Transplant First: Increasing pre-emptive listing and living donor kidney transplantation. How do we turn the dream into reality?

UKKW 2018 Pop up session

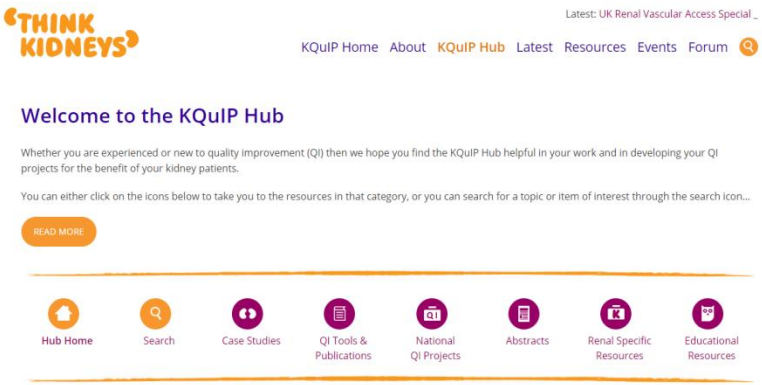
Kerry Tomlinson on behalf of KQUIP

Structure of session

- Aims and introduction
- Breakout 1: Barriers
- Transplant First and KQUIP
- Breakout 2: Solutions
- Summary

Aims

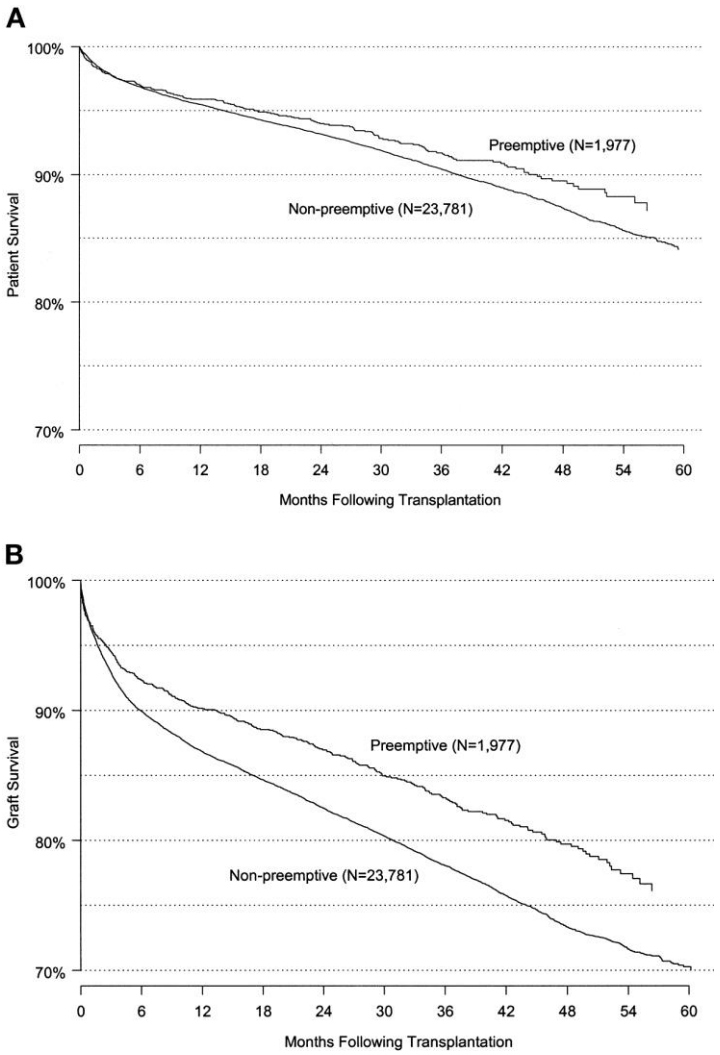
To improve our capability to increase access to transplantation as illustrated by the NHS Change Model



Why do pre-emptive kidney transplant listing and Living Donor Kidney Transplantation (LDKT) matter?

