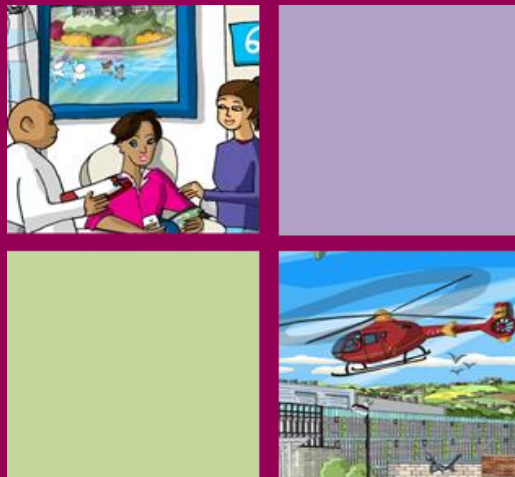


How to deliver Transplant First in your region



KQuIP

The kidney community's quality improvement partnership

How to deliver Transplant First in your region

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1. Foreword

Opening Statement from West Midlands Transplant First Leads

Thank you for reading this guide and considering adopting Transplant First (TF) in your region. We all now increasingly understand that unwarranted variation in healthcare can, and should, be tackled. We initially set up TF in the West Midlands as a local project. We are not particular experts in QI however, since we have been involved in TF we have developed resources and learning that we hope will help others.

Although we have used the NHS change model to structure this guide, the reality is that delivering QI in the real world can be challenging, unpredictable, and highly dependent on human factors. We have tried to point these out in the top tips. We are increasing the rate of pre-emptive transplant listing in the West Midlands and many units have made significant changes in terms of restructuring teams and changed processes. There is no suggestion that every unit should adopt every idea we have come up with, but we have listed the changes we made in this guide.

One of the most rewarding features of the project has been the change we have seen in the contributing teams. There has been a real enthusiasm and pride in our achievements. At our recent Peer Review it was clear that the teams working in transplantation were quickly able to come together productively with a real “can do” attitude. The change from the beginning of the project was obvious and fantastic.

Moving on TF dovetails well with other national initiatives such as increasing living donation (LD2020) and GIRFT (Getting it Right First Time). In adopting the project you will give your region the structure to take these forward. We have also found that as we eliminate simple barriers we are pushing ourselves further. We are now asking more of why complex patients are difficult to list and there is no reason why, in future, TF shouldn't begin to address other groups such as socially disadvantaged patients.

We have more to do but the highest rate of pre-emptive listing in the West Midlands is better than the best transplant unit in the latest NHSBT report. Therefore although we can't all be the best, we can all be better. Good Luck.

Kerry Tomlinson, Consultant Nephrologist and Helen Spooner, Advanced Nurse Practitioner.

November 2017

2. Background

In 2015, the West Midlands region had some of the longest waiting times for kidney transplants in the UK. The chances of a patient getting on the kidney transplant list before dialysis (known as pre-emptive listing) were lower than the average for the UK. Once patients were listed for a kidney transplant, often they would wait more than three years for surgery. There were low acceptance rates for deceased donor kidneys which contributed to long waits on kidney units. Overall, the chance of a patient receiving a pre-emptive transplant in the region was lower than the national average for both deceased and living donor kidneys.

Evidence shows that patients who wait too long for a transplant experience poorer outcomes than those whose wait is shorter. A long wait for a transplant may result in the patient needing to have dialysis, or may prolong dialysis. This can affect the cardiovascular system and reduce life expectancy. Until a patient is on the transplant list there is no possibility of them receiving a kidney, so getting onto the list promptly is crucial.

Below is the sequence of events for the Transplant First project, as detailed in Appendix A.

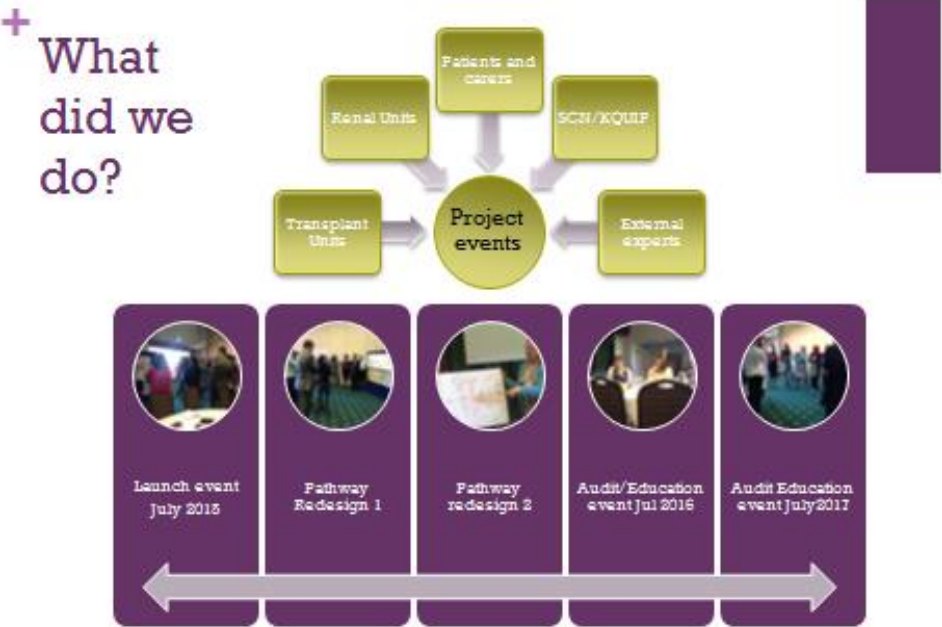


Figure 1 - Sequence of events

3. Use of the NHS Change Model to tell the Transplant First story

Using the [NHS Change Model](#) (Figure 1 below) the West Midlands Clinical Network are able to share how they developed a response to the issue outlined above. The NHS Change Model is a robust framework and approach for developing quality improvement work. It was created to support anyone from any organisation in health and care to adopt a shared approach to leading change and transformation in the delivery of services.

The NHS Change Model comprises eight component parts. The components are used to develop and support a quality improvement project, to ensure that each element is considered and used to make sure your project is complete. Put together, the sum of the parts delivers a complete picture of how to manage and deliver quality improvement. There are eight components of the NHS Change Model – more information on these components can be found at Appendix B.

Each section of this “How to Guide” document includes Top Tips and Key Learning from the West Midlands, these have all been combined into one handy reference guide which can be found at Appendix C. This document explains in more detail how the West Midlands region is delivering Transplant First. All elements of this project could be changed to reflect differences in other regions.



Figure 2 – NHS Change Model

4. Our shared purpose

Transplant First was the region's response to the problem highlighted in section 1. Initiated by renal specialists in the West Midlands and supported by the West Midlands Clinical Network, its aims were to increase access to transplantation for all suitable patients in the region. To find out more about the project please visit the web pages on the KQuIP [website](#).

The project focussed on getting patients onto the transplant list promptly, as well as giving kidney units the opportunity to look at their processes, such as the way they manage living kidney donors. At the same time, surgeons at the transplanting units reviewed their criteria for turning down donor kidneys.

The launch event in July 2015 brought together all seven renal units from across the region. The arguments for change were compelling, so there was no problem in getting buy-in for the project. Building on the appetite for change among renal specialists in the room, Transplant First asked each unit to identify a project lead and to commit to sharing data openly. Transplant First's aims were for 95% of all patients starting renal replacement therapy to have a documented transplant status. It wanted more than half of all patients on the transplant list to be pre-emptive (i.e. on the list before they started dialysis). The aim was for the West Midlands to have the highest rate of pre-emptive listing of any region in the UK and to be in the top 50% of units for pre-emptive transplants.

