**Transplantation**

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

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Dear Editor,

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.

We appreciate your time and look forward to your response.

Your Sincerely,
Rishi Pruthi

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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.

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<th>Abbreviations</th>
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<td>ATTOM</td>
<td>Access to Transplantation and Transplant Outcome Measures</td>
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<td>BMI</td>
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<td>Chronic kidney disease</td>
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<td>eGFR</td>
<td>Estimated glomerular filtration rate</td>
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<td>ESRF</td>
<td>End stage renal failure</td>
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<td>LCC</td>
<td>Low clearance clinic</td>
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<td>MDT</td>
<td>Multi-disciplinary team</td>
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<td>PMP</td>
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<td>RRT</td>
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<td>WTE</td>
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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.

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**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 survival\(^5\), 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 kidneys\(^6\)-\(^7\). 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 world\(^8\)-\(^\text{10}\). 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/1.73m\(^2\) 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 organ\(^8\). 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 available\(^10\).
The term ‘suitable’ used in these guidelines often poses a conundrum for clinicians as objective criteria to confirm suitability for transplantation are not clearly defined and hence are open to interpretation. To assist this process guidelines for the evaluation of candidates for renal transplantation have been published by the American Society of Transplantation\textsuperscript{11}, the European Renal Association and European Society for Organ Transplantation\textsuperscript{12}, the UK Renal Association\textsuperscript{10}, the British Transplantation Society\textsuperscript{13} and Caring for Australasians with Renal Impairment\textsuperscript{14}. Despite the availability of clinical guidelines, significant variations in the assessment practices among transplant centres have been reported in the United States as well as Europe\textsuperscript{15-17}. To explore this further we undertook a national survey as part of the NIHR funded Access to Transplantation and Transplant Outcome Measures (ATTOM) programme to examine whether variation exists in the organisation of renal services in listing patients, and to describe centre practices in the education and the evaluation of potential transplant recipients as well as exploring how decisions are made in the UK.

**Materials and Methods**

A structured online and paper-based survey consisting of 96 questions was developed using the results of two qualitative studies carried out within the ATTOM programme\textsuperscript{18,19}. Qualitative studies included 53 patients and 42 healthcare professionals, and explored patients’ views and experiences of joining the transplant waiting list and staff members’ experiences of listing patients for transplantation. Staff and patients were recruited from a purposive maximum variation sample of nine 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
Surgeon, whilst 4 centres reported no surgical involvement in the decision to list for transplantation.

**The Assessment Process**

Nationally 30% (n=21) of centres did not have a written transplant work-up protocol for recipient assessment, which included 3 transplant centres. Figure 1 shows the frequency with which different investigations were used for the routine assessment of potential renal transplant recipients amongst the 71 centres. Three non-transplanting centres reported having an upper age limit of 75 years (above which patients were only considered in exceptional circumstances for transplantation) whilst all other centres (n=68, 95.6%) did not report any age restrictions. In comparison, Body Mass Index (BMI) was widely used as an exclusion criterion for listing patients, with 81.7% (n=58) of centres excluding patients for transplantation based on BMI. The overall median upper BMI cut off, in these centres was 35 (IQR: 33.25-35), with 36 centres reporting an upper limit of 35, and 5 centres an upper limit of 40 whilst the remaining 17 centres stated a BMI limit between 33-30. The reasons stated for using BMI as an exclusion criterion are summarised in Table 1. These did not differ between centres other than perceived increased cardiovascular risk, which appeared to be more of an issue for non-transplanting (52.5%) than transplanting centres (33.3%), p<0.01.

All transplanting centres, and 87.5% (n=65) of non-transplanting centres reported stratifying patients by risk when deciding which cardiac investigations to perform. Age (median 50 years; IQR: 50-55)(88%), diabetes (97%), previous cardiovascular disease (91%), and an abnormal ECG (89%) were used to determine risk. Thirty-one centres (44%) conducted some form of ‘cardiac stress testing’ even in low risk patients whilst significant variation was seen in the first-line investigation of choice.
for the assessment of coronary artery disease in high risk patients (Table 2). If a coronary angiogram was deemed necessary for listing a low clearance patient, 5.6% (n=4) of centres reported they would refrain from performing the test until patients were on dialysis to avoid precipitating the need for dialysis, with a further 74.6% stating they would ‘sometimes’ refrain from proceeding. Only 19.7% reported always proceeding.

Variation was also seen in screening for malignancies with 38% of centres reporting that screening for cancer such as breast, prostate, bladder and colorectal was part of the routine work-up of transplant recipients, in addition to national screening programmes. In contrast, formal psychological or cognitive assessment of all potential recipients was only performed in 7.0% and 5.6% of centres respectively, with 13.1% of centres reporting no access to psychologist or counsellor services.

