and 52 centres (73.2%) also agreeing that there was a need for a consensus on the entire assessment work-up process (Figure 3).

Inter-Centre Relationships and Future Development

Although 95% of centres reported having a positive relationship with a 'good', 'very good' or 'excellent' relationship with their associated transplanting/non-transplanting centres, one third (n=16) of non-transplanting centres felt that accessing an appointment at their affiliated transplanting centre was a significant source of delay in listing patients.

Factors reported by centres to be most important in improving listing of patients for transplantation included: providing a better evidence base behind necessary assessment work up; improving the commissioning of transplant work up by funders

of the service; and developing a national consensus on the work up of transplant recipients (Figure 3). If extra funding was available, centres stated they would use this to increase the number of transplant co-ordinators and living-donor nurses, increasing the number of operation time slots for transplantation in trusts, and providing administrative support for allied health professionals involved in transplantation would likely improve overall listing and time to listing in their centres (Figure 4).

Discussion

This study provides the most extensive exploration to date of clinical practice patterns within renal centres in listing patients for renal transplantation in the UK; and is the first to account for practice patterns in both transplanting and non-transplanting centres. It provides a comprehensive overview of the transplant-listing pathway including staffing levels, clinic arrangements, provision of patient education on transplantation, decision-making, recipient assessment, surgical review, criteria for listing, and the role of MDTs.

For a national population of 64.1 million²⁰ the number of consultant transplant surgeons reported (1.76 per million population) (pmp) in this survey remains significantly lower than the 2pmp recommended by the Royal College of Surgeons of England²¹. Indeed the number of consultant nephrologists (7.61pmp), transplant co-ordinators (1.14pmp) and living-donor nurses (1.17pmp) are all significantly lower than that recommended by the National Renal Workforce Planning Group and point towards an understaffed service²¹.

1 Despite the UK Renal Association recommending that CKD patients pre RRT should
2 be managed in a dedicated clinic by a MDT²², this study also demonstrated wide
3 variation in the utilisation of low-clearance clinics nationally, with variation also seen
4 in their implementation and entry criteria. There are many studies, albeit small, which
5 have shown that a dedicated pre- dialysis clinic is associated with improved
6 outcomes and reduced urgent initiation of dialysis²³⁻²⁶. These clinics may provide
7 focused opportunity to assess transplantation potential and more timely discussion of
8 options including live donation and pre-emptive transplantation. Similarly, specific
9 transplant-assessment clinics (used by a fifth of centres) enable joint assessment by
10 physician and surgeon; whilst the evidence of their effectiveness is lacking they may
11 be more efficient at transplant listing.
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27 Irrespective of the type of CKD service in place, a broad range of educational
28 methods were utilised across the UK, with one-to-one education being the main
29 route. A significant proportion of centres (28%) did not discuss transplantation as a
30 treatment option with all patients under the age of 75 years, and nearly 50% of
31 patients who had had a decision made about them regarding transplantation were
32 not informed of the decision made. This is of concern, as a patient-centred approach
33 would require that all options are communicated to a patient and their family where
34 possible. There may be exceptional circumstances where this may not always be
35 feasible, but such instances would be expected to be less frequent than was
36 reported in the present study.
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54 Another important observation from this study was that some centres did not
55 consider surgical review to be an absolute requirement for listing patients for
56 transplantation. Eight centres listed without formal review, four of which cited no
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1 surgical involvement at all. The UK Renal Transplant Service specification stipulates
2 that patients should undergo surgical assessment prior to being placed on the
3 transplant list²⁷, however it should be noted that in the US it is not uncommon to
4 have only a subset of patients evaluated by transplant surgery in a face-to-face
5 encounter. Instead, they selectively evaluate higher risk patients, e.g., those with
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Whilst in these centres it might be perceived that informed consent need not be
taken by a surgeon and can instead be obtained by an experienced physician. The
authors question whether without surgical input, patients can truly make an
adequately informed choice and be involved in shared decision-making about
transplantation and the associated surgical risks. Chronic understaffing described
earlier and the belief that surgical evaluation of every patient prior to listing
might reduce/delay access to transplant, may partly explain why centres have
adopted such practices, though its impact on outcome is not known.

Several national guidelines recommend that centres should have written criteria for
acceptance of patients onto the waiting list^{10, 28}, yet nearly a third of centres reported
not having a protocol, including three transplanting centres. The lack of
standardisation in these units could lead to variation in assessment, stereotyping,
individual clinician bias and personal idiosyncrasies contributing to inequity. It was
reassuring that the majority of centres (95.6%) did not use chronological age per se
as an exclusion criterion. This figure is higher than that seen in the US, where 66%
of centres reported having an upper age cut-off (in a similar study of transplanting
centres)²⁹, and acknowledges the notion that age must not be used as a proxy for
the assessment of individual need and suitability. It also highlights how clinicians are

1 aware that chronological age can be very different to biological age in different
2 individuals, and how assessment needs to be tailored on a case-by-case basis to
3
4 avoid unwarranted age discrimination.
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9 In contrast to age, the majority of centres used BMI as an exclusion criterion, similar
10 to findings from studies from the US³⁰, Canada³¹ and Europe³², with a wide upper
11 BMI limit of 30-40. In the context of an increasingly obese population, such a broad
12
13 range has the potential to cause variation in access to transplantation. Obese
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15 patients are certainly at an increased risk of technical difficulties and peri-operative
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17 complications³³⁻³⁴ though evidence in favour of imposing a BMI limit on the basis of
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19 more hard end-points (patient and graft survival) is conflicting³⁵⁻⁴⁰. A number of
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21 reports from nationwide databases, including the USA, Australia and the
22
23 Netherlands^{35, 38, 40}, have shown decreased patient and graft survival in obese
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25 recipients, whilst others showed no differences in survival between obese and non-
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27 obese transplant recipients³⁹. It is unclear in studies where an increase in risk was
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29 noted, how much would be mitigated once co-existing cardiovascular disease was
30
31 accounted for. This raises the notion that if technically feasible, and cardiovascular
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33 disease has been ruled out, most patients should be considered for transplantation
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35 irrespective of their BMI.
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46 As cardiovascular disease remains the main cause of death in transplant
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48 recipients⁴¹, it is unsurprising that most centres invest a great deal of time and
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50 resource in its investigation and management. This study showed that most centres
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52 stratify patients on their level of risk, though the choice of ensuing investigation
53
54 varied greatly with no clear consensus irrespective of risk, from non-invasive
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56 functional tests to invasive angiography. This variation is likely due to a combination
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of factors including lack of evidence on superiority for any one investigation, as well as local cardiac service availability and experience. Centres also differed in their perception of risk associated with angiography in low-clearance patients. Overall this variation has the potential for creating inequity, as centres adopting more intense screening protocols might impede wait-listing for patients with barriers to getting the tests completed.

Another important issue which needs mentioning is the cost implications of changing practice patterns, particularly at a time of receding budgets and rising concern over the cost and value of healthcare. Indeed, it is likely that individual centre practices are in part, a consequence of local infrastructure and availability of service providers, and though instigating some changes may be relatively inexpensive e.g. introducing a written protocol, others e.g. introducing universal invasive cardiac screening for coronary artery disease, may require significant expenditure. Acknowledging this, prior to recommending significant changes to centre practices, it is pertinent to demonstrate the medical efficacy and cost-effectiveness of any proposed changes on access to transplantation which will also assist in ensuring they are long-lasting.