To read more about the compelling case for change presented at the launch meeting click [here](#).

Top Tips & Key Learning:

- Identify the regional units and Clinical Directors to commit to Quality Improvement and to lead the developments and change, to ensure a shared goal and purpose.
- Include patients to hear their experiences about the transplantation process
- Communicate that the project is achievable and will realise important improvements in patient care and experience
- Make all events and sessions as interactive as possible
- For events invite speakers with inspirational stories of change
- Identify project leads and agreed to data sharing openly
- External facilitators can help to challenge project leads and allow everyone to have a voice and gain a shared purpose
- Important for all involved to understand the parameters of the project and the shared purpose to not go off and do their "own thing"
- Importance of agreeing defined pragmatic metrics of outcomes, and committing to collecting these realistic metrics

5. Influencing Factors

The West Midlands Clinical Network agreed that the data analysis (provided by the UKRR & NHS Blood and Transplant) demonstrated that the key drivers and influencing factors contributing towards the formation of Transplant First, were:

- Low live donor and deceased donor kidney transplant rates in the West Midlands compared with national data
- Low pre-emptive kidney transplant listing and transplant rates in the West Midlands compared with national data
- Low acceptance rates for deceased donor kidneys in the west Midlands compared to national data
- The West Midlands had some of the longest waiting times for kidney transplantation in the UK
- The West Midlands as a region had wide variation in transplant listing

Top Tips & Key Learning:

- Understand and own your data to identify key factors and drivers to steer forward change

6. Motivate and Mobilise

The launch event in July 2015, identified significant buy-in, support and appetite to deliver the change required. The Transplant First project, brought together the West Midlands Region inclusive of seven renal units and two transplant units with a shared passion and goal.

The West Midlands Clinical Network formed the following key groups to motivate and mobilise the group:

- Partnership Board
- Sponsorship team
- Project Leads (Nursing /Medical)
- Workstream leads (including patients)
- Wider stakeholder group
- Lead Renal Transplant Physician and Senior Nurse at each Renal Service within the region who were accountable for kidney transplantation development and act as the Project Leads at each Unit, to drive the project forward.

To ensure buy-in from all of the units within the West Midlands letters were sent to the Chief Executives of each of the Trusts involved asking them to pledge their support to the project.

During the life of the project certain issues arose for example BMI came up when writing and agreeing the standards. It was important that the leads within the region could raise areas for concern and these could be debated at a regional level to gain consensus.

Top Tips & Key Learning:

- Hold a launch event to share ideas, information and to bring together the regional renal community to agree the regional project
- Maintain regular face to face meetings/events to discuss progress/ promote cycles of change and hold each other to account
- Be flexible in dealing with issues that arise during the project lifecycle to ensure consensus
- External or experienced facilitators can help to mobilise the region and break down barriers
- Central Project management is key
- Project Groups in each Trust may need support

7. Patient Involvement

Patient involvement in the process was fundamental to the success and impact of the quality improvement project. A patient involvement group was established from the outset to represent the seven units within the west midlands region. The patient representatives were integral to the process mapping sessions to understand the challenges that patients face, and the improvements that would make a real difference, such as information sent from referring units, communication, inconsistent processes and pathways that were streamlined.

The project intended to create standardised patient information documents but it became clear that amongst the patients there were differing views and often documents had to be tailored to local process. Therefore it was decided to produce Guidelines for producing patient information instead. Please see [click here](#) to view or see Appendix G.

Top Tips & Key Learning:

- Include patients to hear their experiences about the transplantation process
- Try and embed patient involvement through every part of the project, recognising that maintaining sustainability of patient involvement can be challenging.
- Ensure issues raised at meetings and events always focus on the patient perspective in addition to healthcare professional perspective
- Involving patients in the project helps healthcare professionals be held to account
- All healthcare professionals want to do their best for patients. Hearing directly from them can be uncomfortable but is a powerful driver for change

8. Leadership by all

In order to progress, a Partnership Board was established that included the sponsor team alongside representatives from national organisations. The Board met frequently at the beginning of the project but the day to day management of the project was led by a sponsor team. The sponsor team included representatives from some of the referring and transplanting units within the West Midlands. This group was established to lead the development of the project and to communicate out to the wider stakeholders of the project across the West Midlands.

Following the launch event in July 2015 and in order to ensure key buy-in from all of the units within the West Midlands letters were sent to the Chief Executives of each of the Trusts involved asking them to pledge their support to the project. In addition all units within the region were asked to identify a project lead and to commit to sharing data openly and streamline pathway processes.

Top Tips & Key Learning:

- Establish key working groups as detailed in figure 2, found in section 9, to ensure the project remains focused to its goals and objectives and delivery
- Avoid the usual hierarchies – acknowledge they may have existed but avoid letting them take over within your geographical location
- Break down barriers and work to overcome friction between receiving and referring units
- Ensure that those involved in the project understand the processes involved in quality improvement projects and provide education wherever possible
- Leadership for the project can come from any member of the MDT
- Recognise that consultants can be powerful in both leading and preventing change

9. Spread and Adoption

The Transplant First project formed a network and held a launch event to spread and adopt the project aims and objectives. The regional clinical leads formally committed (via a letter of commitment) to the project and its developments to ensure the aims and objectives of the project remained the focus for the work. The team also provided a number of events to maintain commitment, development and momentum, further details of the events can be found in the timeline at appendix A.

As the project progressed the participants were given the means to undertake change both in their own units and across the region by participating in two whole day pathway redesign events. There was some formal QI training for those who were unfamiliar. Units were taught how to do process mapping in real time and started the process at the meetings. They went away and returned for the second meeting having identified their own units issues and already made changes. At the second meeting each unit presented its own process map. By working in a facilitated group barriers could be overcome and ideas spread. Importantly this was the main time that all units could talk honestly about the “handover” between referring and transplant units and the group had the will and authority to make some quick win changes

Top Tips & Key Learning:

- Balance of QI education and “doing” is difficult and will depend on your regions skill set- but don’t underestimate that the majority of people will need some support to be empowered to make real lasting change in their own unit
- Don’t let doctors do all the talking – they are often good at the spin but the other healthcare professionals know what goes on really!
- People value this time together greatly, and for many units will be the most “time out” they have had. They will be very cross if it is wasted
- Identify the changes that could be implemented at a regional level and for those focus on consensus – this helps to motivate people. Our quick win changes were:-
 - Establishing a central email address for electronic referrals - see appendix D
 - Mobile numbers for patients shared across units
 - Early donor work up

10. Improvement Tools

The Transplant First project team used the following data tools for analysis and identification of areas of improvement, data sources as follows:

- NHS Blood & Transplant Annual Report on Kidney Transplantation, [click here](#)
- UK Renal Registry Annual Report, [click here](#)

As the project focussed on improving pre-emptive transplant listing in order to measure for improvement an audit tool was developed to perform a broad route cause analysis as to why patients were not pre-emptively listed. The tool is an enhancement of the NHSE dashboard which is collated quarterly by the renal registry. The main purpose of the tool is to allow project leads in each unit to understand why people are not pre-emptively listed in their unit. More information on the measurement regime for the project can be found in section 11. Any tools produced for the project can be found in the appendices.

