NHS

Kidney Care

Blood and Transplant

Transplant First:
Timely Listing for Kidney Transplantation

March 2013

Reader page

Title	**Transplant First: Timely Listing for Kidney Transplantation**
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Publication date	March 2013
Target audience	Commissioners, kidney care community, transplant services, patient associations
Circulation list	Renal unit clinical directors; kidney care network managers; kidney care network clinical leads; renal unit lead nurses; specialised commissioners; clinical commissioning groups; NHS Blood and Transplant; National Kidney Federation
Description/purpose	This document outlines the key learning and outcomes from locally-led and centrally co-ordinated projects to improve access to transplantation within renal units.
Cross Ref	How-to guide – New pathways ensure timely referral for transplant www.kidneycare.nhs.uk/howto_guides1/new_pathways_ensure_timely_referral_for_transplant Timely listing for kidney transplantation: A summary of the literature www.kidneycare.nhs.uk/document.php?o=493 Transplant first: Highlights from four timely listing for transplantation project groups www.kidneycare.nhs.uk/document.php?o=1730
Superseded docs	n/a
Action required	Commissioners and providers of kidney services, including renal units and transplant centres, should review the findings outlined in this report, and consider how they can implement the recommendations in order to improve access to timely listing.
Timing	Ongoing
Contact details	**admin@kidneycare.nhs.uk**

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Foreword

For many people with end stage renal failure, a transplant is the 'gold standard' treatment option. If the best outcomes are to be achieved, transplants need to happen quickly, ideally before the patient has to start dialysis. Despite this being widely recognised, there is still significant variation in the time people have to wait for a transplant across the UK meaning many people undergo months of costly and potentially unnecessary dialysis. This is unacceptable and needs to be addressed.

To tackle this problem, NHS Kidney Care and NHS Blood and Transplant commissioned a number of renal units across the UK to take part in a project looking at timely listing, including pre-emptive transplantation. Participating trusts have successfully implemented changes to their service, which will improve the listing pathways for kidney transplantation. This report summarises the approaches undertaken by the project groups from across the UK, and makes a series of recommendations. NHS Kidney Care, NHS Blood and Transplant and the project groups have led the way in driving service improvement in this area, forging a path that I hope other renal units and transplant centres will follow.

I would urge trusts to review this report, consider how they can implement the recommendations and to instil a culture of 'transplant first'. If the changes put in place by individual units are sustained and the learning used to inform service development in all units, then given time, we can make a real difference to the lives of people with kidney disease across the UK.

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Acknowledgements

NHS Kidney Care and NHS Blood and Transplant would like to thank the members of the project reference group – Dr Chas Newstead (Leeds Teaching Hospitals NHS Trust) and Wendy Brown (West London Renal and Transplant Centre, Imperial College Healthcare NHS West London) for their assistance and their role as clinical advisors to the project groups. Thanks are also due to all the project groups for their enthusiasm and commitment to ensuring the success of this project.

Executive summary and recommendations

Transplantation is the 'gold standard' renal replacement therapy for people with end stage kidney disease (ESKD) who are clinically suitable. Timely listing for transplantation can also lead to improved outcomes for patients as well as reduce the need for dialysis.

In order to address the significant variations that exist in the time it takes for patients to be listed for transplantation across the UK, NHS Kidney Care and NHS Blood and Transplant commissioned a national improvement project to identify the barriers to timely listing for transplantation. Twenty-six renal units took part from across England, Scotland, Wales and Northern Ireland in a six month initiative to develop locally tailored projects to address delays in their transplant assessment pathways. Through audit and process mapping the project has identified three main barriers to timely listing for transplantation:

1. Lack of a standardised referral system or pathway
2. Inadequate patient and professional education and engagement
3. Delays due to efficient use of technology and administrative support

A range of solutions were identified and implemented by the project groups. Many of these have already improved timely listing of patients for transplantation and increased both the number of patients listed for pre-emptive transplantation as well as the number of patients undergoing work-up and achieving pre-emptive transplantation. In order to overcome the barriers listed above and help kidney units implement the solutions identified by these projects to improve timely listing for transplantation, NHS Kidney Care and NHS Blood and Transplant have made the following recommendations:

- Map and audit current practices to identify delays, bottlenecks, variations, and other potential problems and areas for further investigation. Carrying out an initial audit provides a benchmark against which improvements can be measured and can also provide valuable evidence for use in discussions with colleagues and negotiating commissioning arrangements.
- Embed consistency in approach within nephrology practice to listing and preparation for transplantation, especially pre-emptive transplantation in the context of a potential living donor.
- Streamline and clarify processes for listing patients for transplantation through agreed referral criteria such as thresholds and prompts for referral and assessment.
- Further streamline processes through having defined lines of responsibility, with identified clinical contacts in each area.
- Improve the communication and co-ordination with other trusts and clinical departments involved in the work-up process through the use of agreed processes and standardised protocols and proformas.
- Ensure that referral information is consistent and relevant to the patient and includes details of any test results, including those that may be pending, and the outcome of any conversations indicating patient preferences.
- Engage with patients in order to understand their needs and highlight areas that might not previously have been considered.