Limitations

Although this study received a 100% response rate across all parts of the UK and though the survey instrument was piloted and refined to enhance relevance, understandability, and usability; some limitations need to be acknowledged. The survey responses were self-reported by self-selecting renal staff e.g. the clinical lead for transplantation, and their responses will not necessarily reflect those of the broader consultant community. Likewise, as only a small proportion (2.8%) of respondents identified themselves as being a transplant surgeon this may have

1 potentially biased the results due to the under-representation of surgical opinion
2 amongst responders. Equally, we could not check the validity of responses garnered
3
4 and some of these data were necessarily estimates and so should be regarded with
5
6 caution. There may also have been a social desirability bias in the responses as
7
8 respondents may have answered questions to put their centre in a good light.
9
10 Furthermore, most questions in the survey were multiple-choice questions that
11
12 invited respondents to select the best possible answer out of the choices available.
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14 This approach necessarily limits their responses, although an option to select "other"
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16 was provided and the survey was designed following detailed qualitative interviews
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18 with patients and staff to identify core domains.
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25 In conclusion there is wide variation in UK practice patterns in listing patients for
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27 renal transplantation. Potential causes for this are likely to include variation in
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29 international guidelines and a lack of consensus in evaluating patients especially
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31 assessing their cardiovascular risk^{10-14, 28}. Differing local population co-morbidity and
32
33 socioeconomic factors may also be playing a role alongside varying physician
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35 attitudes and beliefs towards transplant listing and risk assessment⁴². Future
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37 research should be directed at developing a national consensus on recipient work up
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39 and in understanding the utility of cardiovascular screening in potential transplant
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41 recipients, as well as gaining better long-term outcome data on the impact of obesity
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43 and age on transplantation.
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50 There is also a need to understand the impact, if any, of this variation on access to
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52 transplantation. In the UK, as part of the NIHR funded ATTOM study, patient
53
54 variables and the impact of centre variables described in this study, will be further
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56 evaluated in a multilevel hierarchical model, in a prospective sample of incident
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dialysis patients recruited as part of the ATTOM Study.

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References

1. Wolfe RA, Ashby VB, Milford EL, et al. Comparison of mortality in all patients on dialysis, patients on dialysis awaiting transplantation, and recipients of a first cadaveric transplant. N Engl J Med.1999 Dec 2;341(23):1725-1730.
2. Oniscu GC, Brown H, Forsythe JLR. Impact of cadaveric renal transplantation on survival in patients listed for transplantation. J Am Soc Nephrol.2005;16(6):1859-1865.
3. Neipp M, Karavul B, Jackobs S, et al. Quality of life in adult transplant recipients more than 15 years after kidney transplantation. Transplantation.2006;81:1640-1644.
4. Abecassis M, Bartlett ST, Collins AJ, et al. Kidney Transplantation as Primary Therapy for End-Stage Renal Disease: A National Kidney Foundation/Kidney Disease Outcomes Quality Initiative (NKF/KDOQITM) Conference. Clin J Am Soc Nephrol.2008 Mar;3(2):471-480.
5. Meier-Kriesche HU, Kaplan B. Waiting time on dialysis as the strongest modifiable risk factor for renal transplant outcomes: a paired donor kidney analysis. Transplantation.2002;74:1377-1381.
6. Organ Procurement and Transplantation Network. OPTN.
http://optn.transplant.hrsa.gov/ContentDocuments/OPTN_Policies.pdf#nameddest=Policy_08. Accessed December 10, 2015.
7. Kidney Allocation Policy – ODT Clinical site.
http://www.odt.nhs.uk/pdf/kidney_allocation_policy.pdf. Accessed December 10, 2015.
8. Kidney transplant referral guide – OPTN Minority affairs committee

http://optn.transplant.hrsa.gov/ContentDocuments/Guidance_Kidney_Transplant_Referral.pdf. Accessed December 10, 2015.

9. Knoll G, Cockfield S, Blydt-Hansen T, et al. Canadian Society of Transplantation consensus guidelines on eligibility for kidney transplantation. CMAJ. 2005 Nov 8;173(10):1181-1184.
10. Assessment of the potential kidney transplant recipient. <http://www.renal.org/guidelines/modules/assessment-of-the-potential-kidney-transplant-recipient#sthash.fl9hWz9C.dpbs>. Accessed December 10, 2015.
11. Kasiske BL, Cangro CB, Hariharan S, et al. The evaluation of renal transplantation candidates: Clinical practice guidelines. Am J Transplant 200; 1 Suppl 2:3-95.
12. Abramowicz D, Cochat P, Claas FH, et al. European Renal Best Practice Guideline on kidney donor and recipient evaluation and perioperative care. Nephrol Dial Transplant. 2015 Nov;30(11):1790-1797.
13. British Transplantation Society. Standards for solid organ transplantation in the United Kingdom. Available at: http://www.bts.org.uk/BTS/Guidelines_Standards/Current/BTS/Guidelines_Standards/Current_Guidelines.aspx?hkey=e285ca32-5920-4613-ac08-fa9fd90915b5. Accessed December 10, 2015.
14. Campbell S, Pilmore H, Gracey D, Mulley W, Russell C, McTaggart S. KHA-CARI Guideline: Recipient Assessment for Transplantation. Nephrology. 2013;18(6):455-462.
15. Ramos EL, Kasiske BL, Alexander SR, et al. The evaluation of candidates for renal transplantation. The current practice of U.S. transplant centers. Transplantation. 1994; 57:490-497.

16. Fritsche L, Vanrenterghem Y, Nordal KP, et al. Practice variations in the evaluation of adult candidates for cadaveric kidney transplantation: A survey of the European Transplant Centers. *Transplantation*. 2000;70:1492-1497.
17. Akolekar D, Oniscu GC, Forsythe JL. Variations in the assessment practice for renal transplantation across the United Kingdom. *Transplantation*. 2008 Feb 15;85(3):407-410.
18. Calestani M, Tonkin-Crine S, Pruthi R, et al; ATTOM Investigators. Patient attitudes towards kidney transplant listing: qualitative findings from the ATTOM study. *Nephrol Dial Transplant*. 2014 Nov;29(11):2144-2150.
19. Pruthi R, Calestani M, Leydon G, et al. Access to transplantation and transplant outcome measures (ATTOM): Exploring healthcare professionals' perspectives on access to renal transplantation in the UK. *Nephrology Dialysis Transplantation*. Conference: 50th ERA-EDTA Congress Istanbul Turkey.
- http://www.abstracts2view.com/era_archive/view.php?nu=ERA13L_453038. Accessed November 5, 2015.
20. Office of National Statistics. <http://www.ons.gov.uk>. Accessed December 10, 2015.
21. Recommendations of the National Renal Workforce Planning Group 2002.
- <http://www.britishrenal.org/BritishRenalSociety/files/24/24f2096f-442e-44c3-9ae0-51d9382b5292.pdf>. Accessed December 10, 2015.
22. Planning, Initiating and Withdrawal of Renal Replacement Therapy.
- <http://www.renal.org/guidelines/modules/planning-initiating-and-withdrawal-of-renal-replacement-therapy#sthash.zl7vrDXg.dpbs>. Accessed December 10, 2015.