Top Tips & Key Learning:

- The tool will not work well for the unit if there is dissociation between those filling in the data and the project leads
- Collect data on individual patients as you go along, when a patient starts dialysis fill in the data sheet, record all pre-emptive transplants as they happen.
- In units where the project leads used their own data they have found it very helpful in identifying areas to change
- The overall project lead will need to sense check returns at least initially both for accuracy , but also to pick up region wide patterns or issues
- Review and understand data submissions on a regular basis to ensure accuracy.
- Have a Multi-disciplinary team approach to managing, owning and improving the data.

11. Project and performance management

In order to progress the project further, the sponsor team established a number of working groups to distribute the workload. The West Midlands Clinical Network identified a project manager to lead this work who provided crucial skills that supported the delivery of this programme. The following key project stages were identified and delivered:

- Identification of the Stakeholder Group and Clinical leads
- Developed a project plan including a timeline for events, meetings, data collation and submission and other activities pertaining to the development of the project. See appendix A for the project timeline
- Capture lessons learnt as the project develops

The Project Manager was a pivotal role that supported the sponsor team and ensured timely communication and action between them and the working groups, established as follows :-



Top Tips & Key Learning:

- Engage a Project Manager to support the Clinical Leads to plan, manage activities and deliver improved clinical outcomes.
- At each event ask units to feedback process. Produce a powerpoint slide deck for all units to present their data ensuring consistency of presentation

12. Measurement

The renal units were already producing data for NHS England via the UK Renal Registry and also NHSBT. In addition the project agreed to create an enhanced dashboard to detail the proportion of patients that are starting dialysis with documented transplant status including support and guidance. The UKRR supported the project by developing a template for data collation, and circulating the template to units in parallel with the NHSE dashboard. The data tool can be found at Appendix E with an example of the tables and figures that are displayed, screenshots of the template to be completed and a list of the data items that are collected. The data tool can be used by any region who wish to do a similar project. The level of support provided by the UK Renal Registry is currently being considered. The project measurements agreed were:

- Numbers of transplants and proportion that were pre-emptive (for both deceased and living donors) at each unit
- Unit-specific pre-dialysis (pre-emptive) renal transplant-listing registration rates as percentage of all kidney transplant-list registrations for each Unit
- Proportion of patients starting dialysis who are documented as unsuitable for transplant OR who are on the transplant list (and for those who are neither - an exploration of *why not*)
- Proportion of total number of patients on the renal transplant waiting list who are suspended (NHSBT)
- Proportion of CKD 5 patients known to each unit who have a documented transplant status on the renal IT system
- Waiting time to renal transplantation for each transplant unit & for West Midlands (longer term measure- NHSBT)
- NHSBT deceased donor Kidney transplant - offer decline rates (NHSBT) in comparison with rates across the UK (6 monthly feedback of rates of deceased donor kidney graft decline rates).
- In addition as a balancing measure transplant outcomes must be monitored although it will take a long time for any changes to become apparent. Transplant outcomes are monitored via the annual regional audit event. Work is ongoing within NHSBT to deliver outcome data devolved to renal units rather than just transplant units

As an example the lessons learnt from our data include transferable causes for missing listing :

- Failing transplants
- Predictable but rapidly declining patients
- Different approaches to cardiac angiography pre-dialysis

Local causes for missing listing :

- Specific clinics (eg diabetes and multi-disciplinary)
- Different feeder hospitals
- Other unit specific issues

Top Tips & Key Learning:

- Identify the key measures for the project at the beginning of the project
- Identify a key lead within the sponsor team to take responsibility for reviewing the regional quarterly dashboard data
- The development of a measurement process is not easy and all project leads need to commit to submit data regularly and in a timely manner ensuring accuracy of this data

How to collect good data that can be used to improve rate of Transplant listing

- Appoint one person to collect and enter the data into spreadsheet or on line
- Make sure that person has a good working relationship with all the team, access to Renal IT system and patient notes
- Identify the patients – all those starting PD or HD who have been seen by the Nephrologist more than 90 days before starting dialysis (we included those with a failing transplant).
- Collect data on each patient as you go along, it is much easier to find information real time than searching weeks after the event
- Set up a practice of recording transplant status in the notes or on Renal IT system on the day they start dialysis. If not listed record the reason why not – from the list in appendix E.
- Record all transplants and enter onto spreadsheet as they happen
- Make sure transplant listing status is up to date for every patient with eGFR < 15 including failing transplants. This is needed for summary data.

Frequency and schedule of data collection

Data is collected on a quarterly basis with the schedule for quarterly data submissions shown below.

Quarter	Data submitted to UKRR
Quarter 2: Apr-June 17	11 August 17
Quarter 3: Jul - Sept 17	17 Nov 17
Quarter 4: Oct-Dec 17	16 Feb 18
Quarter 1: Jan -Mar 18	25 May 18

Future data submission dates to the UKRR will be confirmed in due course.

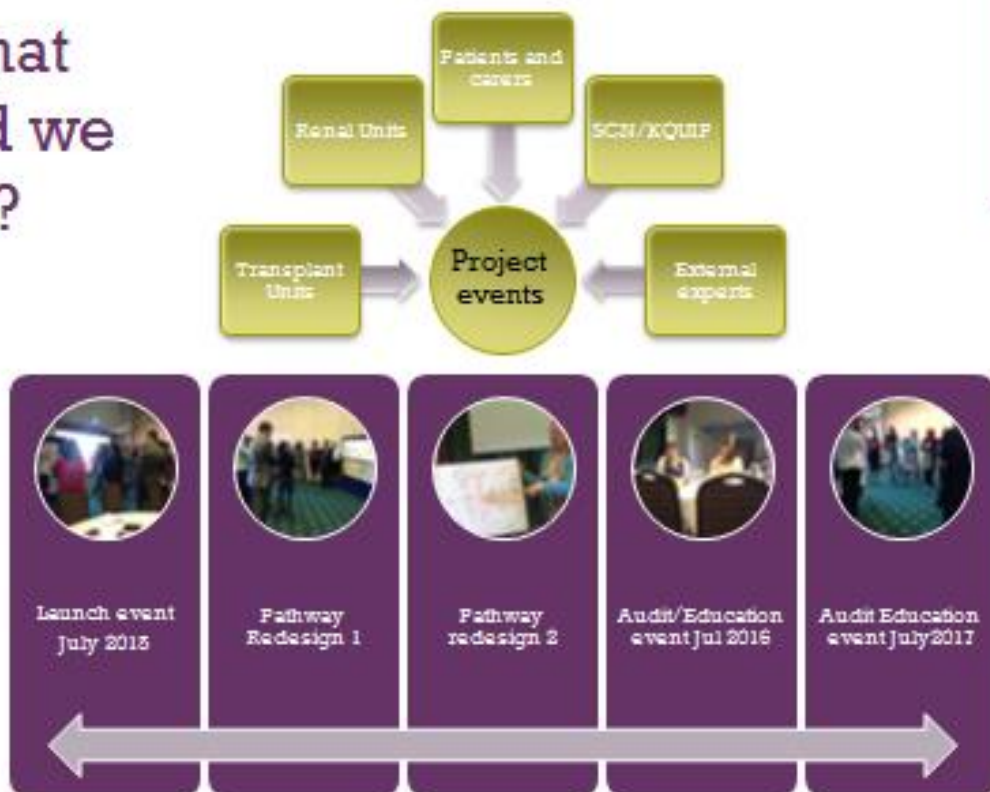
The template used for the data collection will be circulated to participating units a month before the due date for the data submission. Data submitted to the UKRR will be collated for the region and figures and tables generated and displayed.