Executive summary and recommendations

- Improve patient understanding about the options for transplantation, including living donor transplantation, in a timely and appropriate manner. This should include the provision of high quality, accessible information available in a variety of formats, for patients, carers, families and potential donors to help patients make informed choices and facilitate shared decision making at an early stage in the process.
- Create a culture of 'transplant first' with both patients and professionals, through improved understanding of the benefits of pre-emptive transplantation, and of timely listing for transplantation.
- Healthcare professionals should understand their local population and modify services as appropriate.
- Develop IT solutions such as dedicated renal software, electronic communication and electronic proformas, to help streamline processes and reduce delay.
- Ring-fence administrative resources to help ensure prompt and timely recording and communication of information relevant to support timely listing of patients who may be suitable for transplantation.

1. Introduction

For patients who are clinically suitable, kidney transplantation is considered the "gold standard" renal replacement therapy (RRT)[i,ii,iii]. Current guidelines recommend that suitable patients should be listed onto the deceased donation transplant list within six months of their anticipated start of dialysis and are expected to have individualised education on RRT available to enable them to make informed choices[iv] which are then documented[iii,v,vi]. Preparation for pre-emptive living donor transplantation must be considered sufficiently early to allow time to assess both the recipient and one or more potential donors if necessary, and assessment should be tailored to the recipient decline in kidney function to achieve effective pre-emptive transplantation. It is recommended that such discussions are initiated at a recipient eGFR of 20mls/min[ix].

However, data collected by the UK Renal Registry show that pre-emptive transplantation is the initial treatment for only 7.2% of patients beginning RRT[v]. The process of a patient being identified as suitable for transplantation, undergoing the rigorous assessment process and then being placed on the national transplant waiting list for a deceased donor transplant or receiving a kidney from a living donor, can also be unnecessarily lengthy and complex; while accessibility to being listed for kidney transplantation is not uniform across the UK. This variation can be partly explained by the fact that some areas may have a greater proportion of people who are not suitable for a transplant than other areas. However, other significant factors include the organisation of transplant assessment pathways, identification of suitable patients for transplantation as well as patient education and understanding. As a result, some patients may not be given the option of transplantation, or may experience a significant delay in their assessment before being listed on the national transplant list. The more delays that accumulate in the assessment process, the less likely it is that a patient will receive a pre-emptive kidney transplant[vii], increasing the requirement for a period of dialysis before transplantation.

A summary of the literature by NHS Kidney Care demonstrates that there is a paucity of evidence-based strategies that have been shown to improve access to transplantation, despite the fact research into this area is taking place. In 2011, NHS Kidney Care and NHS Blood and Transplant commissioned a multi-centre quality improvement project to improve access to listing for transplantation across the UK. Each of the kidney units involved in the projects had individual and specific issues to address in their own transplantation programmes; as such the approach taken to develop and lead their own improvement project varied across the kidney units.

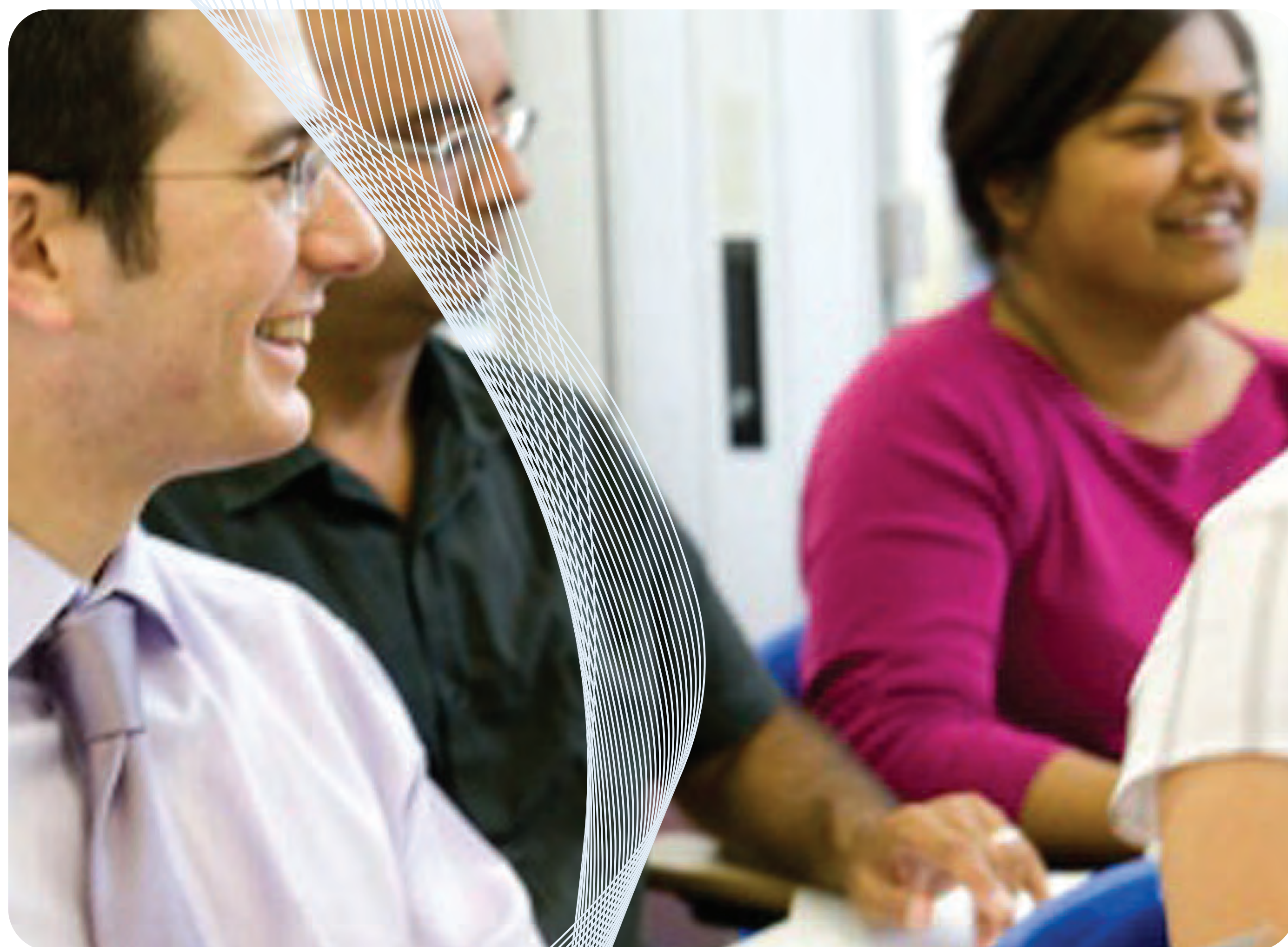
This report provides a summary of the individual reports submitted from the participating units describing their progress, challenges and findings of the individual units throughout the duration over the programme project period.