23. Levin A, Lewis M, Mortiboy P, et al. Multidisciplinary predialysis programs: quantification and limitations of their impact on patient outcomes in two Canadian settings. *Am J Kidney Dis.* 1997;29:533-540.
24. Ravani P, Marinangeli G, Stacchiotti L, Malberti F. Structured pre-dialysis programs: More than just timely referral? *J Nephrology.* 2003;16:862-869.
25. Ravani P, Marinangeli G, Tancredi M, Malberti F. Multidisciplinary chronic disease management improves survival on dialysis. *J Nephrology.* 2003;16:870-877.
26. Buck J, Baker R, Cannaby A-M, Nicholson S, Peters J, Warwick J. Why do patients known to renal services still undergo urgent dialysis initiation? A cross-sectional survey. *Nephrol Dial Transplant.* 2007;22:3240-3245.
27. Renal Transplantation – NHS England. <https://www.england.nhs.uk/wp-content/uploads/2014/04/a07-renal-transpl-ad-0414.pdf>. Accessed December 10, 2015.
28. Batabyal P, Chapman JR, Wong G, et al. Clinical practice guidelines on wait-listing for kidney transplantation: consistent and equitable? *Transplantation* 2012; 94:703.
29. Ramos EL, Kasiske BL, Alexander SR, et al. The evaluation of candidates for renal transplantation. The current practice of U.S. transplant centers. *Transplantation.* 1994 Feb 27;57(4):490-7.
30. Pondrom S. The AJT report: news and issues that affect organ and tissue transplantation. *Am J Transplant.* 2012;12(7):1663-1664.
31. Stenvinkel P, Ikizler TA, Mallamaci F, et al. Obesity and nephrology: results of a knowledge and practice pattern survey. *Nephrol Dial Transplant.* 2013;28(suppl 4):iv99-iv104.

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32. Chan G, Soucisse M. Survey of Canadian Kidney Transplant Specialists on the Management of Morbid Obesity and the Transplant Waiting List. *Canadian Journal of Kidney Health and Disease*. 2016;3:2054358116675344.
 33. Modlin CS, Flechner SM, Goormastic M, et al. Should obese patients lose weight before receiving a kidney transplant? *Transplantation*. 1997;64:599-604.
 34. Lynch RJ, Ranney DN, Shijie C, Lee DS, Samala N, Englesbe MJ. Obesity, surgical site infection, and outcome following renal transplantation. *Annals of Surgery*. 2009; 250:1014-1020.
 35. Gore JL, Pham PT, Danovitch GM, et al. Obesity and outcome following renal transplantation. *Am J Transplant*. 2006;6:357-363.
 36. Glanton CW, Kao TC, Cruess D, Agodoa LY, Abbott KC. Impact of renal transplantation on survival in end-stage renal disease patients with elevated body mass index. *Kidney Int*. 2003;63(2):647-653.
 37. Meier-Kriesche H-U, Arndorfer JA, and Kaplan B. The impact of body mass index on renal transplant outcomes: a significant independent risk factor for graft failure and patient death. *Transplantation*. 2002;73:70-74.
 38. Aalten J, Christiaans MH, de Fijter H, et al. The influence of obesity on short- and long-term graft and patient survival after renal transplantation. *Transpl Int*. 2006;19: 901-907.
 39. Howard RJ, Thai VB, Patton PR, et al. Obesity does not portend a bad outcome for kidney transplant recipients. *Transplantation*. 2002;73:53-55.
 40. Chang SH, Coates PTH, McDonald SP. Effects of body mass index at transplant on outcomes of kidney transplantation. *Transplantation*. 2007;84:981-987.

1 41. Collins A. US renal data system 2012 annual report. Am J Kidney Dis.

2 2013;6:A7, e1-476.

3
4
5 42. Calestani M, Tonkin-Crine S, Pruthi R, et al. Patient attitudes towards kidney

6
7 transplant listing: qualitative findings from the ATTOM study. Nephrology

8
9 Dialysis Transplantation. 2014;29(11):2144-2150. doi:10.1093/ndt/gfu188.

Table 1: Reasons for considering raised BMI as a contraindication for transplantation by centres adopting a maximum exclusion criterion

	Transplanting Centre		Non-Transplanting Centre		Overall Nationally	
	N	% (of Centres)	N	% (of Centres)	N	% (of Centres)
Increased post-operative complication risk	16	88.9	34	85	50	86.2
Increased technical difficulty in performing procedure	14	77.8	30	75	44	75.9
Increased cardiovascular risk	6	33.3	21	52.5	27	46.6
Lower Graft survival compared to a normal BMI	6	33.3	9	22.5	15	25.9
Lower patient survival compared to normal BMI	6	33.3	9	22.5	15	25.9
Other (please specify)	2	11.1	10	25	12	20.7
Total	50		113		163	

Table 2: First-line investigation of choice for the assessment of coronary artery disease in high-risk patients

	Transplanting Centre		Non-Transplanting Centre		Overall Nationally	
	N	% (of Centres)	N	% (of Centres)	N	% (of Centres)
Exercise Tolerance Test	5	21.7	1	20.8	1	21.1
Thallium Stress Test	7	30.4	1	35.4	2	33.8
Stress Echocardiography	2	8.7	7	14.6	4	12.7
Dobutamine Stress Tc Scan	3	13.0	7	12.5	9	12.7
Coronary Angiography	1	4.3	6	4.2	3	4.2
CPEX Testing*	1	4.3	2	4.2	3	4.2
Other (please specify)	4	17.4	4	8.3	8	11.3

*Cardio-Pulmonary Exercise Test

Table 3: Continued surveillance of cardiac disease in asymptomatic patients on the waiting list reported across UK renal centres

	Transplanting Centre		Non-Transplanting Centre		Overall Nationally	
	N	%	N	%	N	%
No routine surveillance if asymptomatic	6	26.1	13	27.1	19	26.8
All patients screened irrespective of remaining asymptomatic	4	17.4	16	33.3	20	28.2
Surveillance only in high risk groups	12	52.2	11	22.9	23	32.4
Varies, no specific policy	1	4.3	8	16.7	9	12.7
Other (please specify)	0	0.0	0	0.0	0	0.0
Total	23	100.0	48	100.0	71	100.0

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2 **Figure Legends:**
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4 **Figure 1:** Bar chart showing proportion of UK Centres performing each investigation
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6 as part of their routine assessment of patients under consideration for renal
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8 transplantation wait listing at UK renal centres.
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13 **Figure 2:** Bar chart showing distribution across renal units of responses to the
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15 question: **“Please indicate your views on whether the following factors**
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17 **influence the decision to list a patient”** Please indicate how strongly each would
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19 influence a decision. Values are expressed as percentage of units (n=71).
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26 **Figure 3:** Bar chart showing distribution across renal units of responses to the
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28 question: **“What is your opinion on the following statements about whether they**
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30 **would improve listing of patients for transplantation?”** Please indicate how
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32 strongly you agree or disagree with each of the following.” Values are expressed as
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34 percentage of units (n=70).
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42 **Figure 4:** Bar chart showing distribution across renal units of responses to the
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44 question: **“What is your opinion on whether more funding for the following**
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46 **resources would improve overall listing and time to listing in your unit?** Please
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48 indicate how strongly you agree or disagree with each of the following.” Values are
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50 expressed as percentage of units (n=70).
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Figure 1: Proportion of UK Centres performing each investigation as part of their routine assessment of patients under consideration for renal transplantation wait listing at UK renal centres.