Future plans

The UKRR will be developing a dashboard that can be used by participating units/regions for data entry and automatic generation and display of the data in tables and figures. Participating units will be contacted by the UKRR when the dashboard is available for implementation.

Appendix A- Sequence of Events

+ What did we do?



Appendix B - NHS Change Model



The NHS Change Model is a robust framework and approach for developing quality improvement work. It was created to support anyone from any organisation in health and care to adopt a shared approach to leading change and transformation in the delivery of services.

The NHS Change Model comprises eight component parts. The components are used to develop and support a quality improvement project, to ensure that each element is considered and used to make sure your project is complete. Put together, the sum of the parts delivers a complete picture of how to manage and deliver quality improvement. There are eight components of the NHS Change Model:

- **Our shared purpose**

A clear sense of shared purpose about what you want to improve is essential for successful change, as well as shared objectives and good understanding of what you are trying to achieve.

- **Influencing factors**

Conditions need to be right for change to occur so it's important that at the start you are aware of the drivers for your improvement work, the incentives and the potential challenges. Being able to recognise and respond to influences on your work over the period of your project will ensure success.

- **Motivate and mobilise**

Motivation and mobilisation of people is essential to keep the momentum of any project on track. It's an important element of engaging people and leading for change.

6 Leadership by all

This describes the approach, skills and behaviours needed to lead significant change. It is based on the theory of shared (or distributed) leadership, where acts of leadership can come from leaders wherever they are in the kidney community including patients.

6 Spread and adoption

To accelerate the speed and extent of successful quality improvement initiatives we must share them across the community through spread and adoption. This should be planned to ensure that there is less reinventing the wheel, making good use of resources to ensure that the outcome of change benefits everyone.

6 Improvement tools

Using evidence-based improvement tools ensure that quality improvement will be delivered in a planned, proven way that follows established methods. There are a wider range of improvement tools to support varying levels of change.

6 Project and performance management

A proven programme, project management approach will increase the likelihood that changes will deliver the planned benefits. This requires discipline and focus and is not optional, as without programme and project management, other elements of the change model will fail.

6 Measurement

Measuring the outcome of change continuously is crucial to provide evidence that the change is happening and the desired results are being achieved. Using appropriate measurement techniques ensures that success can be celebrated, remedial action can be taken to mitigate risk and the unforeseen consequences can be dealt with promptly

Appendix C – Top Tips & Key Learning

Running the Project

- Process map, process map, process map (all units were surprised what and how much they learned)
- Maintain equal partnership for referring and receiving organisations
- Include patients and in shaping and redesigning pathways
- Agree to collect and share data
- Know your data and use it
- Project leads need to know what their data managers/coordinators are returning
- Agree regional standards and guidance where needed
- Agree activities and timeline to maintain project momentum
- Ensure robust project management support
- Get Clinical Director and Nursing commitment in each trust
- Have regular face to face “doing” meetings (e.g. every 6 months)
- Use the same template for meeting updates to ensure teams stay “on message”
- Ensure all the multi-disciplinary team (MDT) have a voice
- Communicate within local teams to collaborate with colleagues
- Low eGFR teams in Renal Units need to be involved
- Maintain long term focus when things get difficult or go wrong
- Don’t relax when you think a problem is sorted
- Be honest, self critical, and open to challenge
- Don’t point fingers but do talk openly

Changes, ideas and learning from our project (note not all units had the same strategy)

- Appointing lead nurse and doctor for transplantation in each renal unit (now mandated)
- Appointing transplant co-ordinator
- Centralising referrals to transplant centre via one e mail address
- Sending patients mobile number with referrals so they could be texted to avoid DNA
- Joint assessments clinics set up with transplant centre
- Set up transplant listing clinic in Renal Units (may be nurse led)
- Restructuring Renal /Diabetes clinic which had a high rate of “missed” patients
- Transplant centre MDT to speed up complex decision making
- Regular feedback to teams as to why patients were “missed”
- Renal unit low eGFR MDT meetings systematically including transplant status (may include co-ordinator)
- Systematically recording CKD5 patients transplant status in their letters and IT system
- Using IT to produce reports of CKD5 patients without transplant status
- MDTs to discuss listed patients
- Recording Living Donor workup on IT system
- Collaborative working became more normal
- Increasing early transplant discussion (defining pathway, cue cards, team education)
- One stop/fewer stop recipient or Living donor clinics
- Shared regional practise (e.g. early cardiology assessment) to encourage adoption

Appendix D - Establishing a central email address for referrals

Subject: Referral email UHB - Transplant First Project.

Dear Transplant First Leads.

Regarding: “Renal transplant assessment surgical referrals to be sent via a UHB dedicated nhs.net account only”.

As part of the transplant first initiatives the group agreed to send renal transplant assessment surgical referrals via a dedicated UHB nhs.net email account, to help streamline the patients transplant assessment process.

Please send all future referrals to uhb-tr.renaltransplantcoordinators@nhs.net.

This email address will only be used for referrals only and will not be looked at frequently for urgent communication.

You will receive an automated response so you are aware we have received your email. Please attach necessary reports (chest film, ECG, echo, +/- MPI and other reports required).

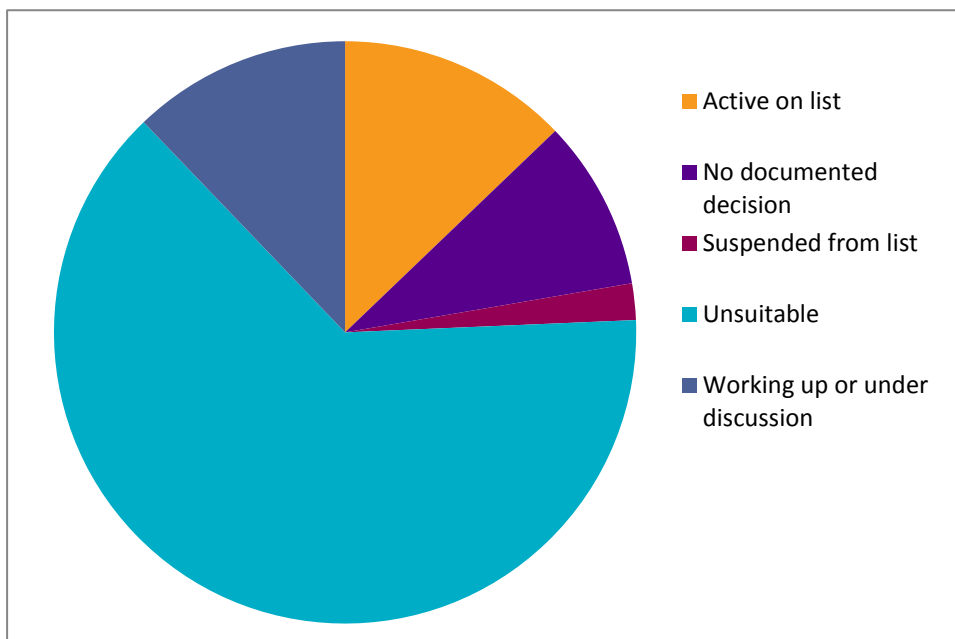
We will not accept faxed or posted referrals from October 1st 2016.

Please disseminate amongst your teams regarding this change in practice. We hope this new initiative will improve patients access to the national transplant list in a more timely manner.