- UK Renal Association: Planning, Initiating and Withdrawal of Renal Replacement Therapy
- We recommend that all medically suitable patients should be informed about the advantages of pre-emptive living kidney transplantation and efforts made to identify a potential donor to allow pre-emptive transplantation before the need for renal replacement therapy

Why does pre-emptive listing matter?



Relationship between pre-emptive transplantation and outcomes among recipients of deceased donor kidney transplants.

Bertram L. Kasiske et al. JASN 2002;13:1358-1364

JASN

Does pre-emptive transplantation versus post start of dialysis transplantation with a kidney from a living donor improve outcomes after transplantation? A systematic literature review and position statement by the Descartes Working Group and ERBP

	Pre-emptive better	Same	Not clear
Patient survival	47%	21%	31%
Graft Survival	56%	9%	34%
Acute Rejection	77%	15%	8%
Delayed Graft Function	2-3.37%		4-9.7%

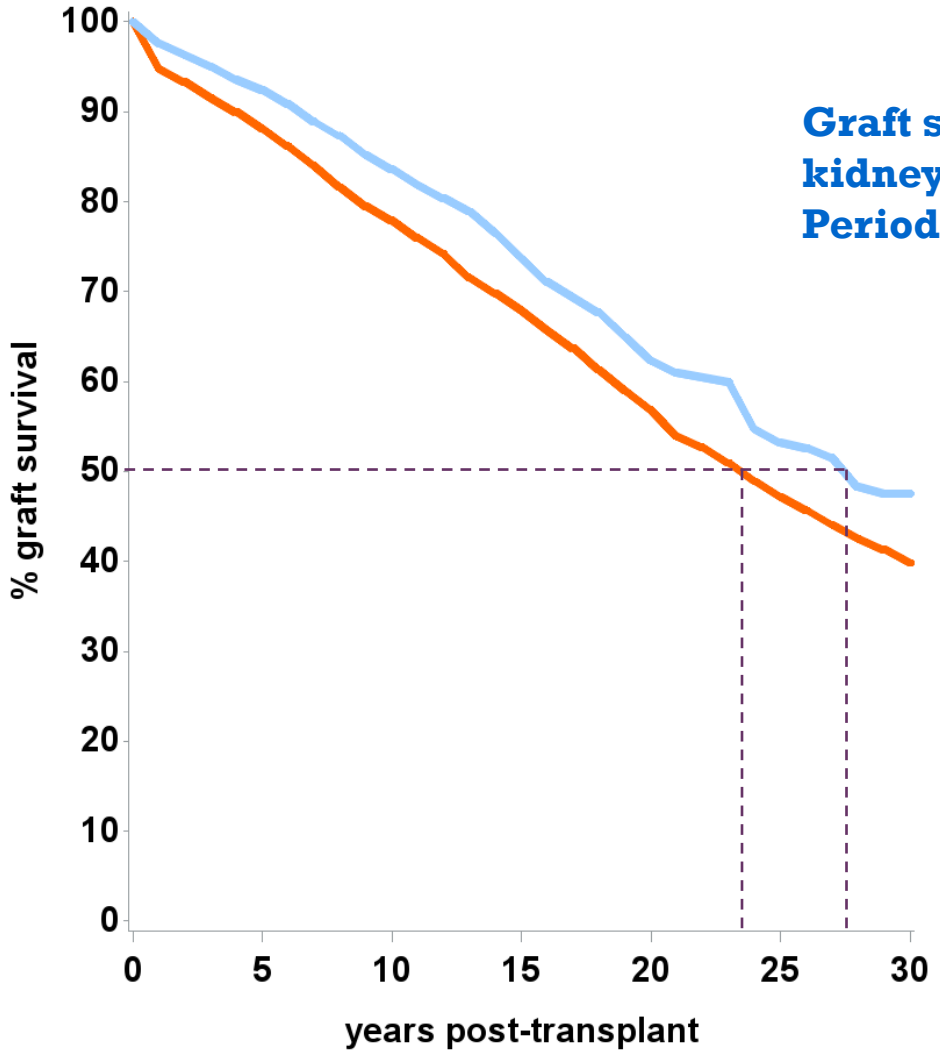
Within 1 year of dialysis probably makes little difference