2. Profile of the project groups

All kidney transplant centres and units within District General Hospitals (DGHs) in England were invited to submit a project profile to NHS Kidney Care detailing the barriers to listing patients for transplantation in their practice and outlining strategies to address these, including specifics of methodology to assess quality improvement. NHS Blood and Transplant (NHSBT) commissioned a parallel programme across Wales, Scotland and Northern Ireland. Resources from the NHS Kidney Care commissioned programme and the NHSBT programme were exchanged between all participating units so that learning and benefits could be shared across borders.

Twenty one units in England submitted project applications and were provided with funding and support from NHS Kidney Care to implement their projects, while an additional five projects were sponsored by NHSBT across the nations. Details of the 26 kidney units from across the UK can be found in appendix 1.

The findings presented here are based on the findings from 23 project groups in their end-of-project reports submitted to NHS Kidney Care and NHS Blood and Transplant between July and October 2012.



3. Aims and objectives

In addition to the locally agreed aims and objectives of each project, NHS Kidney Care and NHS Blood and Transplant identified three key objectives, each with defined measurable outcomes. These were:

1. **To identify barriers to pre-emptive transplantation in the individual funded renal units, and across regional networks, and to agree areas for improvement.**

Measurable outcome: an action plan from each unit including a timetable for implementation and agreement to roll out shared learning and best practice nationally.

2. **Establish clinical pathways that support appropriate discussion and education and support timely listing of transplantation using evidence-based clinical guidelines. Pathways must reflect differences in timeframes that are central to living versus deceased donation. For deceased donation the recommended time for listing is six months prior to the start of RRT. For living donation referral is based on recipient eGFR and decline of renal function with enough time to allow one or more donor to be assessed in order to achieve timely transplantation.**

Measurable outcome: Established clinical pathways in each unit.

3. **Develop activity reporting in collaboration with NHSBT to reflect change in practice.**

Measurable outcome: increased number of patient listed for deceased donor transplantation and increased number of scheduled pre-emptive living donor kidney transplants by unit.

Nearly all of the project groups undertook an audit exercise to determine their situation with regards to current processes and outcomes for listing patients for transplantation and identify any barriers. In most cases the outcome of the audit was presented to the multidisciplinary team (MDT) to encourage discussion of potential solutions.

4. Findings against the aims

4.1 Identify barriers and solutions

Three key barriers to timely listing of kidney patients for transplantation were identified:

1. Lack of a standardised referral system or pathway
2. Inadequate patient and professional education and engagement
3. Delays due to efficient use of technology and administrative support

A more detailed explanation of these barriers and potential solutions is given below; however a summary of the solutions and key actions against these barriers for each of the project groups is provided in appendix 2. Further details of the solutions identified by Bradford Teaching Hospitals NHS Foundation Trust, Brighton and Sussex University Hospitals NHS Trust, Nottingham University Hospitals NHS Trust and Edinburgh NHS Scotland can be found in an accompanying how-to guide. (http://www.kidneycare.nhs.uk/document.php?o=1730)