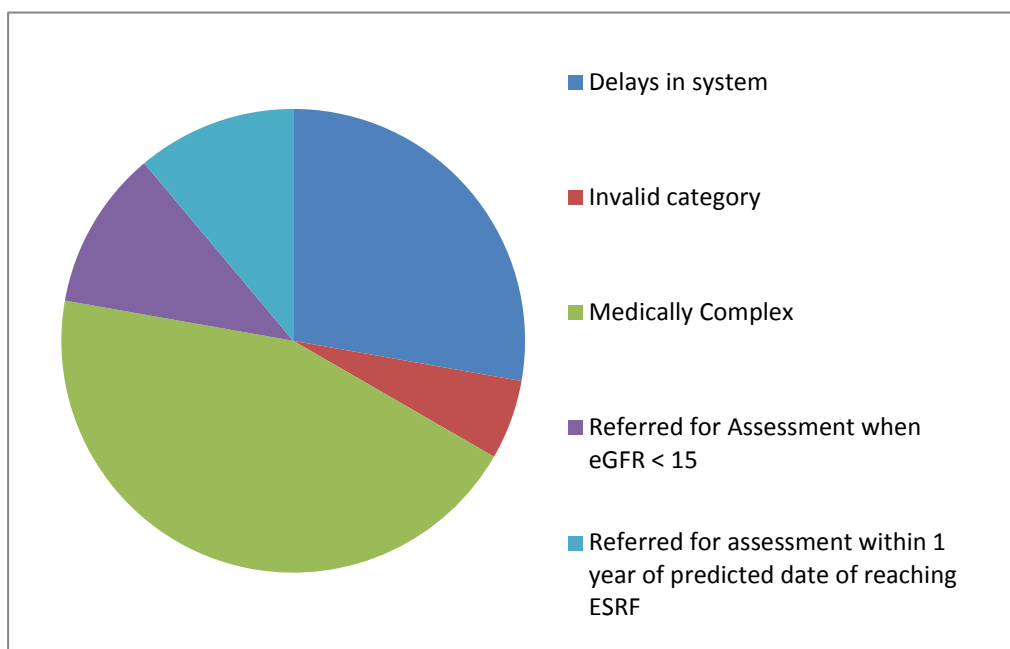
Appendix E – Measurement Dashboard

To view the full dashboard, please [click here](#). The dashboard data for 2017 for all patients who start dialysis in a planned fashion the units return their transplant status (summary example below):

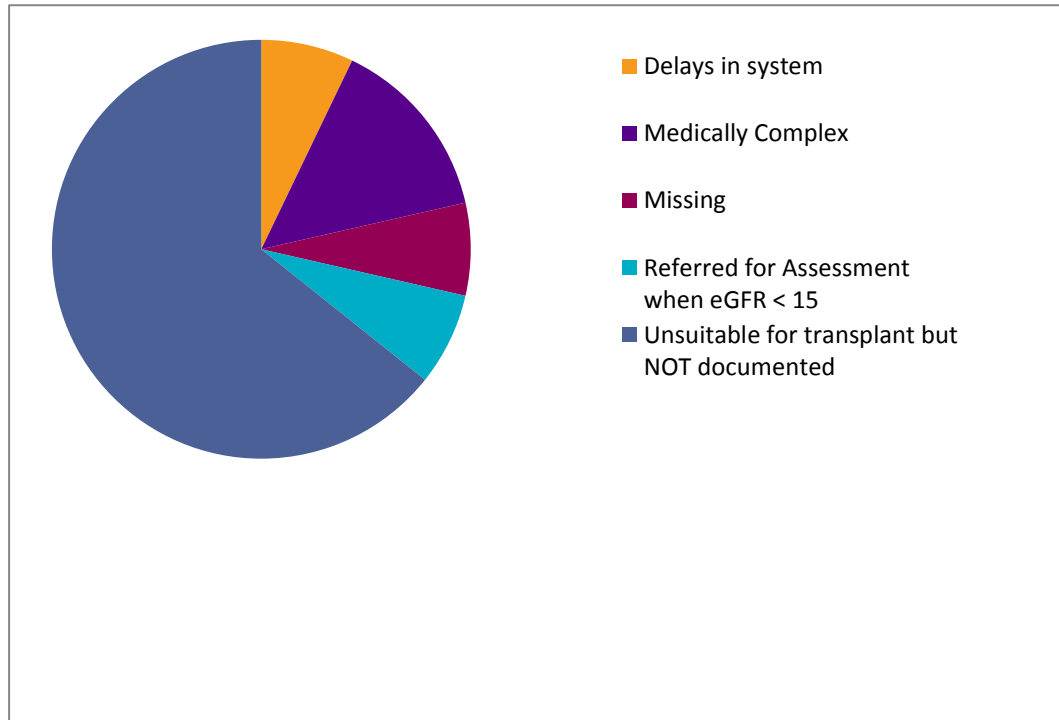
Transplant Listing status



Patients in the categories “no documented decision” or “working up or under discussion” count as missed and units are asked the reason why in defined categories. Although the units don’t have to go into details it is helpful if they do and expected that the local TF lead understands the details to inform change. Examples are shown below:



For patients "in working up or under discussion" For patients "no documented decision" , please see below:



Units are asked to similarly look at patients who are listed for transplant and categorise those who were not listed pre-emptively. Included below are screenshots from the data collection tool:

Screenshot 1:

West Midlands Strategic Clinical Network	Transplant FIRST
Quarter 1 2017 01/01/2017 - 31/03/17	Renal Unit <input type="text"/>
	Contact Email <input type="text"/>
This spreadsheet allows data collection for your involvement in the Transplant First project	
Its primary use is for you to be able to identify patterns and reasons why patients are not listed for transplantation pre-emptively. In this way you can use it to improve quality in your unit. To maximise usefulness there should be clinical involvement and feedback to your local team.	
The data will also be collated by the Renal Registry so that trends over time can be identified- you will have access to this along with the other units in your region who have agreed to share this data as part of the project.	
In order to collate the data please only use the dropdown definitions provided- do not cut and paste from other spreadsheets or manually add free text where a drop down list is provided	
Please refer to the explanatory notes on each sheet and on the final sheet which explains the dropdown categories in detail	
There are 3 parts to the data collection	
Enhanced Dashboard data- This is an expansion of NHS England Renal Indicator 3 - Access to Transplantation and looks at patient starting dialysis and whether they were listed at that point	
Transplant listing data- This look at all patients who were listed in a quarter, and when they were listed in relation to starting dialysis	
Summary- this is some additional data	

Screenshot 4:

Quarterly Data summary collection		Quarter ending					
Data	No in Quarter					Note	
	Total (nb should add up to total of next 3 columns)	Transplanted at UHB	Transplanted at UHCW	Patients transplanted at other units (Kidney alone)	Patients transplanted at other units (Kidney/Pancreas)		
Numbers of transplants	LD pre-emptive						
	LD Dialysis						
	CD pre-emptive						
	CD Dialysis						
Proportion transplant list suspended (Note this is for prevalent patients not just those new to list)	% of list suspended						
Proportion of CKD 5 patients who have a transplant status on the renal IT system Transplant status can include 1. Unsuitable, 2. Working up or under discussion, 3. On transplant list, 4. Suspended on transplant list							
Note optional breakdown by RRT type. If not broken down, complete totals only	Total number of patients	Number of patients with transplant status	Percentage of patients with transplant status				
HD							
PD							
Transplant with eGFR<15							
CKD5 not yet on dialysis							
Total							

Screenshot 5:

ENHANCED DASHBOARD	
Transplant Status	Explanatory notes
Active on list	
Suspended from list	
Unsuitable	Note patients who are currently unsuitable but may be later e.g due to weight can be put in this category
Working up or under discussion	
No documented decision	
Reason patient still "working up or under discussion" or "no documented decision"	Explanatory notes
Referred for Assessment when eGFR <15	Assessment means whatever local process begins process of assessment e.g review in an MDT clinic or dedicated assessment clinic. If this category is present it overrides all other categories. Include patients who may be suitable but no referral has been made
Referred for assessment within 1 year of predicted date of reaching ESRF	If this category present overrides all other categories except A
Patient DNA on at least 3 separate assessment appointments	Patient must DNA three separate appointments as part of process to fulfill this category
Medically Complex	Patient must have a medical condition which delays listing significantly or requires recovery/procedures prior or listing. Examples include requiring a CABG but would not include requiring a cardiology appointment and assessment.
Unsuitable for transplant but NOT documented	
Delays in system	Please comment on nature of delay
TRANSPLANT LISTING DATA	
Reason patient not listed pre-emptively	Explanatory notes
Referred for assessment when eGFR <15	Assessment means whatever local process begins process of assessment e.g review in an MDT clinic or dedicated assessment clinic. If this category is present it overrides all other categories.
Referred for assessment within 1 year of predicted date of reaching ESRF	If this category present overrides all other categories except A
Patient DNA on at least 3 separate assessment appointments	Patient must DNA three separate appointments as part of process to fulfill this category
Medically complex	Patient must have a medical condition which delays listing significantly or requires recovery/procedures prior or listing. Examples include requiring a CABG but would not include requiring a cardiology appointment and assessment.
Previously unsuitable but became suitable	Examples would include significant weight loss, recovery from cancer, cardiac surgery etc
Unplanned start	For purposes of this data include patients who were known to renal services less than 6 months before starting dialysis OR those known to renal services who's eGFR fell from 20 or over to dialysis in less than 6 months and that this fall was unpredictable*
Transferred in	Patient who was transferred to your renal service less than 6 months before listing*
Delays in System	Please comment on nature of delay
Patient Choice	
*NOTE we have used 6 months rather than 90 days due to the fact that unplanned start and unprepared patients often find transplant workup in addition to dialysis workup very psychologically stressful. Therefore it is not appropriate in all cases to push for rapid listing (NICE suggests within 12 months for unplanned start patients)	

Dataset

INDIVIDUAL PATIENT DATA	
1	Patient ID number
2	Transplant Listing status
3	Reason no Transplant Status
4	Reason patient not listed pre-empively
5	Date patient started dialysis
6	Date patient was transplant listed
7	Number of days from start of Dialysis to listing
8	Adjusted with pre-emptive listed = 0
SUMMARY DATA	
9	Number of Live donor pre-empive transplants done in this unit
10	Number of Live donor pre-empive transplants done elsewhere
11	Number of Live donor transplants (patient on dialysis)done in this unit
12	Number of Live donor transplants (patient on dialysis)done elsewhere
13	Number of cadaveric pre-empive transplants done in this unit
14	Number of cadaveric pre-empive transplants done elsewhere
15	Number of cadaveric (patient on dialysis) transplants done in this unit
16	Number of cadaveric (patient on dialysis) transplants done elsewhere
17	Number of patients on Transplant List
18	Number of patients on Transplant list who are suspended
19	Number of HD patients in the unit
20	Number of HD patients who have a transplant status recorded
21	Number of PD patients in the unit
22	Number of PD patients who have a transplant status recorded
23	Number of patients with a Transplant with eGFR<15
24	Number of patients with a Transplant with eGFR<15 who have a transplant status recorded
25	Number of patients with CKD5 not yet on dialysis
26	Number of patients with CKD5 not yet on dialysis who have a transplant status recorded
27	Total number of patients on HD, PD, Transplanted with eGFR <15, CKD5 not yet on Dialysis
28	Total number of patients on HD, PD, Transplanted with eGFR <15, CKD5 not yet on Dialysis who have a transplant status recorded

Appendix F – Standards and Guidelines

Transplant First

Standards & Guidelines for Renal Transplantation in the West Midlands

Final version - 091116

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Background

Standards and Guidelines for the assessment of patients for transplantation have been laid out by the Renal Association and the British Transplant Society. The current service specifications A06 and A07 also define standards for the identification, assessment and management of patients for renal transplantation; any future amendments or refinements to those service specifications should be implemented.

The purpose of this document is to establish a common guideline for all renal centres in the West Midlands to ensure all patients approaching or with end stage kidney disease have appropriate access to renal transplantation.

Patients on the transplant list require on-going management and annual assessment for suitability. Where patients are deemed unsuitable for transplantation or require temporary suspension consistency in practice should exist across the region.

Referral for transplantation listing

Identification of patients suitable for transplantation will occur locally by nephrologists in dialysis and CKD clinics. In those patients approaching end stage kidney disease (ESKD) discussion and local workup of transplantation should begin when eGFR falls below 20ml/min/1.732 or dialysis requirement is predicted to be <1year as part of ESKD counselling.

All discussions should be documented in patient record. Cardiac tests should be requested at this stage (see below).

Where it is deemed appropriate, the patient should be referred to the transplant centre at eGFR15 or when predicted to be within nine months of starting dialysis, whichever is sooner. Some patients will require earlier referral for assessment as clinically or logistically required.

All patients, whether suitable or not, with an eGFR of < 20ml/min/1.73m² or with ESKD should have a documented decision regarding transplantation entered into their patient record. For audit purposes this should be updated regularly to reflect for instance suspension or an 'under work up' status.

Opportunity for local discussion and counselling, including local transplant seminars should be available for patients when requested. This should include all transplant options including living donation.

Patients who are suitable for transplantation as well as those with uncertainty surrounding suitability should be referred to the transplant surgical team for formal assessment.

A referral letter containing relevant clinical details should be sent to the transplant unit (QEHB or Coventry) as well as a completed transplant proforma according to the transplant unit policy. Any specific requirements such as interpreter requirements, communication difficulties etc. should be noted. Patient's mobile phone contact details should be included at this stage to facilitate communication. Patient's blood group should be included to reduce delays.

Timelines

Local workup should proceed such that when referred, patients are suitable for listing. From receiving of referral to review in listing clinic should be <8 weeks and exceptions to this recorded.

Information

Patient information about transplantation should be available locally prior to referral.

Consent

Guidelines for consent have been published by the BTS. Written consent will be taken at the transplant centre and documented within the patient record.

Acceptance on the waiting list

Patients will be assessed for acceptance on the national waiting list. Renal association/BTS Guidelines “Assessment of the potential kidney transplant recipient” should be followed and assessment should be guided by European Best Practice Guidelines (NDT 15 supply 7).

Guidance for contraindications to transplantation listing includes:

- Life expectancy of <5years (unless failing access)
- For directed LD transplant life expectancy <2years if acceptable to donor and recipient
- Predicted graft loss >50% at 1 year
 - Specific individualised advice should be given and latest evidence used.
- Malignancy
 - All active malignancy
 - Melanoma, colorectal, breast within 5 years
 - Others within 2 years (excluding in situ carcinoma, BCC, SCC, incidental (non-metastatic) renal cancer once resected)
 - Specific advice may need to be sought for different malignancies
 - If asymptomatic no screening for prostate or native RCC is required
- HIV positive patients not treated with HAART or already progressed to AIDs
- Non-compliance considered sufficient to prevent adequate immunosuppression.
- BMI >40
 - BMI >40 unlikely to benefit from transplantation
 - BMI 35-40 a careful risk assessment should be made. Surgical complications are higher in patients with BMI >35. Local dietician input and formal obesity management are required. Patients should be assessed through careful consideration by surgical, nephrology teams and patient and risk assessment made.
 - BMI 30-35. Risk may be increased but transplantation listing should not be contraindicated.
- Significant co-morbidity such that the patient is unlikely to survive operation or tolerate immunosuppression without significant harm e.g.
- Severe LV dysfunction
- Severe untreatable vascular disease
 - Severe respiratory disease

- Patient does not want transplant
- In patients with the following conditions transplantation may need to be delayed pending adequate treatment
 - Active vasculitis
 - Anti GBM disease (while GBM antibody positive and 6 months after)
 - Active infection (e.g. within 1 year of TB, Hep B) refer to current guidelines.