Nephrology Dialysis Transplantation, Volume 31, Issue 5, 1 May 2016, Pages 691–697

Improving pre-emptive listing is not about:

- Transplanting people earlier than is good for them
- Changing listing criteria
- Favouring the care of pre-emptive patients over those on dialysis

Why does Living Donor Kidney Transplantation matter?



Graft survival estimates following kidney transplant
Period analysis, 01Apr12 – 31Mar16

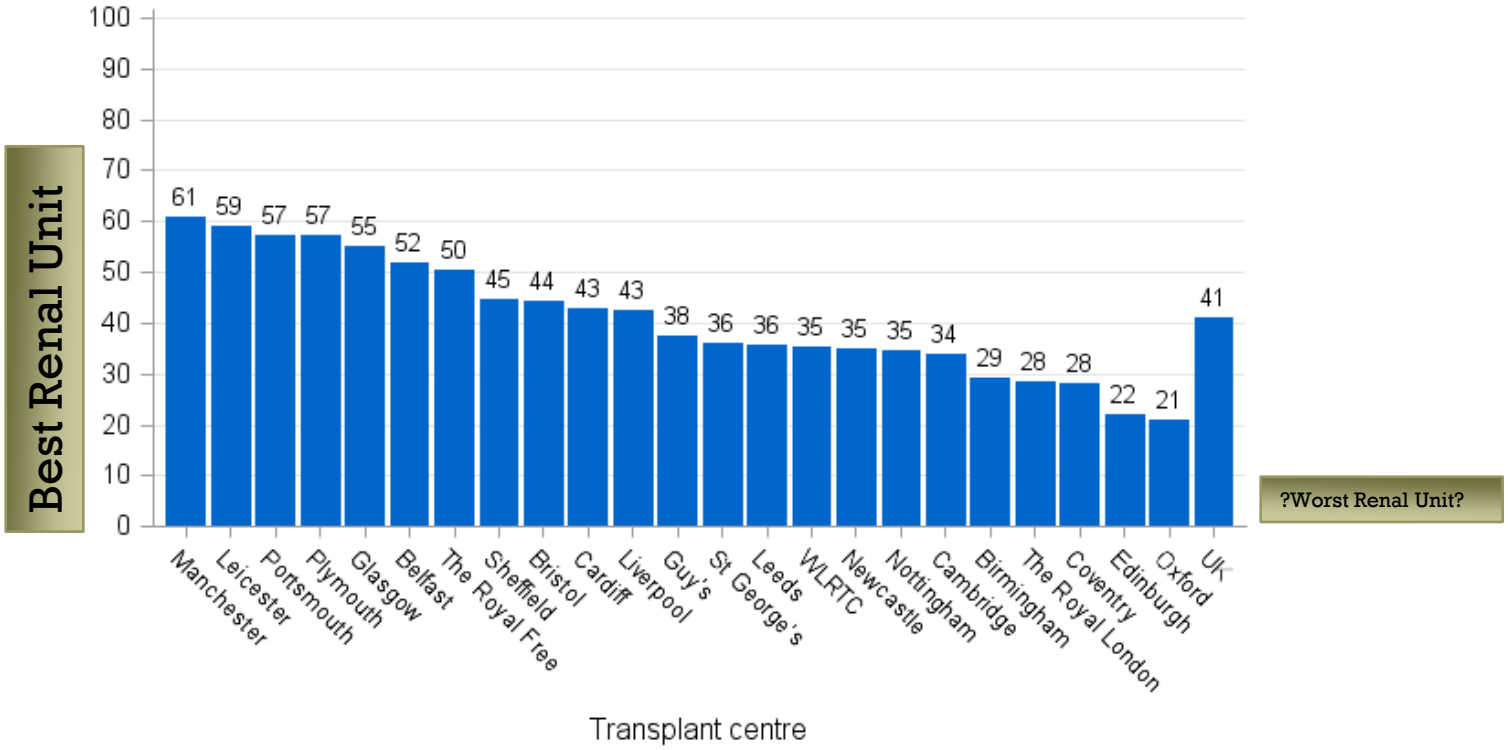
Median survival estimates:
Living donor ~ 27 years
DBD donor ~ 23 years