Lack of a standardised referral system or pathway

The absence of a standardised referral system or pathway was a common theme running through many of the projects. Streamlining investigations and improving processes through the use of prompts, improved pathway efficiencies, assessment tools and clear lines of responsibility for identifying patients, can alleviate some of the delay that is occurring. Key solutions identified by the project groups were:

- Agree referral thresholds
- Create defined lines of responsibility, potentially with a key contact for each clinical area
- Co-ordinate listing processes with other trusts
- Ensure that all information about a patient is available at the point of referral for listing
- Improve communication with other clinical departments through streamlining process with shared and agreed care pathways, pre-referral assessments and proformas

A number of projects reported that it was not always clear where a patient was in the transplant preparation and assessment process, or the reasons why they were not being assessed. Under these circumstances it is difficult to determine whether transplantation had been considered and ruled out or had not yet been discussed. To overcome this, pre-referral assessments and proformas have been established by many of the project groups to ensure that the correct information is collected in a timely and prompt manner and passed on to the relevant departments. A range of prompts have also been shown to be effective to remind staff of the necessary considerations for listing patients for transplantation (see appendix 2).

Co-ordination of investigations for work up with other clinical departments has been highlighted as a significant barrier, most notably with cardiology but also in relation to pelvic MRI scans, urology, dental services, radiology, general practitioners, endocrinology as well as histocompatibility and immunogenetics. One solution adopted by a number of units is to have one or two named consultants in each speciality who have an understanding of the transplant assessment process. A second has been the development of shared care pathways between nephrologists and cardiologists in order to streamline cardiac workup of patients eligible for transplantation.

Other units have engaged the cardiology team and encouraged them to devise a cardiology algorithm which has been rolled out to referring nephrology teams. Cardiff was one unit that carried out this approach, and the project team reported that it has led to improved communications, allowed direct access to the cardiology team and helped to ensure that the right tests are done at the right time.

4. Findings against the aims

4.1 Identify barriers and solutions

Patient and professional education and engagement

Education of staff, both nursing and medical, as well as patients was an essential component of the project to affirm kidney transplantation as the gold standard for ESKD for clinically suitable patients. Findings from across the project groups suggest that there is variation in the provision of patient education material throughout the UK. Evidence shows that patients who are more informed and educated about their condition and the options available to them are likely to be more empowered, engaged and more activated in their own healthcare[viii]. A number of units also made the observation that education programmes should include staff, who may not be directly involved in the transplant workup pathway, but have a significant involvement in the care of patients as they move through the renal programme and have the potential to support patients in opting for transplantation and finding a potential donor.

Five key areas were identified that should be addressed in order to improve patient and professional education and engagement:

- Engage with patients in order to understand their views
- Improve patient understanding of transplantation and living donor transplantation
- Improve professional understanding of the benefits of pre-emptive transplantation
- Create a culture of 'transplant first' with both patients and professionals
- Understand the local population

Surveys and interviews with patients revealed that many patients would like to have more information on a range of subjects. However, when and how such information is given to patients is key to ensuring they engage in the process without overwhelming people with too much information too soon. It was noted that patients who had experienced unplanned dialysis felt that the process of being listed for transplantation should not start too soon; these patients were reported as often in a state of shock and unable to take in all the information required. There is also evidence from Manchester Royal Infirmary Transplant Centre that patients who fail to understand the importance of tests, such as Cardiac Perfusion scans, Echocardiograms or cervical smears, during the assessment process often missed these key tests and subsequently experienced delays in progressing through the transplant assessment pathway. An audit carried out by the Freeman Hospital in Newcastle also noted that a significant reason for delays in listing patients was due to non-attendance by patients to out-patient appointments.

The absence of a 'transplant first' culture can be largely attributed to a lack of education and awareness of the benefits of timely listing for transplantation on behalf of healthcare professionals, which is a barrier to patients being fully informed. One theory is that this may be due to the efforts to ensure adequate preparation for dialysis which has diverted focus away from timely assessment for kidney transplantation. Indeed, several units reported that there was a culture towards dialysis as the 'gold standard' RRT rather than transplantation. Furthermore, living donation appears to be discussed less than deceased donor transplantation. Many of the project groups sought to address this through revision and modification of patient pathway and patient education, as well as education and engagement of team members.

4. Findings against the aims

4.1 Identify barriers and solutions

Administrative delays

Administrative delays due to typing and sending referral letters between departments and trusts through lack of use of electronic documents and electronic filing, as well as issues pertaining to staffing resources, were identified across many of the project groups. Two main solutions were identified:

- Develop IT solutions; for example through the use of dedicated renal software, electronic communication and electronic proformas
- Ring-fencing dedicated staffing resources to support timely listing

A number of solutions, such as the use of electronic proformas and the use of email or proformas that can be readily faxed, have helped to reduce the impact that administrative delays can have in listing patients for transplantation. However, the lack of flexibility within some renal IT systems continues to provide a barrier in some trusts that wish to develop tools such as alerts for consultants to identify patients in whom eGFR has fallen below the given threshold. Examples that may help to improve the listing of patients include:

- Allowing dedicated specialist administrative staff to carry out administrative duties to free up nursing time
- Dedicated nurse and nurse led clinics to speed up the process by tracking the patient pathway and co-ordinating relevant tests
- Transplant Link Nurse Teams in the inpatient ward and Renal Donor Units to support and sign post staff and patients

4. Findings against the aims

4.2 Established clinical pathways

The findings outlined above indicate that most, if not all, of the projects involved in this initiative have gone some way to establishing clinical pathways for timely listing of transplantation for both living and deceased donation. Many of the barriers highlighted above are being addressed through a range of measures, including;

- streamlining the patient pathway through minimising traditional obstacles to pre-emptive transplantation and creating trigger points or prompts for referral
- improving patient education and staff awareness
- improving communication both within and between departments
- improved use of available technology
- having ring-fenced staff time dedicated to transplantation.

At Aintree University Hospitals NHS Foundation Trust a new Multi-Professional Team clinic (MPT clinic) has been developed, where all patients with advanced CKD are reviewed. This, alongside other measures such as a guideline eGFR of 20mls/min to trigger transplant assessment and preparation, the introduction of mandatory referral pro-forma and involvement of a single cardiologist with particular expertise in cardiac imaging, has streamlined the pathway and helped to ensure that tailored decisions are made with respect to RRT options, including listing for transplantation.

Other specific examples include:

- the establishment of a common pathway for listing pre-dialysis patients for kidney transplantation in South West Wales
- the introduction of a trigger eGFR of 20 mls/min for timely listing for living donation in Edinburgh NHS, Scotland
- the launch of new 12 week recipient and donor pathways at the Brighton and Sussex kidney unit, as well as the development of a transplant timeline that reflects the stages for recipient and donor work-up.

At the University Hospital Trust North Staffordshire, a new pathway has been devised for unplanned dialysis starters. This includes an improved referral proforma from the acute ward team to explicitly include a comment about fitness to go in to the unplanned dialysis transplant assessment pathway. Written information explains to patients that they will be invited for transplant assessment and preparation three months after initially needing dialysis, and explains the reason why this is deferred. Contact numbers are provided so that the patient or any potential donors can contact the transplant team if they wish to proceed more quickly.

4. Findings against the aims

4.3 Development of activity reporting

Some of the units were not in a position to identify any changes at the time of reporting, in part due to the short timescale for this project during which time barriers needed to be identified and solutions implemented. However, as all the units undertook an audit exercise as part of the project work, they now all have baseline data with which to compare future activity. Many teams specified plans to compare audit data with data collected 6–12 months post project to assess potential increases in the numbers of patients listed or transplanted pre-emptively and to review the duration of assessment for listed patients once the changes have been implemented. Specific aims include:

- increasing the number of referrals for transplant assessment where patients are not established on dialysis
- achieving a greater proportion of patients being listed for, and receiving, pre-emptive kidney transplant.

In order to determine how the transplantation process was working at the start of the project, and to allow for re-auditing the effect of any changes on completion of the project, Nottingham University Hospitals NHS Trust and Royal Derby Hospitals Foundation Trust worked together to develop eight key metrics covering all aspects of the current transplantation process:

1. Percentage of patients with progressive chronic kidney disease (CKD) (eGFR<23) with documentation of transplant eligibility.
2. Percentage of eligible patients with eGFR<15 either active on the transplant list, or completed full transplant assessment but not listed due to stable eGFR.
3. Time of cardiac status assessment to surgical assessment (allowing for clock stops).
4. Time of surgical referral to transplant listing (allowing for clock stops).
5. Number of pre-emptive live donor transplants as a proportion of all live donor transplants.
6. Percentage of performed transplants that receive a kidney from a live donor.
7. Time taken for late referrals to be listed once starting dialysis.
8. Percentage of patients and/or donors who receive a patient information leaflet on transplantation.

Many units have however been able to clearly demonstrate the impact of the changes that have been implemented with regards to:

- Improved time from initial referral to registering on the kidney transplant waiting list
- Increased number of patients listed for pre-emptive transplantation
- Increased pre-emptive transplantation rate
- Increased number of patients being assessed for pre-emptive transplantation, living and/or deceased or both.

A summary demonstrating these outcomes for those projects who reported is provided in table 1.

4. Findings against the aims

4.3 Development of activity reporting

Table 1: Summary of outcomes from those projects who reported them (* represents outcomes that were not demonstrated in the time frame of the project but were reported as anticipated outcomes following implementation of the improvements identified by the project work).