**Decision Making**

Overall 76.1% (n=54) of centres utilised an MDT approach when listing patients for transplantation. This proportion was greater amongst transplanting centres where all but one centre (95.7%) used an MDT, compared to 66.7% (n=54) in non-transplanting centres. MDTs occurred more frequently in transplanting centres with a median of 4 meetings a month (IQR 1.25-4) as compared to 2 a month (IQR 1-4; p=0.001) in non-transplanting centres.

If a patient was not deemed suitable for listing for deceased donor transplantation, 76.1% of centres said that they would consider listing them for living donor transplantation if a suitable donor was available. Living donor availability was generally seen as a positive driver for listing, alongside patient enthusiasm, whilst the majority of centres did not perceive socioeconomic factors, including employment
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 million 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 England. 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 service.
Despite the UK Renal Association recommending that CKD patients pre RRT should be managed in a dedicated clinic by a MDT\textsuperscript{22}, this study also demonstrated wide variation in the utilisation of low-clearance clinics nationally, with variation also seen in their implementation and entry criteria. There are many studies, albeit small, which have shown that a dedicated pre-dialysis clinic is associated with improved outcomes and reduced urgent initiation of dialysis\textsuperscript{23-26}. These clinics may provide focused opportunity to assess transplantation potential and more timely discussion of options including live donation and pre-emptive transplantation. Similarly, specific transplant-assessment clinics (used by a fifth of centres) enable joint assessment by physician and surgeon; whilst the evidence of their effectiveness is lacking they may be more efficient at transplant listing.

Irrespective of the type of CKD service in place, a broad range of educational methods were utilised across the UK, with one-to-one education being the main route. A significant proportion of centres (28\%) did not discuss transplantation as a treatment option with all patients under the age of 75 years, and nearly 50\% of patients who had had a decision made about them regarding transplantation were not informed of the decision made. This is of concern, as a patient-centred approach would require that all options are communicated to a patient and their family where possible. There may be exceptional circumstances where this may not always be feasible, but such instances would be expected to be less frequent than was reported in the present study.

Another important observation from this study was that some centres did not consider surgical review to be an absolute requirement for listing patients for transplantation. Eight centres listed without formal review, four of which cited no
surgical involvement at all. The UK Renal Transplant Service specification stipulates that patients should undergo surgical assessment prior to being placed on the transplant list\textsuperscript{27}, however it should be noted that in the US it is not uncommon to have only a subset of patients evaluated by transplant surgery in a face-to-face encounter. Instead, they selectively evaluate higher risk patients, e.g., those with vascular disease.

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\textsuperscript{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)\textsuperscript{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
aware that chronological age can be very different to biological age in different individuals, and how assessment needs to be tailored on a case-by-case basis to avoid unwarranted age discrimination.

In contrast to age, the majority of centres used BMI as an exclusion criterion, similar to findings from studies from the US\textsuperscript{30}, Canada\textsuperscript{31} and Europe\textsuperscript{32}, with a wide upper BMI limit of 30-40. In the context of an increasingly obese population, such a broad range has the potential to cause variation in access to transplantation. Obese patients are certainly at an increased risk of technical difficulties and peri-operative complications\textsuperscript{33-34} though evidence in favour of imposing a BMI limit on the basis of more hard end-points (patient and graft survival) is conflicting\textsuperscript{35-40}. A number of reports from nationwide databases, including the USA, Australia and the Netherlands\textsuperscript{35, 38, 40}, have shown decreased patient and graft survival in obese recipients, whilst others showed no differences in survival between obese and non-obese transplant recipients\textsuperscript{39}. It is unclear in studies where an increase in risk was noted, how much would be mitigated once co-existing cardiovascular disease was accounted for. This raises the notion that if technically feasible, and cardiovascular disease has been ruled out, most patients should be considered for transplantation irrespective of their BMI.

As cardiovascular disease remains the main cause of death in transplant recipients\textsuperscript{41}, it is unsurprising that most centres invest a great deal of time and resource in its investigation and management. This study showed that most centres stratify patients on their level of risk, though the choice of ensuing investigation varied greatly with no clear consensus irrespective of risk, from non-invasive functional tests to invasive angiography. This variation is likely due to a combination
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
potentially biased the results due to the under-representation of surgical opinion amongst responders. Equally, we could not check the validity of responses garnered and some of these data were necessarily estimates and so should be regarded with caution. There may also have been a social desirability bias in the responses as respondents may have answered questions to put their centre in a good light. Furthermore, most questions in the survey were multiple-choice questions that invited respondents to select the best possible answer out of the choices available. This approach necessarily limits their responses, although an option to select “other” was provided and the survey was designed following detailed qualitative interviews with patients and staff to identify core domains.