In all patients careful assessment of co-morbid factors is required in order to assess the benefits versus the risks of transplantation. Whilst age is in itself not a contraindication to transplant older patients are likely to have increased co-morbidity and to tolerate complications less well and have higher peri-operative mortality.

The benefits of transplantation in older patients (>65) appear to be in quality of life rather than quantity of life. In some older patients who experience post-transplant complications quality of life may be decreased despite a successful kidney transplant. In practice many patients over 70 with co-morbidities are unlikely to be suitable for a transplant. In such patients this should be discussed prior to referral.

Cardiovascular assessment

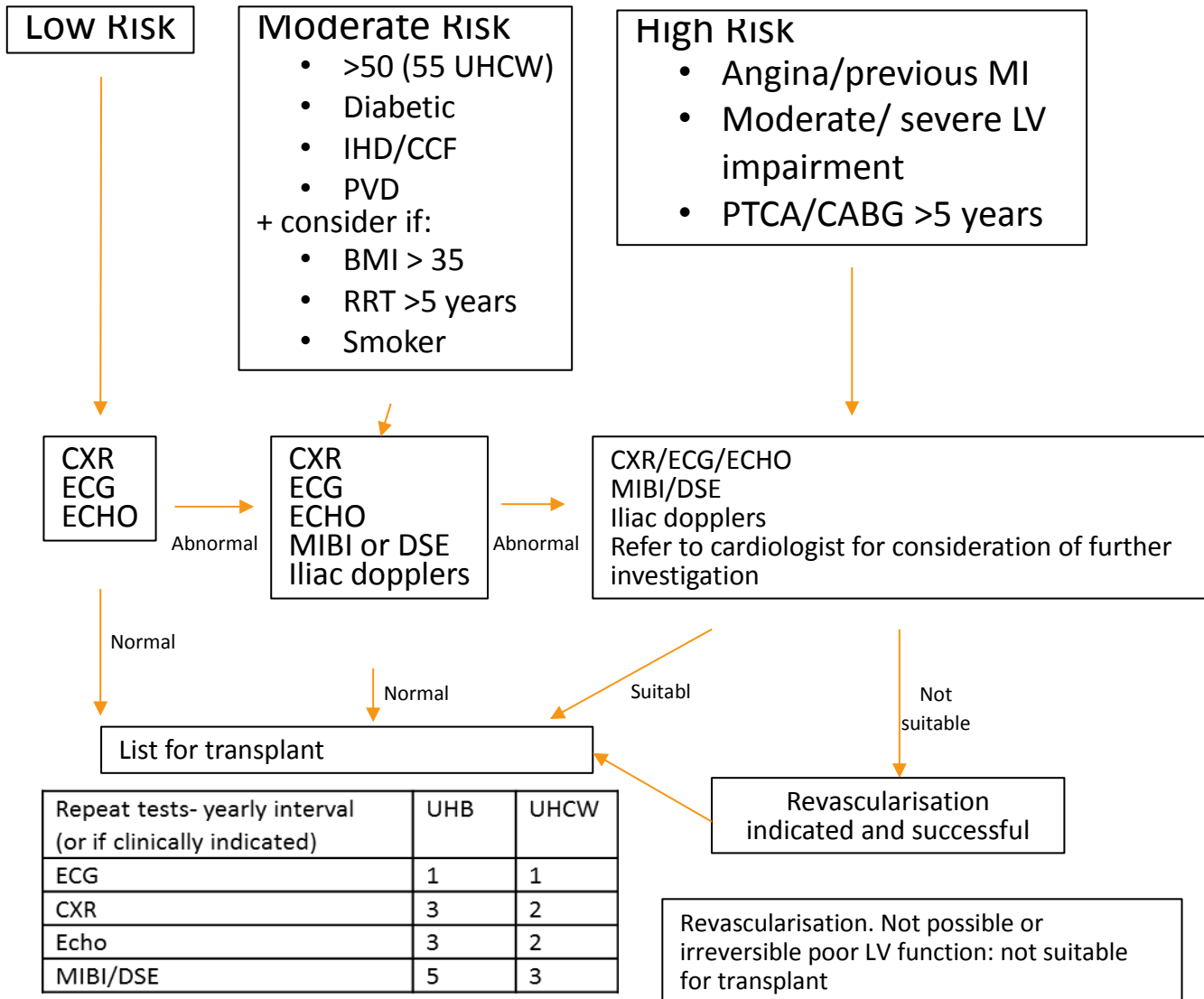
All patients require cardiovascular assessment prior to going on the transplant list. This should take place as part of the local assessment investigations organised with a referral to cardiology if required. The purpose of this assessment is to identify patients with significant cardiac disease and establish whether treatment is possible to reduce perioperative cardiovascular risk or whether disease is severe enough to preclude listing. It also facilitates anaesthetic assessment. Patients should be advised and supported to stop smoking or make other lifestyle modifications as appropriate.

The presence of cardiovascular disease is not an absolute contraindication as the risk of disease progression may be reduced by having a successful transplant.

Ideally Clopidogrel should be stopped prior to transplantation. This does not require stopping before referral and further discussion with the cardiologist as to the timing of transplantation following cardiac stenting can be addressed on an individual basis.

To prevent delays in activating patients onto the transplant list investigations should be performed following the flowchart as below and patients can be divided into those at low, moderate or high cardiovascular risk.

Patients can be divided into those at low, moderate or high cardiovascular risk:



NB LVH on echo counts as normal

Acceptance criteria – Living Donor kidneys

The outlined assessment process is for listing for cadaveric kidneys. However, some patients unsuitable for cadaveric transplantation may be suitable for live donor (LD) transplantation due to the ability to plan surgery, counsel risk and optimise clinical status to minimise the likelihood of complications. Patients who are unsuitable for a cadaveric transplant due to high risk of mortality or transplant loss may be considered for referral for LD transplant if predicted life expectancy post-transplant > 2 years.

Acceptance criteria – Desensitisation

ABO incompatible transplants do not represent a higher risk to the recipient and therefore acceptance criteria are the same.

Mortality is higher for HLA desensitisation transplants (around 5%). Patients should therefore in general be fitter than the standard criteria. However mortality with this procedure may still be less than remaining on the waiting list for a long period due to a low chance of transplantation because of high HLA sensitisation. Individualised decisions therefore need to be made. In general, patients should be advised about paired exchange prior to going for desensitisation. The ODT website tools should be used to determine the chance of transplant on wait list and paired exchange.

Waiting list review

Patients on the waiting list must be reviewed annually (including reiterating consent) and cardiac and other tests kept up to date. To ensure this service standard is met a reminder letter will be sent from the transplant centre to both the patient and nephrologist at 3 months prior to annual review date.

Patients without annual review by 3 months after the annual review date will be suspended until confirmation of review is made.

If any change in clinical condition occurs it should also be notified to the transplant team. Those with surgical risk will be reviewed in the transplant centre where required and additional risks reiterated and consent approved.