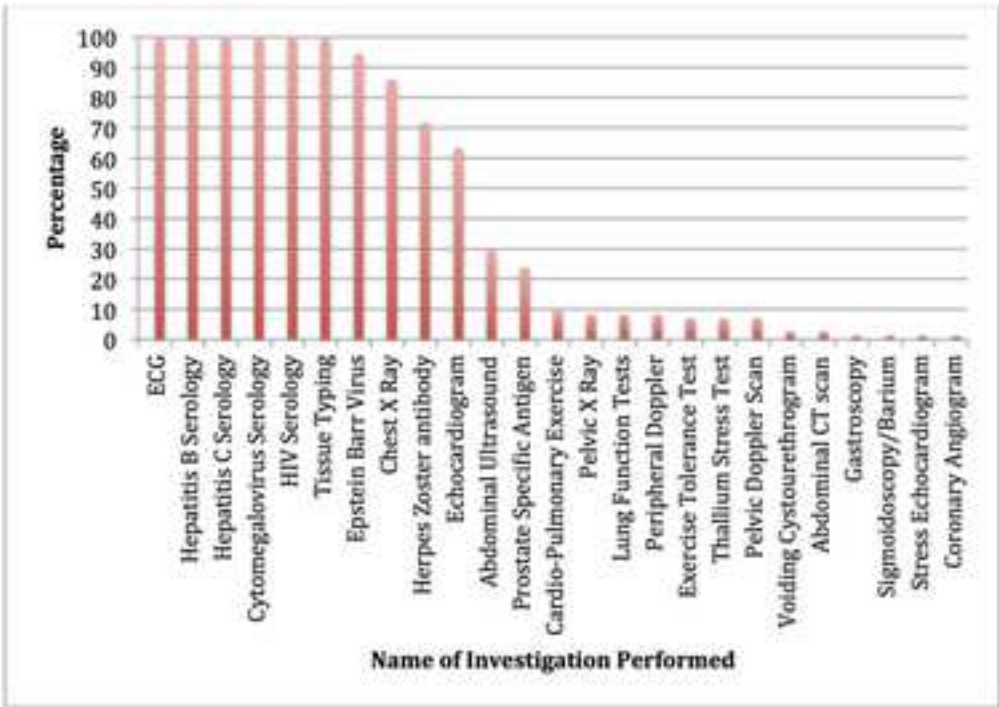


Figure 2: Distribution across renal units of responses to the question: **"Please indicate your views on whether the following factors influence the decision to list a patient"** Please indicate how strongly each would influence a decision. Values are expressed as percentage of units (n=71).

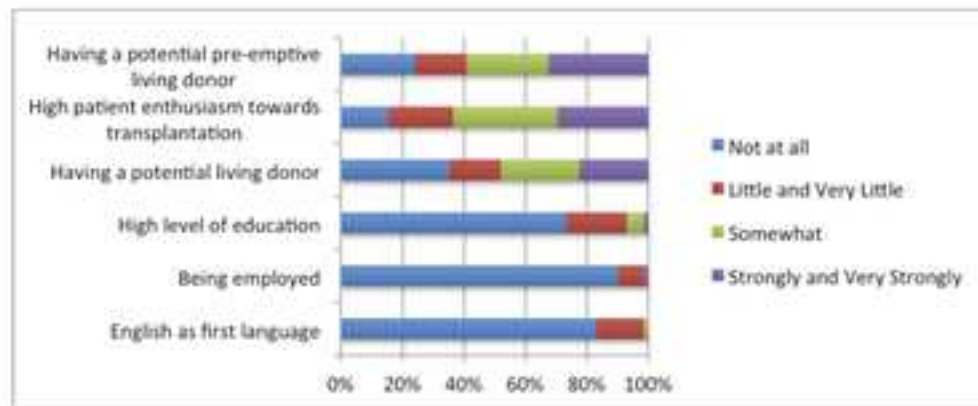


Figure 3: Distribution across renal units of responses to the question: **"What is your opinion on the following statements about whether they would improve listing of patients for transplantation?"** Please indicate how strongly you agree or disagree with each of the following." Values are expressed as percentage of units (n=70).

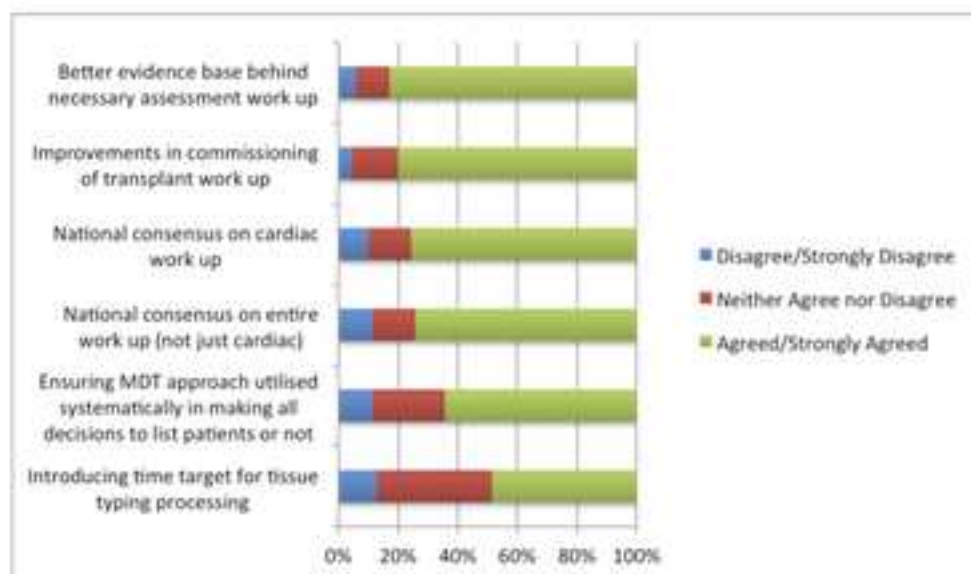
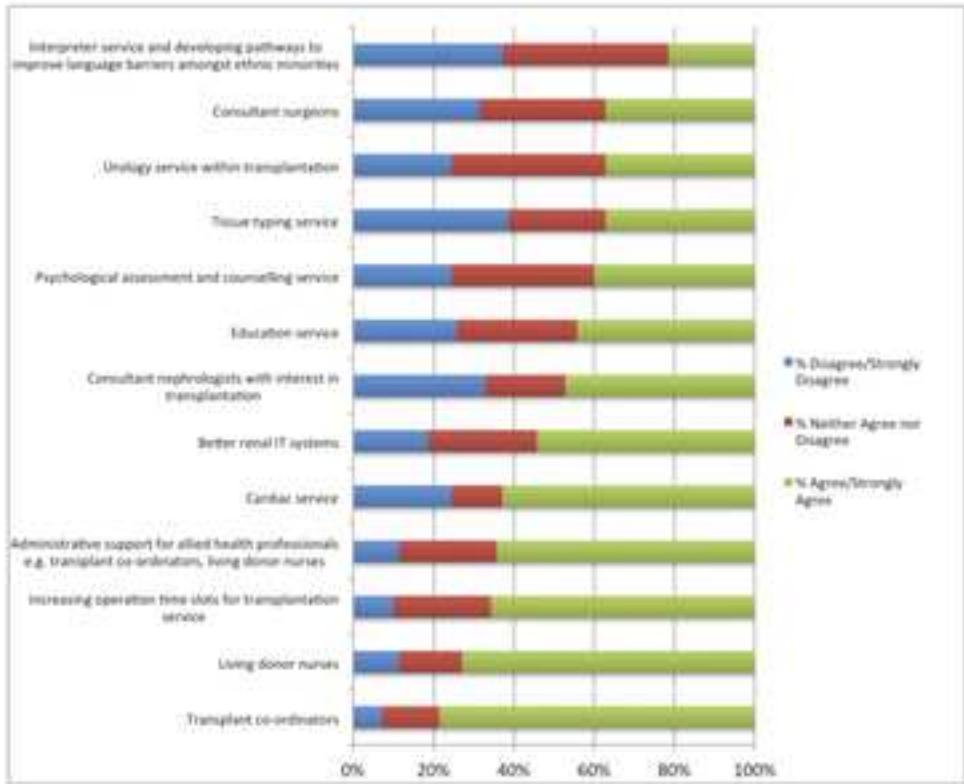


Figure 4: Distribution across renal units of responses to the question: **"What is your opinion on whether more funding for the following resources would improve overall listing and time to listing in your unit? Please indicate how strongly you agree or disagree with each of the following."** Values are expressed as percentage of units (n=70).



ID

ATTOM Survey

A national survey of practice patterns in UK renal units in listing patients for renal transplantation

Transplant Units

Thank you for completing this survey

This questionnaire asks about the transplant listing process in your unit.