In conclusion there is wide variation in UK practice patterns in listing patients for renal transplantation. Potential causes for this are likely to include variation in international guidelines and a lack of consensus in evaluating patients especially assessing their cardiovascular risk\textsuperscript{10-14, 28}. Differing local population co-morbidity and socioeconomic factors may also be playing a role alongside varying physician attitudes and beliefs towards transplant listing and risk assessment\textsuperscript{42}. Future research should be directed at developing a national consensus on recipient work up and in understanding the utility of cardiovascular screening in potential transplant recipients, as well as gaining better long-term outcome data on the impact of obesity and age on transplantation.

There is also a need to understand the impact, if any, of this variation on access to transplantation. In the UK, as part of the NIHR funded ATTOM study, patient variables and the impact of centre variables described in this study, will be further evaluated in a multilevel hierarchical model, in a prospective sample of incident
dialysis patients recruited as part of the ATTOM Study.

Acknowledgments

We would like to thank all clinical directors of the renal units and the additional staff members who responded to the survey.
References


8. Kidney transplant referral guide – OPTN Minority affairs committee


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

<table>
<thead>
<tr>
<th>Reason</th>
<th>Transplanting Centre</th>
<th>Non-Transplanting Centre</th>
<th>Overall Nationally</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>% (of Centres)</td>
<td>N</td>
</tr>
<tr>
<td>Increased post-operative complication risk</td>
<td>16</td>
<td>88.9</td>
<td>34</td>
</tr>
<tr>
<td>Increased technical difficulty in performing procedure</td>
<td>14</td>
<td>77.8</td>
<td>30</td>
</tr>
<tr>
<td>Increased cardiovascular risk</td>
<td>6</td>
<td>33.3</td>
<td>21</td>
</tr>
<tr>
<td>Lower Graft survival compared to a normal BMI</td>
<td>6</td>
<td>33.3</td>
<td>9</td>
</tr>
<tr>
<td>Lower patient survival compared to normal BMI</td>
<td>6</td>
<td>33.3</td>
<td>9</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>2</td>
<td>11.1</td>
<td>10</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>50</strong></td>
<td></td>
<td><strong>113</strong></td>
</tr>
</tbody>
</table>
Table 2: First-line investigation of choice for the assessment of coronary artery disease in high-risk patients

<table>
<thead>
<tr>
<th></th>
<th>Transplanting Centre</th>
<th>Non-Transplanting Centre</th>
<th>Overall Nationally</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>% (of Centres)</td>
<td>N</td>
</tr>
<tr>
<td>Exercise Tolerance Test</td>
<td>5</td>
<td>21.7</td>
<td>1</td>
</tr>
<tr>
<td>Thallium Stress Test</td>
<td>7</td>
<td>30.4</td>
<td>1</td>
</tr>
<tr>
<td>Stress Echocardiography</td>
<td>2</td>
<td>8.7</td>
<td>7</td>
</tr>
<tr>
<td>Dobutamine Stress Tc Scan</td>
<td>3</td>
<td>13.0</td>
<td>6</td>
</tr>
<tr>
<td>Coronary Angiography</td>
<td>1</td>
<td>4.3</td>
<td>2</td>
</tr>
<tr>
<td>CPEX Testing*</td>
<td>1</td>
<td>4.3</td>
<td>2</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>4</td>
<td>17.4</td>
<td>4</td>
</tr>
</tbody>
</table>

*CPEX Testing: Cardio-Pulmonary Exercise Test
Table 3: Continued surveillance of cardiac disease in asymptomatic patients on the waiting list reported across UK renal centres

<table>
<thead>
<tr>
<th>Method of Surveillance</th>
<th>Transplanting Centre</th>
<th>Non-Transplanting Centre</th>
<th>Overall Nationally</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
</tr>
<tr>
<td>No routine surveillance if asymptomatic</td>
<td>6</td>
<td>26.1</td>
<td>13</td>
</tr>
<tr>
<td>All patients screened irrespective of remaining asymptomatic</td>
<td>4</td>
<td>17.4</td>
<td>16</td>
</tr>
<tr>
<td>Surveillance only in high risk groups</td>
<td>12</td>
<td>52.2</td>
<td>11</td>
</tr>
<tr>
<td>Varies, no specific policy</td>
<td>1</td>
<td>4.3</td>
<td>8</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>0</td>
<td>0.0</td>
<td>0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>23</strong></td>
<td><strong>100.0</strong></td>
<td><strong>48</strong></td>
</tr>
</tbody>
</table>
Figure Legends:

Figure 1: Bar chart showing 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: Bar chart showing 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: Bar chart showing 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: Bar chart showing 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).
**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).
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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 Ravanan, 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)

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

   □ Other criteria (Please specify)
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**]
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)

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)
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
- Weekly
- Fortnightly
- Monthly
- Less than 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
- Local Associate specialist/staff grade
- Transplant surgeon
- Transplant nephrologist
- Other (Please specify)
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)
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

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

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?