Discussion about living donors should be revisited at review clinic.

Suspension from the list

A patient's status on the transplant list should be reviewed:

- Whenever there is a change in the patients' medical condition
- Each time they are admitted
- During clinic visits

If a doctor / nurse decide that the patient should be suspended from the list this should be communicated to the patient. If there is any doubt this should be discussed with the responsible consultant and /or the transplant centre team/surgeon.

The transplant coordinators should be contacted to suspend the patient.

Out of hours the transplant recipient co-ordinator at UHB/UHCW should be contacted and the patients name, DOB and reason for suspension stated.

The reason for suspension and action taken should be documented in the patient notes by the person arranging the suspension.

Holiday/patient choice suspension

Patients who wish to be suspended through choice or for holidays will do this via the transplant nurses and coordinators. The following criteria are advised for holiday suspension:

Advice to Patients

- Patients on the transplant list will be asked to inform the recipient coordinator when they go on holiday. If they going outside the UK they will need to be suspended (see below)
- When a patient informs recipient coordinator about their UK holiday plans, they will be asked whether they want to be contacted if a kidney becomes available.
 - If no, patient will be suspended for the duration of their holiday
 - If yes, patients will be told they will need to be able to return to the transplant centre (Birmingham (Queen Elizabeth Hospital) or Coventry) in 4-6 hours depending on the kidney that is available for them

Advice to Clinicians

- Transplant status after travel: Patients who are active on the transplant list and who dialyse away from base (DAFB) outside the UK should be suspended from the transplant list for the duration of their holiday. Following dialysis or medical treatment in high risk countries, suspension is normally for 3 months and clinicians should refer to national DAFB guidelines. Patients should be informed locally of this need suspension when they are planning such travel.

Review of suspended patients

Local review of the list of suspended patients will occur weekly and further discussion / review facilitated if required to minimise delays in reactivation on the list.

Once clinical condition has improved to allow re-activation, the transplant nurse will communicate with transplant coordinators to reactivate the patient.

In complex cases the renal consultant will review them locally and communicate with coordinators and/or transplant surgeon. Further assessment and or counselling may be required.

When a patient is reinstated on the transplant list contact with the transplant unit coordinators and also with the patient should be documented.

Long term suspended patients should be reviewed in the wait list clinic 6 monthly and following 12months of suspension should be considered for removal from the list unless exceptions are noted.

If a patient is to be permanently removed from the list they will be offered an appointment locally to discuss and inform them of the reasons and further treatment options. An appointment to discuss with the transplant list centre may be made at patient's request.

Living donor transplantation

As stated above, all patients considered for referral for transplant listing should receive information regarding transplant options including living donor transplantation. In addition, where possible potential donors should be identified for an assessment.

It should be explained that different donor types may be possible including blood group incompatible, unrelated donation, paired donation and directed unrelated donation. The benefits of living donation, particularly better and longer graft survival with shorter wait times, including increased possibility of pre-emptive transplantation should be promoted as part of transplantation workup.

The risks to the donor should be explained in context and appropriate information made available. Donors should be allowed to make a voluntary and informed choice regarding donation and offers to assist this should be made by providing relevant information and contact details for discussion.

Donor workup

Full guidelines for donor workup are available from:

<https://www.bts.org.uk/Documents/Guidelines/Active/UK%20Guidelines%20for%20Living%20Donor%20Kidney%20July%202011.pdf> and these may be revised in 2016.

In those individuals coming forward as potential donors, initial contact should be through the donor coordinators who are best served to provide advice and direct the initial investigations. In addition advice regarding overseas donors will be available from the living donor coordinators and/or transplant nurses. In order to ensure pre-emptive transplantation and prompt live donation where possible, donor workup will often need to begin before a recipient is formally signed off as suitable by the transplant centre. Phase 1 testing of donors can be started by the Donor co-ordinator when they have been informed of probable recipient suitability by the treating nephrologist. However, donors should not have invasive tests (phase 2) until the recipients are known to be suitable for transplantation.

Donor assessment should be planned to reflect the wishes of the donor as far as possible and to minimise inconvenience Flexibility in terms of timescales, planning consultations, attending for investigations and date of surgery is helpful.

Assessment process should be achieved in a focused, coherent fashion with good communication between all parties. This is achieved most effectively by a designated co-ordinator.

The results of investigations should be relayed accurately, appropriately and efficiently to the potential donor. Emphasis should be placed on identifying unsuitable donors at the earliest possible stage of assessment.

A policy should be established for managing prospective donors who are found to be unsuitable and provision should be made for appropriate follow up and support.

To facilitate pre-emptive transplantation, donor evaluation should start sufficiently early to allow time for more than one donor to be assessed if necessary. Information should be provided at an early stage and discussion with potential donors and recipients should be started when the recipient eGFR is approximately 20 ml/min. Thereafter, recipient and donor assessment should be tailored according to the rate of decline in recipient renal function, taking into account disease specific considerations and individual circumstances.

According to BTS guidelines, an 18 week pathway should be followed from LD referral to operation unless exceptions occur. This is appropriate for all donors presenting for recipients who are already on the list. For those who are still in work up, the donor pathway may be appropriately longer to avoid them being worked up too soon and needing to repeat tests.

Donor evaluation should proceed according to BTS living donor guidelines.

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NHS England (2016) **Dialysis Away From Base (DAFB) Frequently Asked Questions** https://www.engage.england.nhs.uk/consultation/specialised-services-policies/user_uploads/dafb-faqs.pdf

UK Renal Association (2011) **Assessment of the Potential Kidney Transplant Recipient**, 2010, 5th edition Available from: <http://www.renal.org/guidelines/modules/assessment-of-the-potential-kidney-transplant-recipient#sthash.eGtAl92m.dpbs>

Appendix G – Guidelines for producing patient information

Transplant First Patient Information Guidelines – June 2017

Recommendations for patient information

Local Information leaflets may be appropriate particularly if work up is done outside of the transplanting units

General recommendations

- Ensure that the title of the leaflet clearly explains what it is about
- Clearly state in the opening paragraph who the information is for
- Only cover one treatment / condition in a leaflet
- Use every day non-technical language but if this is unavoidable ensure explanations are given for all medical terminology.
- Non frightening explanations and information - Help people make decisions by giving them facts
- Use patient friendly text – e.g. use pronouns such as ‘we’ and ‘you’
- Avoid confusing double negative statements
- Use Clear headings - Question and answer formats are useful as they split the text up
- Use bullet points or numbers
- Keep blocks of text and paragraphs short with white space around them as it makes them easier to read
- Do not use Serif fonts, italics or underlining as these can make it difficult to read
- Needs to look ‘good’ – not photocopied / no typing / spelling errors
- Ensure it is developed with and peer reviewed by patients
- For local information ensure that there are appropriate links back – contact details and telephone numbers, service email addresses are very useful and must be reviewed regularly to ensure they are up to date
- Patient information must be available in alternative languages or format if requested

Transplant specific recommendations

- Include encouragement to approach friends and relatives regarding donation
- Benefits of live versus cadaveric donation
- Benefits of transplantation versus long term dialysis

Nationally available patient information resources for kidney transplantation

www.britishkidney-pa.co.uk/information

www.kidneyresearchuk.org/health-information/kidney-transplantation

Living Donor specific leaflets - UKBT

Could I be a living kidney Donor?’ and ‘Can I donate a kidney to someone I don’t know?’

<https://www.nhsbt.nhs.uk/get-involved/promoting-donation-hub/download-digital-materials/organ-donation-graphics/>