	Improved time from initial referral to placing on the renal transplant waiting list	*Increased number of patients listed for pre-emptive transplantation*	*Increased pre-emptive transplantation rate*	*Increased number of patients being worked-up pre-emptively for donation*		
				DD	*LD*	*Not specified*
Aintree University Hospitals NHS Foundation Trust	✓ *	✓ *	✓ *			
Bradford Teaching Hospitals NHS Foundation Trust	✓		✓ *			✓ *
James Cook University Hospital, Middlesbrough						✓ *
East and North Hertfordshire NHS Trust (Lister)	✓		✓			✓
Manchester Royal Infirmary	✓		✓ *			
Nottingham University Hospitals NHS Trust	✓ *		*			
Birmingham Heartlands	✓	✓				
Salford Royal Hospital						✓
North Bristol NHS Trust	✓ *		✓ *			✓ *
Sussex Kidney Unit, Brighton & Sussex University Hospitals NHS Trust		✓	✓	✓	✓	
Edinburgh NHS, Scotland	✓				✓	
Belfast City Hospital		✓ *	✓ *			
Morriston Hospital, Swansea, Wales	✓ *		✓ *			
University of Cardiff Hospital	✓ *					

4. Findings against the aims

4.4 Other key findings and outcomes

In addition to establishing defined clinical pathways and the development of activity reporting, the wider ranging benefits of this work included a change in culture in favour of transplantation as well as improvements in the provision of timely, effective, tailored advanced kidney care. As a consequence, units anticipate improvements in;

- patient understanding and satisfaction
- home therapies
- timely vascular access
- links with palliative care
- implementation of Advanced Care Planning as well as a wider uptake of care plans and access to Renal Patient*View*.

In addition, streaming pathways through, for example, involvement of the transplant co-ordinators with patients and carers at an early stage of their kidney disease, will hopefully improve pre-dialysis listing prospects as well as pre-emptive transplantation opportunities.

5. Sustainability

Ensuring that the improvements funded by this work are sustainable is crucial to building upon the learning that is summarised here to ensure that all suitable patients can benefit from timely listing for transplantation. Solutions given by the project groups to help ensure that this work continues include:

- Recorded evidence of the recommendations from the project in the minutes of the notes of the multi disciplinary team to ensure that they become embedded in daily practice and that performance against them can be monitored by the team.
- Re-audit and assessment of new or revised pathways to be carried out as a matter of routine. A number of units highlight that programme of work that has already been implemented will allow more comprehensive data to be gathered.
- On-going review of progress and stakeholder feedback.
- Electronic recording of outcomes from the multi professional or disciplinary clinical teams with designated clinical leads.
- On-going audit with respect to transplant review subject to local CQUINs (Commissioning for Quality and Innovation schemes).
- Medical led monthly review of transplant wait list status of patients with eGFR less than 20 ml/min.
- Continued staff and patient education and engagement programmes to instil a culture of "Transplant First". This principle is embedded in the current NHS BT UK strategy for living donor kidney transplantation[x].

Conclusion and recommendations

The work carried out by kidney transplant centres and referring DGH nephrology centres across the UK has identified three main barriers to improving timely listing for transplantation:

1. Lack of a standardised referral system or pathway
2. The need to improve education and engagement of patients and staff
3. Delays due to ineffective use of technology and administrative support.

Confronted with these barriers, the 23 project groups that reported to NHS Kidney Care and NHS Blood and Transplant implemented a number of solutions that have already produced demonstrable improvements to timely listing for both transplantation and pre-emptive transplantation. In addition, this has led to both increased pre-emptive transplant rates as well as an increase in the numbers of patients being assessed for potential pre-emptive transplantation.

The findings from these projects have informed the following recommendations for kidney units and transplant centres:

- Map and audit current practices to identify delays, bottlenecks, variations, and other potential problems and areas for further investigation. Carrying out an initial audit provides a benchmark against which improvements can be measured and can also provide valuable evidence for use in discussions with colleagues and negotiating commissioning arrangements.
- Embed consistency in approach within nephrology practice to listing and preparation for transplantation, especially pre-emptive transplantation in the context of a potential living donor.
- Streamline and clarify processes for listing patients for transplantation through agreed referral criteria such as thresholds and prompts for referral and assessment.
- Further streamline processes through having defined lines of responsibility, with identified clinical contacts in each area.
- Improve the communication and co-ordination with other trusts and clinical departments involved in the work-up process through the use of agreed processes and standardised protocols and proformas.
- Ensure that referral information is consistent and relevant to the patient and includes details of any test results, including those that may be pending, and the outcome of any conversations indicating patient preferences.
- Engage with patients in order to understand their needs and highlight areas that might not previously have been considered.
- Improve patient understanding about the options for transplantation, including living donor transplantation in a timely and appropriate manner. This should include the provision of high quality, accessible information available in a variety of formats, for patients, carers, families and potential donors to help patients make informed choices and facilitate shared decision making at an early stage in the process.
- Create a culture of ‘transplant first’ with both patients and professionals through improved understanding of the benefits of pre-emptive transplantation.
- Healthcare professionals should understand their local population and modify services as appropriate.

- Develop IT solutions such as dedicated renal software, electronic communication and electronic proformas to help to streamline processes and reduce delay.
- Ring-fence administrative resources to help ensure prompt and timely recording and communication of information relevant to support timely listing of patients who may be suitable for transplantation.