<table>
<thead>
<tr>
<th>Investigation</th>
<th>For all patients</th>
<th>Only for specific indications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chest x ray</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pelvic X Ray</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ECG</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hep B antigen</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hep C antibodies</td>
<td></td>
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<tr>
<td>CMV Serology</td>
<td></td>
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</tr>
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<td>EBV</td>
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<td>HIV</td>
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<tr>
<td>PSA</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Herpes Zoster antibody</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tissue typing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lung Function Tests</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Upper GI Endoscopy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sigmoidoscopy/Barium enema</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Does your unit have an upper age limit for listing for transplantation?

- **Yes** (Please specify the upper age limit) [Box]
- **No** [Box]

### 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** [Box]
- **65-69** [Box]
- **70-75** [Box]
- **>75** [Box]

#### BMI

### Does your unit have a BMI exclusion criterion for listing?

- **Yes** (Please specify minimum and maximum criteria) [Box]

- **No** (go to question 35) [Box]
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
- Exercise tolerance test
- Stress Echocardiography
- Coronary Angiography
- 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
- Stress Echocardiography
- Coronary Angiography
- 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
### Logistics of cardiac investigations

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

<table>
<thead>
<tr>
<th>Test</th>
<th>Local acute hospital</th>
<th>Non-transplant renal unit hospital</th>
<th>Transplant renal unit hospital</th>
<th>Waiting time</th>
</tr>
</thead>
<tbody>
<tr>
<td>ECHO</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Exercise Tolerance Test</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Thallium Stress Test</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Stress Echocardiography</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Dobutamine Stress Tc Scan</td>
<td></td>
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<tr>
<td>Coronary Angiography</td>
<td></td>
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<tr>
<td>CPEX Testing</td>
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<tr>
<td>Other (Please state)</td>
<td></td>
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</tr>
</tbody>
</table>

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
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
- Rarely
- Sometimes
- 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?

- 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
☐ Breast
☐ Skin
☐ Other (Please specify)
☐ Bladder
☐ Cervical
☐ Colorectal

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:
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

<table>
<thead>
<tr>
<th>Factor</th>
<th>Not at all</th>
<th>Somewhat Disagree</th>
<th>Somewhat Agree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being employed</td>
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<tr>
<td>High patient enthusiasm towards transplantation</td>
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<tr>
<td>High level of education</td>
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<tr>
<td>English as first language</td>
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<tr>
<td>Having a potential living donor</td>
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<tr>
<td>Having a potential pre-emptive living donor</td>
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<tr>
<td>Question</td>
<td>Text</td>
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</tbody>
</table>
| 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 your 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) [ ] [ ] months |
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
- [ ] 6 Monthly
- [ ] Other **(Please specify)**

<table>
<thead>
<tr>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>3 Monthly</td>
</tr>
<tr>
<td>Annually</td>
</tr>
</tbody>
</table>

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

Tick all that apply

- [ ] HIV & Hepatitis Serology
- [ ] DRE
- [ ] Pap smear
- [ ] Mammography
- [ ] Cognitive assessment
- [ ] PSA
- [ ] Pelvic examination
- [ ] Breast examination
- [ ] Colonoscopy/sigmoidoscopy
- [ ] None of the above

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

- [ ] ECG
- [ ] Exercise tolerance test
- [ ] Stress Echocardiography
- [ ] Coronary Angiography
- [ ] ECHO
- [ ] Thallium Stress Test
- [ ] Dobutamine Stress Tc Scan
- [ ] CPEX Testing
- [ ] Other (Please specify)