Some of the questions address practice patterns that may vary among staff members in your unit. Please try to give the answer that is most representative of the unit as a whole (i.e. the whole renal service including satellite units).

In order to complete this questionnaire, you may want to consult other members of the renal team or to delegate this task to a more appropriate person who has responsibility for such patients (e.g. you will be asked who participates in the decision-making process; how the decision is taken). The questionnaire will take about 45 minutes to fill in.

Instructions for completing the questionnaire

- Please answer each question by ticking the appropriate box(es).
- The survey can be completed by multiple respondents.
- Please return the survey in the FREEPOST envelope provided.

We would be very grateful if you could complete the survey as soon as possible.

Prof Paul Roderick, Professor of Public Health, University of Southampton
Dr Rommel Ramanan, Consultant Nephrologist, Southmead Hospital, Bristol
Dr Gabriel Oniscu, Consultant Transplant Surgeon, Royal Infirmary of Edinburgh, Edinburgh
Dr Rishi Pruthi, ATTOM Clinical Research Fellow, UK Renal Registry, Bristol

**If you have any queries regarding this questionnaire, please contact:
Dr Sarah Tonkin-Crine on 023 8024 1080, S.K.Tonkin-Crine@soton.ac.uk**

Before asking questions regarding your CKD service workforce and organisation in your unit, we would like to know the name of your unit and your occupation.

In order to supplement the data publicly available from the UK Renal Registry, please answer the following questions.

1 Please state your role within the renal unit:

Please tick one

☐ Clinical Director

☐ Consultant Transplant Surgeon

☐ Consultant Nephrologist
(other than Clinical Director)

☐ Transplant Co-ordinator

☐ Other **(Please specify)**

2 Please enter the name of your renal unit:

1. Understanding your CKD Service Workforce and Organisation

3 For each of the staff roles listed, please provide the number of Whole Time Equivalent (WTE) in your centre (e.g. Full-time=1.0 WTE, Half-time=0.5 WTE, Three Full-time staff = 3.0 WTE).

Put 0 if you do not have any staff in a particular role or leave blank if you do not know the answer.

Please combine contributions across directorates if not all under one single directorate.

Consultant Nephrologists

Consultant Transplant Surgeons

Transplant Staff grade/Associate specialist

Nephrology Staff grade/Associate specialist

Transplant recipient Co-ordinators

Living kidney Donor Nurses

4 How many neighbouring hospitals do you provide a service to?

Enter number for all that apply

For managing patients with chronic kidney disease

For transplantation

5 Which statement best describes how pre-dialysis patients are managed in your unit?

- ☐ All pre-dialysis patients are seen in dedicated low clearance clinics
- ☐ Some pre-dialysis patients are seen in a low clearance clinic whilst some are seen as part of a general nephrology clinic
- ☐ All pre-dialysis patients are seen in a mixed general nephrology clinic alongside other CKD patients as there are no specific low clearance clinics (go to question 14)

6 What are the entry criteria for being referred to your low clearance clinic?

Tick and complete all that apply

☐ eGFR (Please specify)

☐ No defined criteria

☐ Expected/projected time frame before needing to commence renal replacement therapy (Please specify in months)

☐ Other criteria (Please specify)

continued
over ➡

7 **Who primarily leads the delivery of your low clearance service?**

(If jointly led, tick all that apply)

- ☐ Consultant Nephrologist ☐ Nurse
- ☐ Staff Grade nephrologist

8 **In how many of the neighbouring hospitals that you serve for chronic kidney disease do you have a dedicated low clearance clinic?**

(Please enter number)

9 **Which statement most accurately describes your LCC service?**

- ☐ 'Single Hub and Spokes': CKD clinics present at all neighbouring hospitals feed into a single main LCC clinic based at Main renal unit/hospital
- ☐ LCC clinics present at >50% of neighbouring hospitals served by unit
- ☐ LCC clinics present at <50% of neighbouring hospitals served by unit

10 **Are all pre-dialysis patients referred to a LCC clinic?**

- ☐ Yes **(go to question 13)**
- ☐ No

11 **If No, please explain why a pre dialysis patient might not be referred to a low clearance clinic?**

Tick all that apply

- ☐ Consultant responsible wishes to maintain continuity
- ☐ To avoid longer travel times for patient
- ☐ Patient choice
- ☐ Consultant's belief it would not add any additional value
- ☐ Patient's belief it would not add any additional value
- ☐ Other

If you do not have a Low Clearance Clinic what are the reasons for this?

2 Discussing Transplantation

13 **Is transplantation discussed with all pre dialysis patients under 75 years?**

☐ Yes (**go to question 15**)

☐ No

14 **If transplantation is not discussed with all patients, please explain how this decision is most commonly made:**

☐ Consultant nephrologist decides alone

☐ Consultant nephrologist decides in discussion with other consultants

☐ Consultant nephrologist decides with input from other professionals from an MDT meeting

☐ Clinical nurse specialist/consultant nurse decides alone

☐ Clinical nurse specialist/consultant nurse decides with input from other consultants

☐ Clinical nurse specialist/consultant nurse decides with input from other professionals from an MDT meeting

☐ Other (**Please specify**)

15 **When is transplantation most commonly first discussed with a patient?**

☐ When they are referred to the low clearance clinic

☐ When their eGFR reaches a certain level
(**Please specify**)

☐ At a specific time point prior to the anticipated start of dialysis
(**Please specify in months**)

☐ When symptoms start

☐ After being established on dialysis

☐ Other (**Please specify**)

16

Who plays the lead/main role in the discussion of transplantation with a patient?

- ☐ Consultant Nephrologist
- ☐ Consultant Surgeon
- ☐ Transplant Co-ordinator
- ☐ Nurse (Pre Dialysis Nurse/Low clearance Nurse/Education Nurse)
- ☐ Other **(Please specify)**

17

Which of the following applies to how education about transplantation is delivered across the hospitals you serve?**Tick all that apply**

- ☐ One to One consultation
- ☐ DVD education material to take home
- ☐ Written material to take home
- ☐ Translated (if appropriate) written material to take home
- ☐ Computer-based education programme
- ☐ Group session with other pre-dialysis patients discussing all options of RRT
- ☐ Group session with other patients considering transplantation discussing just transplantation
- ☐ Talk from a patient with a functioning transplant
- ☐ Talk from a patient with failed transplant
- ☐ Cultural/language matched nurse educators
- ☐ Home visit education
- ☐ Education session (based only at main unit)
- ☐ Education session (based at local hospital)
- ☐ Other **(Please specify)**

continued
over ➡

3 Understanding Transplant listing processes

18 **Which type of clinic do patients undergoing transplant work up have their medical assessment e.g. tissue typing, cardiac work up?**

- ☐ In their usual general nephrology clinic (**go to question 24**)
- ☐ In a Low Clearance clinic (**go to question 24**)
- ☐ In Clinic run by nephrologist with interest in transplantation (**go to question 24**)
- ☐ In a specific transplant assessment clinic (**go to question 19**)
- ☐ Other (if none of the above accurately describe your unit's organisation please briefly describe here) (**go to question 24**)

19 **How frequently does the transplant assessment clinic take place?**

- ☐ More than once weekly
- ☐ Fortnightly
- ☐ Less than monthly
- ☐ Weekly
- ☐ Monthly
- ☐ Other (**Please specify**)

20 **At which point is a patient referred to the transplant unit?**

- ☐ Before undergoing any investigations
- ☐ After completing some baseline investigations
- ☐ After completing all necessary investigations
- ☐ Other (**Please specify**)