Almost all the project groups have been able to demonstrate positive outcomes for the first two objectives identified by NHS Kidney Care and NHS Blood and Transplant – to identify barriers and establish clinical pathways that support appropriate discussion and education and support timely listing of transplantation. The third objective – to develop active reporting with NHSBT to reflect change in practice – was more challenging to achieve within the timeframe of the project, which accounts for main performance variation in this domain. However, if the key findings identified within this project are embedded effectively into future clinical practice, the benefits of transplantation will be extended to more patients with ESKD.

Appendix 1:

Renal units that participated in the Timely Listing for Transplantation project

The successful renal units commissioned by NHS Kidney Care were:

- Aintree University Hospitals NHS Foundation Trust (Aintree)
- Bradford Teaching Hospitals NHS Foundation Trust (Bradford)
- Colchester Hospital University NHS Foundation Trust (Colchester)
- Plymouth Hospitals NHS Trust
- Freeman Hospital, Newcastle-upon-Tyne Hospitals NHS Foundation Trust (Newcastle)
- West London Renal and Transplant Centre, Imperial College Healthcare NHS Trust (WLRTC)
- James Cook University Hospital, South Tees Hospitals NHS Foundation Trust (Middlesbrough)
- East and North Hertfordshire NHS Trust (Lister)
- Manchester Royal Infirmary Transplant Centre
- New Cross Hospital, The Royal Wolverhampton Hospitals NHS Trust (Wolverhampton)
- City Hospital, Nottingham University Hospitals NHS Trust (Nottingham)
- Queen Elizabeth Hospital, University Hospitals Birmingham NHS Foundation Trust (QEH Birmingham)
- Birmingham Heartlands Hospital NHS Trust
- The Royal Berkshire Foundation Trust (Berkshire)
- Royal Derby Hospitals Foundation Trust (Derby)
- Shrewsbury & Telford Hospital NHS Trust (Shrewsbury)
- Salford Royal NHS Foundation Trust (Salford)
- Southmead Hospital, North Bristol NHS Trust (Bristol)
- Sussex Kidney Unit, Brighton & Sussex University Hospitals NHS Trust (Brighton)
- University Hospital North Staffordshire NHS Trust
- Royal Preston Hospital, Lancashire Teaching Hospitals NHS Foundation Trust

The five projects sponsored by NHS Blood and Transplant were based at the following kidney units:

- Edinburgh NHS, Scotland (Edinburgh)
- Belfast City Hospital, Belfast, Northern Ireland (Belfast)
- Morriston Hospital, Swansea, Wales (Swansea)
- Cardiff, University of Cardiff Hospital, Wales
- Royal Liverpool Infirmary – North Wales

Appendix 2:

Summary of solutions and outcomes for each of the 23 project groups that reported to NHS Kidney Care and NHS Blood and Transplant

Barrier:	Lack of standardised referral system				Education and engagement of patients and staff			Administrative delays	
Solutions:	**Clarification of referral criteria with prompts**	**Defined lines of responsibility**	**Coordination with other trusts**	**Coordination with clinical departments**	**Improve patient understanding**	**Promote 'transplant first' culture**	**Understand the local population**	**Improved use of technology**	**Dedicated staffing support**
Aintree University Hospitals NHS Foundation Trust	eGFR trigger	Single cardiologist takes responsibility for patient assessment		Streamlined patient pathway with Multi Professional Team clinic	Improved patient education	MPT clinic to encourage communication			
Bradford Teaching Hospitals NHS Foundation Trust	Clinic specific prompt sheets and referral forms eGFR register CQUINS Prompts to discuss dentition, breast & cervical screening and BMI			Unplanned starter care bundle Nurse clinic review and 'one stop' medical review Single repository of information Registration of patients on SystmOne at time of referral New checklists		Promotion in junior staff induction All staff encouraged to consider transplantation Monthly HD checklist		3 way emailing with colleagues in co-ordinating trusts	
Colchester Hospital University NHS Foundation Trust			Agreed cardiac proforma		Planned education package and group discussion sessions *		Low clearance spread sheet	Agreed cardiac proforma	

Appendix 2:

Summary of solutions and outcomes for each of the 23 project groups that reported to NHS Kidney Care and NHS Blood and Transplant

Barrier:	**Lack of standardised referral system**				**Education and engagement of patients and staff**			**Administrative delays**	
Solutions:	**Clarification of referral criteria with prompts**	**Defined lines of responsibility**	**Coordination with other trusts**	**Coordination with other clinical departments**	**Improve patient understanding**	**Promote 'transplant first' culture**	**Understand the local population**	**Improved use of technology**	**Dedicated staffing support**
Derriford Hospital, Plymouth	eGFR trigger Pro-forma for referral	Increased awareness within team	Link nurse programme Use of video link LD[1] coordinator visits	Ensure surgical commitment to transplant assessment clinic	Education programme of self-care eGFR <25 RRT programme for eGFR <20	Monthly & weekly meetings with team Education programme		LD[1] spread sheet Template for electronic vitaldata page	Transplant secretary to co-ordinate transplant assessment clinic
Freeman Hospital, Newcastle	<1 year to needing RRT Changes in pathway processes	Transplant co-ordinators included earlier		Transplant surgical review for dialysis access with assessment for transplantation	Patient held care plan Increased counselling about transplantation	Care plan		Integrated single page database into CV[5]	
Imperial College Healthcare NHS Trust				Transplant status highlighted on new referral form to dialysis clinic	Information for patients suitable DD[3] only				