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)
<table>
<thead>
<tr>
<th>Question</th>
<th>Text</th>
</tr>
</thead>
<tbody>
<tr>
<td>76</td>
<td><strong>Which of the following accurately describes your local practice in continued surveillance of cardiac disease in asymptomatic patients on the waiting list?</strong>&lt;br&gt;☐ No routine surveillance if asymptomatic&lt;br&gt;☐ All patients screened irrespective of remaining asymptomatic&lt;br&gt;☐ Surveillance only in high risk groups&lt;br&gt;☐ Variable, no specific policy&lt;br&gt;☐ Other <em>(Please specify)</em></td>
</tr>
<tr>
<td>77</td>
<td><strong>Is psychological support offered routinely to patients listed?</strong>&lt;br&gt;☐ Yes <em>(go to question 79)</em>&lt;br&gt;☐ No</td>
</tr>
<tr>
<td>78</td>
<td><strong>If No, what is the main reason for this?</strong>&lt;br&gt;☐ Not perceived to be an area where patients require support&lt;br&gt;☐ Lack of resources/overburdened counselling service&lt;br&gt;☐ Do not think that patients' would make use of this service if offered&lt;br&gt;☐ Other <em>(Please specify)</em></td>
</tr>
<tr>
<td>79</td>
<td><strong>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?</strong>&lt;br&gt;☐ At routine outpatient appointment with regular nephrologist&lt;br&gt;☐ At a follow up transplant assessment clinic appointment&lt;br&gt;☐ At a MDT&lt;br&gt;☐ Other <em>(Please specify)</em></td>
</tr>
</tbody>
</table>
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?**

<table>
<thead>
<tr>
<th></th>
<th>□ Excellent</th>
<th>□ Very Good</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Good</td>
<td>□ Fair</td>
<td></td>
</tr>
<tr>
<td>□ Poor</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither agree nor disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Little communication exists with non-transplanting units</td>
<td></td>
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</tr>
<tr>
<td>Non-Transplanting units always refer patients with complete investigations</td>
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<td></td>
</tr>
<tr>
<td>Non-Transplanting units adhere to agreed work up protocol</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Non-transplanting units do not have access to adequate cardiology</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>investigations/opinions</td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Statement</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Everyone has a positive attitude towards listing patients pre-emptively</td>
<td></td>
</tr>
<tr>
<td></td>
<td>with no exceptions</td>
</tr>
<tr>
<td>□ The majority of individuals have a positive attitude towards pre-emptive</td>
<td></td>
</tr>
<tr>
<td></td>
<td>listing</td>
</tr>
<tr>
<td>□ The unit is split roughly 50 50</td>
<td></td>
</tr>
<tr>
<td>□ The majority have a negative attitude towards pre-emptive transplantation</td>
<td></td>
</tr>
<tr>
<td>□ Everyone has a negative attitude towards pre-emptive transplantation</td>
<td></td>
</tr>
</tbody>
</table>
### 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:

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither agree nor disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>There is limited evidence that listing patients pre-emptively is more beneficial as compared to listing after starting dialysis</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>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</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>The experience of dialysis before transplantation is better for patients as it improves their post-transplantation adherence and patients value their transplant more</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>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.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

### 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:

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither agree nor disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>The work up required to assess suitability of living donors for kidney donation is well defined</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Living donor work up commences only once potential recipient has been assessed as being suitable and activated on the transplant list</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Potential donors can self-refer for assessment</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Potential donors need to be referred by a health professional</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Transplant opportunities have been delayed/missed due to failure to identify existing potential donor early in process</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Donation from young female donors often poses moral dilemmas for health professionals involved in transplantation</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>High cost of living donation work up is a hindrance to working up multiple donors simultaneously</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Question</td>
<td>Options</td>
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<td>-------------------------------------------------------------------------</td>
<td>----------------------------------------------</td>
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<tr>
<td>85 What level of administrative support is provided to the living donor nurse/transplant co-ordinator?</td>
<td>☐ Nil ☐ Designated specific secretary ☐ Shared secretary ☐ Other <em>(Please specify)</em></td>
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<tr>
<td>86 Do you have an on-site tissue typing service?</td>
<td>☐ Yes ☐ No</td>
<td></td>
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<tr>
<td>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?</td>
<td>☐ <em>(Please specify number of weeks)</em></td>
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<tr>
<td>88 Has processing of tissue typing samples ever been the source of significant delays in listing patient for transplantation?</td>
<td>☐ Yes ☐ No</td>
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</tbody>
</table>
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:

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

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither agree nor disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>National consensus on cardiac work up</td>
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<td></td>
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<tr>
<td>National consensus on entire work up (not just cardiac)</td>
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<tr>
<td>Improvements in commissioning of transplant work up</td>
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<td>Ensuring MDT approach utilised systematically in making all decisions to list patients or not</td>
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<td>Introducing time target for tissue typing processing</td>
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<td>Better evidence base behind necessary assessment work up</td>
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Further comments on transplant listing

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

[Empty space provided for comments]
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.