21 **Who is involved in the transplant assessment clinics?**

Tick all that apply

- ☐ Usual named consultant nephrologist
- ☐ Transplant surgeon
- ☐ Other (**Please specify**)
- ☐ Local Associate specialist/staff grade
- ☐ Transplant nephrologist

22 **Do any of the following allied health professionals attend transplant assessment clinics?**

Tick all that apply

☐ Education Nurse

☐ Transplant Co-ordinator

☐ Living Donor Nurse

☐ Other **(Please specify)**

23 **Which statement best describes the purpose of the transplant assessment clinic:**

☐ To assess medical suitability prior to referring patient for surgical review **(go to question 24)**

☐ To assess medical and surgical suitability prior to referring patient for surgical review
(go to question 27)

☐ Other **(if none of the above are suitable, please specify)**

Surgical Review

24 **Are all patients seen by a transplant surgeon prior to being listed for transplantation?**

☐ Yes **(skip to question 26)**

☐ No

25 **If no, are all patients discussed with a transplant surgeon prior to being listed for transplantation?**

☐ Yes

☐ No

26 **Which statement best describes the timing of surgical involvement/referral?**

☐ Patients are referred for surgical assessment as soon as they agree to undergo assessment prior to completing any investigations

☐ Patients are referred for surgical assessment after completing their medical assessment

☐ Patients are referred for surgical assessment whilst medical assessment is on-going

☐ Medical and surgical assessment occurs concurrently at the same clinic appointment

☐ None of the above **(Please specify)**

4 The Assessment Process

27 **Please identify the lead/key healthcare professional(s) responsible for performing each of the following processes:**

Tick all that apply for each

	Consultant Nephrologist	Transplant Surgeon	Staff Grade	Transplant Co-ordinator	Pre-dialysis nurse	Other
Identifies patient for assessment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Refers patient for assessment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Requests investigations for assessment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Follows up investigation results	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Organises additional reviews (if required)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Requests Surgical Review	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Makes decision to activate patient onto list	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Requests NHSBT to activate patient	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In charge of overseeing entire process	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

28 **Does your unit have a written transplant work up protocol used for assessment?**

If yes, please could you return this in the stamped addressed envelope with this survey or email it to Rishi.Pruthi@nbt.nhs.uk

☐ Yes

☐ No

29 **Which of the following investigations are performed as part of routine assessment?**

	For all patients	Only for specific indications
Chest x ray	<input type="checkbox"/>	<input type="checkbox"/>
Pelvic X Ray	<input type="checkbox"/>	<input type="checkbox"/>
ECG	<input type="checkbox"/>	<input type="checkbox"/>
Hep B antigen	<input type="checkbox"/>	<input type="checkbox"/>
Hep C antibodies	<input type="checkbox"/>	<input type="checkbox"/>
CMV Serology	<input type="checkbox"/>	<input type="checkbox"/>
EBV	<input type="checkbox"/>	<input type="checkbox"/>
HIV	<input type="checkbox"/>	<input type="checkbox"/>
PSA	<input type="checkbox"/>	<input type="checkbox"/>
Herpes Zoster antibody	<input type="checkbox"/>	<input type="checkbox"/>
Tissue typing	<input type="checkbox"/>	<input type="checkbox"/>
Lung Function Tests	<input type="checkbox"/>	<input type="checkbox"/>
Upper GI Endoscopy	<input type="checkbox"/>	<input type="checkbox"/>
Sigmoidoscopy/Barium enema	<input type="checkbox"/>	<input type="checkbox"/>

	For all patients	Only for specific indications
CPEX Testing	<input type="checkbox"/>	<input type="checkbox"/>
Echo	<input type="checkbox"/>	<input type="checkbox"/>
ETT	<input type="checkbox"/>	<input type="checkbox"/>
Stress Echo	<input type="checkbox"/>	<input type="checkbox"/>
Thallium Stress Test	<input type="checkbox"/>	<input type="checkbox"/>
Coronary angiogram	<input type="checkbox"/>	<input type="checkbox"/>
Peripheral Doppler	<input type="checkbox"/>	<input type="checkbox"/>
Pelvic Doppler	<input type="checkbox"/>	<input type="checkbox"/>
Voiding Cystourethrogram	<input type="checkbox"/>	<input type="checkbox"/>
Abdo USS	<input type="checkbox"/>	<input type="checkbox"/>
Abdo CT	<input type="checkbox"/>	<input type="checkbox"/>
Other (Please specify)	<input type="checkbox"/>	<input type="checkbox"/>
<input type="text"/>		

30 **Does your unit have an upper age limit for listing for transplantation?**

☐ Yes **(Please specify the upper age limit)**

☐ No

31 **Amongst your prevalent CKD 5 and dialysis population which of the following age bands corresponds to the level at which you would not expect to see more than 5% listed?**

☐ 60-64

☐ 70-75

☐ 65-69

☐ >75

BMI

32 **Does your unit have a BMI exclusion criterion for listing?**

☐ Yes **(Please specify minimum and maximum criteria)**

Minimum

Maximum

☐ No **(go to question 35)**

33 **Why does your unit consider a raised BMI a contraindication for transplantation?**

Tick all that apply

- ☐ Increased cardiovascular risk
- ☐ Lower Graft survival compared to a normal BMI
- ☐ Lower Graft survival compared to a normal BMI
- ☐ Increased technical difficulty in performing procedure
- ☐ Increased post-operative complication risk
- ☐ Other **(Please specify)**

34 **If obesity is deemed to rule a patient out for transplantation, which of the following actions are routinely employed to facilitate weight loss and subsequent listing of a patient?**

Tick all that apply

- ☐ Verbal motivation in clinic
- ☐ Provide written weight loss education
- ☐ Conservative 'wait and see' approach
- ☐ Refer to dietician
- ☐ Refer to physiotherapists/physical activity specialist
- ☐ Refer to specific weight loss clinic/services
- ☐ Refer to other specialists e.g endocrinologists
- ☐ Prescribe anti-obesity drugs
- ☐ Refer to surgeon specialized in bariatric surgery
- ☐ Other **(Please specify)**

Cardiac investigations

35 **Does your unit stratify patients to guide cardiac investigations?**

- ☐ Yes ☐ No **(go to question 37)**

36 **If Yes which factors are taken into account when stratifying risk**

☐ Age **(Please specify)** years

☐ Known history of Diabetes

☐ BMI **(Please specify)**

☐ Smoking history

☐ BP (Hypertension/hypotension)

☐ Abnormal ECG

☐ Previous CVD

☐ Significant family history

☐ Other **(Please specify)**

37 **What is the minimum cardiac work-up undertaken?**

Tick all that apply

☐ ECG

☐ ECHO

☐ Exercise tolerance test

☐ Thallium Stress Test

☐ Stress Echocardiography

☐ Dobutamine Stress Tc Scan

☐ Coronary Angiography

☐ CPEX Testing

☐ Other **(Please specify)**

38 **What is your first line investigation for assessing possible underlying coronary artery disease in high risk patients if you risk stratify, or any patient if you do not risk stratify?**

☐ Exercise Tolerance test

☐ Thallium Stress Test

☐ Stress Echocardiography

☐ Dobutamine Stress Tc Scan

☐ Coronary Angiography

☐ CPEX Testing

☐ Other **(Please specify)**

39 **Who primarily decides which cardiac investigations are required for a moderate to high risk patient before listing?**

Please tick one

- ☐ Consultant Nephrologist
- ☐ Consultant Transplant Surgeon
- ☐ Consultant Cardiologist
- ☐ Consultant Anaesthetist
- ☐ MDT approach
- ☐ Other **(Please specify)**

40 **What are the indications for performing coronary angiography at your unit?**

Tick all that apply. (Note: these are not mutually exclusive)