[1] Living Donation
[2] CV5 is the IT system used at the Freeman Hospital, Newcastle
[3] Deceased Donation

Appendix 2:

Summary of solutions and outcomes for each of the 23 project groups that reported to NHS Kidney Care and NHS Blood and Transplant

Barrier:	Lack of standardised referral system				Education and engagement of patients and staff			Administrative delays	
Solutions:	**Clarification of referral criteria with prompts**	**Defined lines of responsibility**	**Coordination with other trusts**	**Coordination with other clinical departments**	**Improve patient understanding**	**Promote 'transplant first' culture**	**Understand the local population**	**Improved use of technology**	**Dedicated staffing support**
James Cook University Hospital, Middlesbrough	Time targets for pathway	New LKD[4] clinic	Improved engagement with Freeman Hospital, GPs, radiology and histocompatibility	Monthly transplant MDT	New LKD consent form Report for hospital newspaper	Promotion of Living Kidney Donation	Prevalence of deprivation	New database of all LKDs	Defined administrative roles for SpN and secretarial staff
East and North Hertfordshire NHS Trust (Lister)				Transplant link nurse with pre-dialysis team Cardiology, Radiology and Pathology streamlined for single day of tests	Information days, displays	Staff study days Monthly Renal Management Group education sessions			
Manchester Royal Infirmary	Defined pre-referral assessments			Introduction of nurse led-clinic to co-ordinated tests etc Defined cardiology referring pathway	Information through nurse-led clinic	Education sessions	Religious and cultural perspective		

[4] Living Kidney Donation

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Nottingham University Hospitals NHS Trust	eGFR trigger			Advanced kidney care proforma Regular monitoring of metrics	Patient information leaflets Local DVD Experience Based Design Tools	Programme of all staff communication			
QEH, University Hospitals Birmingham NHS Foundation Trust	Living donor pathway			Buddying of LD co-ordinators with recipient co-ordinators		Need for education identified			
Birmingham Heartlands				See improved technology		Renal Transplant link nurse study days		Access to electronic waiting lists from H and I[5] labs	
The Royal Berkshire Foundation Trust					Patient information		Multicultural population		
Shrewsbury & Telford Hospital NHS Trust	Establish defined pathways		Strengthen links with UHB[6] (principle transplant centre)	Transplant listing clinics	Update and improved patients education				

[5] Human Histocompatibility Immunogenetics Laboratories
[5] University Hospital Birmingham

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Salford Royal Hospital	One-stop transplant work-up clinic	Protocol investigations requested by CKD team only and tracked.	Patient, carers and primary care access to listing information on RPV[7]	Revised referral pathway and agreed workup protocols	Revised patient leaflet; recruitment to RPV			Electronic patient record 'knowledge tree'	
North Bristol NHS Trust (Bristol)	eGFR trigger		Inclusion of transplant co-ordinator from point of referral Surgical referral form Surgeons and transplant co-ordinator to attend local MDT clinics	Agreed surgical referral form Cardiac referral in parallel with surgical Regular MDT to include transplant co-ordinators				eGFR flag on IT system Letters available on local Proton system	
Brighton & Sussex University Hospitals NHS Trust	eGFR trigger 12 week recipient donor pathway			Dedicated time slots with cardiac team Transplant wait list status flagged at nurse & MDT meetings	eGFR trigger for information South Eastern KPA provided with patient information Patient information leaflets on types of donation	Education and emphasis on pre-emptive transplantation to change culture Priority given to transplant work-up process			

[7] Renal Patient*View*

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University Hospital, North Staffordshire NHS Trust	eGFR trigger (not yet implemented)			Improved referral proforma for unplanned starters Need for psychological support for unplanned starts identified	Concerns raised about timing of information for unplanned starters Peer support need identified			IT system to flag eGFR (not yet implemented)	
Edinburgh NHS, Scotland	eGFR trigger		Agreed standardised pathway across referring region		Transplant road shows in three referring regions	Transplant road shows Teaching sessions with staff in Edinburgh			
Belfast City Hospital, Northern Ireland	eGFR trigger	Defined responsibilities within teams	Work-up standardised across Northern Ireland	Recipient assessment tool agreed with surgeons, anaesthetists, cardiologists	Review of education material to low clearance patients			Electronic record	

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Morriston Hospital, Swansea, Wales		Lead cardiologist identified	Common pathway for listing pre-dialysis patients across Wales	Shared care pathway between nephrologists and cardiologists				Electronic documentation and filing of transplant status of all on RRT and stage of investigation for those listed	
University of Cardiff Hospital, Wales	eGFR trigger			Cardiac pathway				Electronic database	Secretarial support for listing

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