- ☐ All symptomatic patients
- ☐ Prior CVD
- ☐ Patients with a positive stress test
- ☐ All diabetics
- ☐ Asymptomatic patients with risk factors
- ☐ Asymptomatic older patients **(Please specify age)**
- ☐ No specific policy
- ☐ Other **(Please specify)**

41 **If a coronary angiogram is deemed necessary for listing in a low clearance patient, would your unit refrain from performing the test until they were on dialysis to avoid precipitating the need for dialysis?**

- ☐ Always
- ☐ Sometimes
- ☐ Never

42 **Logistics of cardiac investigations**

If cardiac investigations are required where are they performed and what are the approximate median waiting times in weeks

Test	Local acute hospital	Non-transplant renal unit hospital	Transplant renal unit hospital	Waiting time
ECHO	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Exercise Tolerance Test	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Thallium Stress Test	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Stress Echocardiography	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Dobutamine Stress Tc Scan	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Coronary Angiography	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
CPEX Testing	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Other (Please state)	<input type="text"/>			
	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

43 **Does your unit have a named cardiologist to provide advice/review patients undergoing assessment for suitability for transplantation?**

☐ Yes

☐ No (go to question 45)

44 **Where are they based and what are the approximate waiting times for review?**

- ☐ Median waiting time (in weeks)
- ☐ Local acute hospital
- ☐ Non-transplant renal unit hospital
- ☐ Transplant renal unit hospital

continued
over ➡

45 **If cardiology investigations and/or a cardiology opinion have been performed by a referring non-transplanting unit are these ever repeated at your transplanting unit?**

☐ Often

☐ Sometimes

☐ Rarely

☐ Never **(go to question 47)**

46 **If you selected often/sometimes/rarely please describe why this tends to occur.**

Peripheral vascular disease assessment

47 **In the evaluation of lower limb peripheral vascular disease, peripheral doppler studies are obtained on which of the following?**

Note: these are not mutually exclusive

☐ Asymptomatic older patients

☐ All diabetics

☐ Symptomatic patients

☐ Asymptomatic patients with poor peripheral pulses

☐ Patients with asymptomatic bruit

☐ History of smoking

☐ Other **(Please specify)**

Malignancies

48 **Does your unit routinely screen for malignancies as part of transplant assessment work up?**

☐ Yes

☐ No **(go to question 50)**

49 **Which of the following malignancies are routinely screened for?**

☐ Prostate

☐ Bladder

☐ Breast

☐ Cervical

☐ Skin

☐ Colorectal

☐ Other **(Please specify)**

Urological evaluation

50 **Which statement best describes the urological service available to your unit in assessing patients for transplantation?**

☐ Designated urologist with interest in transplantation available on site within urology department

☐ In House trained urologist available as part of surgical transplant team

☐ No designated urologist with an interest in transplantation available

☐ Other **(Please specify urological support)**

Psychological assessment

51 **Do most patients undergoing assessment for transplant suitability undergo formal psychological assessment?**

☐ Yes

☐ No **(go to question 53)**

52 **If yes, could you briefly describe what psychological assessment they undergo:**

continued
over ➡

53 **Do most patients undergoing assessment for transplant suitability undergo formal cognitive assessment?**

☐ Yes

☐ No

54 **What psychological support is available at your unit?**

Tick all that apply

☐ Renal Counsellor

☐ Renal Psychologist

☐ Psychologist/Counsellor shared with other specialities

☐ Other **(Please specify)**

5 Decision Making Process to list patient

55 **How is the final decision to list a patient for transplantation most commonly reached?**

- ☐ By usual named consultant nephrologist
- ☐ By Consultant nephrologist at Transplant unit
- ☐ Jointly by usual Consultant nephrologist and Consultant Transplant surgeon
- ☐ Jointly by Consultant nephrologist (at transplanting unit) and Consultant Transplant Surgeon
- ☐ By Consultant Transplant Surgeon
- ☐ At MDT meeting at transplanting unit
- ☐ Other **(Please specify)**

56 **How is the final decision to list a patient for transplantation, whose CKD/dialysis care is under a non-transplant renal unit, most commonly reached?**

- ☐ By usual named consultant nephrologist
- ☐ By Consultant nephrologist at Transplant unit
- ☐ Jointly by usual Consultant nephrologist and Consultant Transplant surgeon
- ☐ Jointly by Consultant nephrologist (at transplanting unit) and Consultant Transplant Surgeon
- ☐ By Consultant Transplant Surgeon
- ☐ At local MDT at non-transplanting unit (without representation present from transplanting unit)
- ☐ At local MDT at non-transplanting unit (with representation present from transplanting unit)
- ☐ At MDT meeting at transplanting unit (without representation present from non-transplanting unit)
- ☐ At MDT meeting at transplanting unit (with representation present from non-transplanting unit)
- ☐ Other **(Please specify)**

57 **Do you utilise an MDT approach in listing patients for transplantation?**

- ☐ Yes ☐ No **(go to question 61)**

58 **If yes, what purpose does it serve?**

Tick all that apply

- ☐ To discuss ALL patients prior to them being listed
- ☐ To discuss complex/borderline patients prior to deciding whether to list or not
- ☐ Other **(Please specify)**

59 **How frequently is your MDT held?**

(Please specify) every weeks

60 **Who attends your MDT (either in person or via teleconference/video link up)?**

- ☐ Consultant nephrologist from non-transplanting unit
- ☐ Consultant nephrologist from transplant unit
- ☐ Consultant surgeon
- ☐ Transplant co-ordinator from non-transplanting unit
- ☐ Transplant co-ordinator from transplanting unit
- ☐ Living Kidney Donor Nurse from non-transplanting unit
- ☐ Living Kidney Donor Nurse from transplanting unit
- ☐ Other **(Please specify)**

61 **Please indicate your views on whether the following factors influence the decision to list a patient**

Please indicate how strongly you agree or disagree with each of the following

	Not at all					Very Strongly
Being employed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
High patient enthusiasm towards transplantation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
High level of education	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
English as first language	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having a potential living donor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having a potential pre-emptive living donor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

62 **If a patient is not suitable for deceased donor transplantation but has a potential living donor, would you consider transplantation with a living donor acceptable?**

☐ Yes

☐ No

63 **What proportion of CKD stage 5 patients and dialysis patients under age 75 are informed of the decision to list or not?**

☐ All

☐ Most

☐ Some

☐ Few

☐ None

64 **Do you routinely record all decisions made on the suitability of a patient for transplantation on their electronic patient record?**

☐ Yes

☐ No (go to question 67)

65 **If yes, do you audit this?**

☐ Yes

☐ No (go to question 67)

66 **If yes, how frequently do you audit this?**

(Please specify) every months

67 **How long on average does the overall assessment process take from beginning transplant work up to being listed in your unit?**

(Please give median answer in months)

continued
over ➡

6 Post Assessment/Re-evaluation on the waiting list

68 **Do you have a unit protocol for the monitoring of patients activated on the transplant list?**

If yes, please could you return this in the stamped addressed envelope with this survey or email it to Rishi.Pruthi@nbt.nhs.uk

☐ Yes

☐ No

69 **Once activated on the transplant list how frequently are patients usually monitored for continued suitability?**

☐ Never

☐ 3 Monthly

☐ 6 Monthly

☐ Annually

☐ Other **(Please specify)**

70 **Who reviews/monitors the continued suitability of patients activated on the list?**

☐ Usual dialysis nephrologist at a routine follow up appointment

☐ Transplant nephrologist in a transplant assessment review clinic

☐ Transplant surgeon in a transplant assessment review clinic

☐ Both nephrologist and transplant surgeon in a transplant assessment review clinic

☐ Other **(Please specify)**

71 **Do you have a specific transplant review clinic for listed patients?**

☐ Yes

☐ No **(go to question 83)**

72 **If yes, how frequently are patients seen in this review clinic?**

☐ 6 months

☐ Annually

☐ Every two years

☐ Other **(Please specify in months)**

☐ N/A

73 **Which of the following investigations are routinely performed when patients are reviewed?**

Tick all that apply

- | | |
|---|--|
| <input type="checkbox"/> HIV & Hepatitis Serology | <input type="checkbox"/> PSA |
| <input type="checkbox"/> DRE | <input type="checkbox"/> Pelvic examination |
| <input type="checkbox"/> Pap smear | <input type="checkbox"/> Breast examination |
| <input type="checkbox"/> Mammography | <input type="checkbox"/> Colonoscopy/sigmoidoscopy |
| <input type="checkbox"/> Cognitive assessment | <input type="checkbox"/> None of the above |

74 **Which of the following cardiac investigations (if any) are repeated?**

- | | |
|--|--|
| <input type="checkbox"/> ECG | <input type="checkbox"/> ECHO |
| <input type="checkbox"/> Exercise tolerance test | <input type="checkbox"/> Thallium Stress Test |
| <input type="checkbox"/> Stress Echocardiography | <input type="checkbox"/> Dobutamine Stress Tc Scan |
| <input type="checkbox"/> Coronary Angiography | <input type="checkbox"/> CPEX Testing |
| <input type="checkbox"/> Other (Please specify) | |

75 **How often are these cardiac investigations repeated?**

Provide answers in months

ECG

ECHO

Exercise tolerance test

Thallium Stress Test

Stress Echocardiography

Dobutamine Stress Tc Scan

Coronary Angiography

CPEX Testing

Other (Please state)

76 **Which of the following accurately describes your local practice in continued surveillance of cardiac disease in asymptomatic patients on the waiting list?**

- ☐ No routine surveillance if asymptomatic
- ☐ All patients screened irrespective of remaining asymptomatic
- ☐ Surveillance only in high risk groups
- ☐ Variable , no specific policy
- ☐ Other **(Please specify)**

77 **Is psychological support offered routinely to patients listed?**

- ☐ Yes **(go to question 79)**
- ☐ No

78 **If No, what is the main reason for this?**

- ☐ Not perceived to be an area where patients require support
- ☐ Lack of resources/overburdened counselling service
- ☐ Do not think that patients' would make use of this service if offered
- ☐ Other **(Please specify)**

79 **How are patients deemed unsuitable for transplantation in their current state, but with the potential to be listed in the future (depending on changing circumstances/factors) re-assessed?**

- ☐ At routine outpatient appointment with regular nephrologist
- ☐ At a follow up transplant assessment clinic appointment
- ☐ At a MDT
- ☐ Other **(Please specify)**

7 Working relationships, attitudes and other allied health professionals & services involved in transplant listing

80 **How would you describe your relationship with your local non-transplanting units?**

- ☐ Excellent ☐ Very Good
- ☐ Good ☐ Fair
- ☐ Poor

81 **What is your view of the following statements regarding your unit's interaction with local non-transplanting units?**

Please indicate how strongly you agree or disagree with each of the following

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Little communication exists with non-transplanting units	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Non-Transplanting units always refer patients with complete investigations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Non-Transplanting units adhere to agreed work up protocol	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Non-transplanting units do not have access to adequate cardiology investigations/opinions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

82 **Which statement best describes the attitude of your unit staff towards pre-emptive transplant listing?**

- ☐ Everyone has a positive attitude towards listing patients pre-emptively with no exceptions
- ☐ The majority of individuals have a positive attitude towards pre-emptive listing
- ☐ The unit is split roughly 50 50
- ☐ The majority have a negative attitude towards pre-emptive transplantation
- ☐ Everyone has a negative attitude towards pre-emptive transplantation

83 **What is your opinion on the following statements as to the reason behind why certain individuals may have a negative attitude towards pre-emptive listing?**

Please indicate how strongly you agree or disagree with each of the following

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
There is limited evidence that listing patients pre-emptively is more beneficial as compared to listing after starting dialysis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There is strong evidence to support pre-emptive listing, though there is a lack of appreciation of this evidence amongst those who are less keen to list pre-emptively	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The experience of dialysis before transplantation is better for patients as it improves their post-transplantation adherence and patients value their transplant more	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It is unfair to allocate an organ to a patient who has not been on dialysis when there are many on the waiting list who have been waiting for many years.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

84 **What is your opinion on the following statements regarding living donation within your unit?**

Please indicate how strongly you agree or disagree with each of the following

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
The work up required to assess suitability of living donors for kidney donation is well defined	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Living donor work up commences only once potential recipient has been assessed as being suitable and activated on the transplant list	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Potential donors can self-refer for assessment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Potential donors need to be referred by a health professional	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Transplant opportunities have been delayed/missed due to failure to identify existing potential donor early in process	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Donation from young female donors often poses moral dilemmas for health professionals involved in transplantation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
High cost of living donation work up is a hindrance to working up multiple donors simultaneously	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

85 **What level of administrative support is provided to the living donor nurse/transplant co-ordinator?**

☐ Nil

☐ Designated specific secretary

☐ Shared secretary

☐ Other **(Please specify)**

86 **Do you have an on-site tissue typing service?**

☐ Yes

☐ No

87 **How long does it usually take for tissue typing to process final samples and request NHSBT to activate a patient once decision taken to list?**

☐ **(Please specify number of weeks)**

88 **Has processing of tissue typing samples ever been the source of significant delays in listing patient for transplantation?**

☐ Yes

☐ No

continued
over ➡

8 Improving transplant listing

89 **Does your unit undertake any regular audit of whether CKD 5 patients and or those on dialysis have been listed?**

☐ Yes, 1 to 2 per year

☐ Yes, 3 to 4 per year

☐ Yes, 5 or more per year

☐ No

☐ Other **(Please specify)**

90 **Has there been any significant improvement in the time taken to complete the overall assessment process in your unit over the last year?**

☐ Yes

☐ No **(go to question 92)**

91 **If yes, please describe briefly what improvement there has been and how it was achieved.**

What is your opinion on whether more funding for the following resources would improve overall listing and time to listing in your unit?

Please indicate how strongly you agree or disagree with each of the following

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Cardiac service	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tissue typing service	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Education service	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Transplant co-ordinators	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Living donor nurses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Urology service within transplantation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Consultant nephrologists with interest in transplantation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Consultant surgeons	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Interpreter service and developing pathways to improve language barriers amongst ethnic minorities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Administrative support for allied health professionals e.g. transplant co-ordinators, living donor nurses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Better renal IT systems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychological assessment and counselling service	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Increasing operation time slots for transplantation service	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (Please specify and rate)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="text"/>					

93 **What is your opinion on the following statements about whether they would improve listing of patients for transplantation?**

Please indicate how strongly you agree or disagree with each of the following

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
National consensus on cardiac work up	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
National consensus on entire work up (not just cardiac)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Improvements in commissioning of transplant work up	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ensuring MDT approach utilised systematically in making all decisions to list patients or not	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Introducing time target for tissue typing processing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Better evidence base behind necessary assessment work up	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Further comments on transplant listing

94 **If you would like to make any further comments on listing for transplantation, please use the space below:**

9 Details of person completing the questionnaire

95 **If someone else helped you complete this questionnaire, please give their role in renal unit.**

96 **Please provide your contact details in case we need to contact you. This information is confidential and will not be used in any research reports.**

Name

Your role in the renal unit

Email

Tel

If you previously indicated that your unit has a written transplant work up protocol and/or a protocol for monitoring patients on the transplant list please could you post these back with this survey.



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Abstract, References, and Tables.)**

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