Increased numbers of transplants

Variability, Variability, Variability

NHS Blood and Transplant

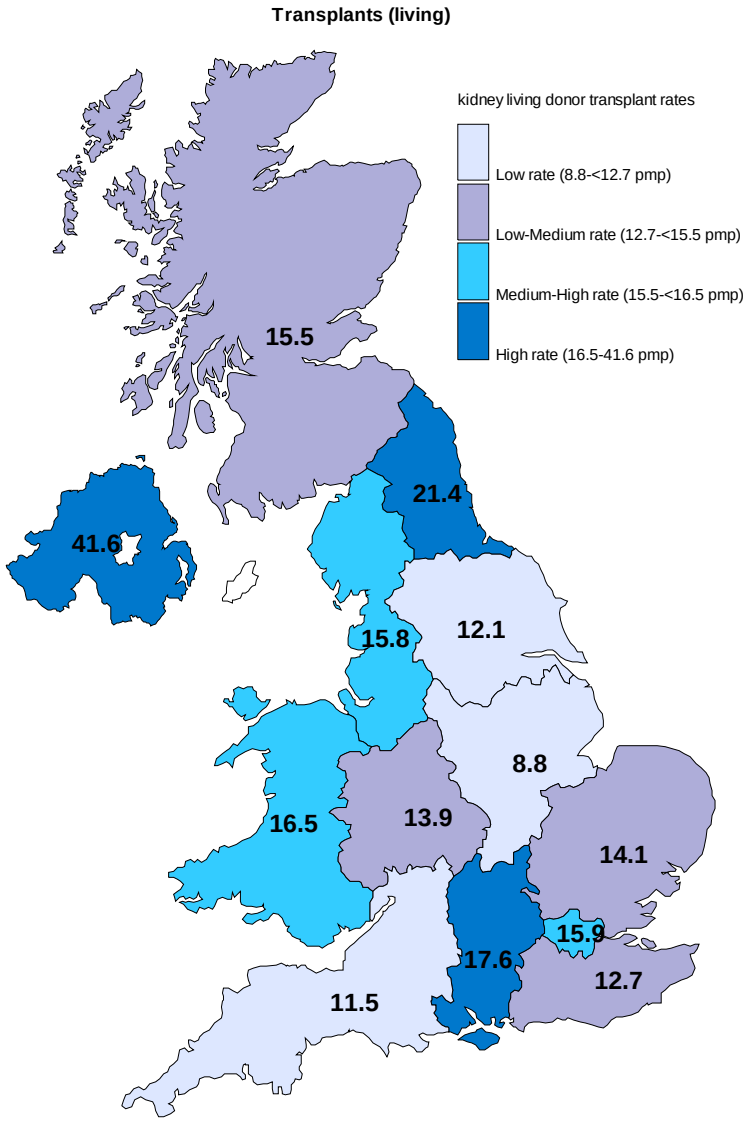
Figure 3.11 **Adult pre-emptive listing rates by centre, registrations between 1 April 2015 and 31 March 2016**



Source: Annual Report on Kidney Transplantation 2016/17, NHS Blood and Transplant

Figure 2.7 **Living donor kidney transplant rates (pmp) by recipient country/Strategic Health Authority of residence**

NHS Blood and Transplant



Source: Annual Report on Kidney Transplantation 2016/17, NHS Blood and Transplant

- Your chance of getting a LDKT, getting on the transplant list in a timely fashion and getting a pre-emptive transplant varies widely in the UK

- Is that acceptable?

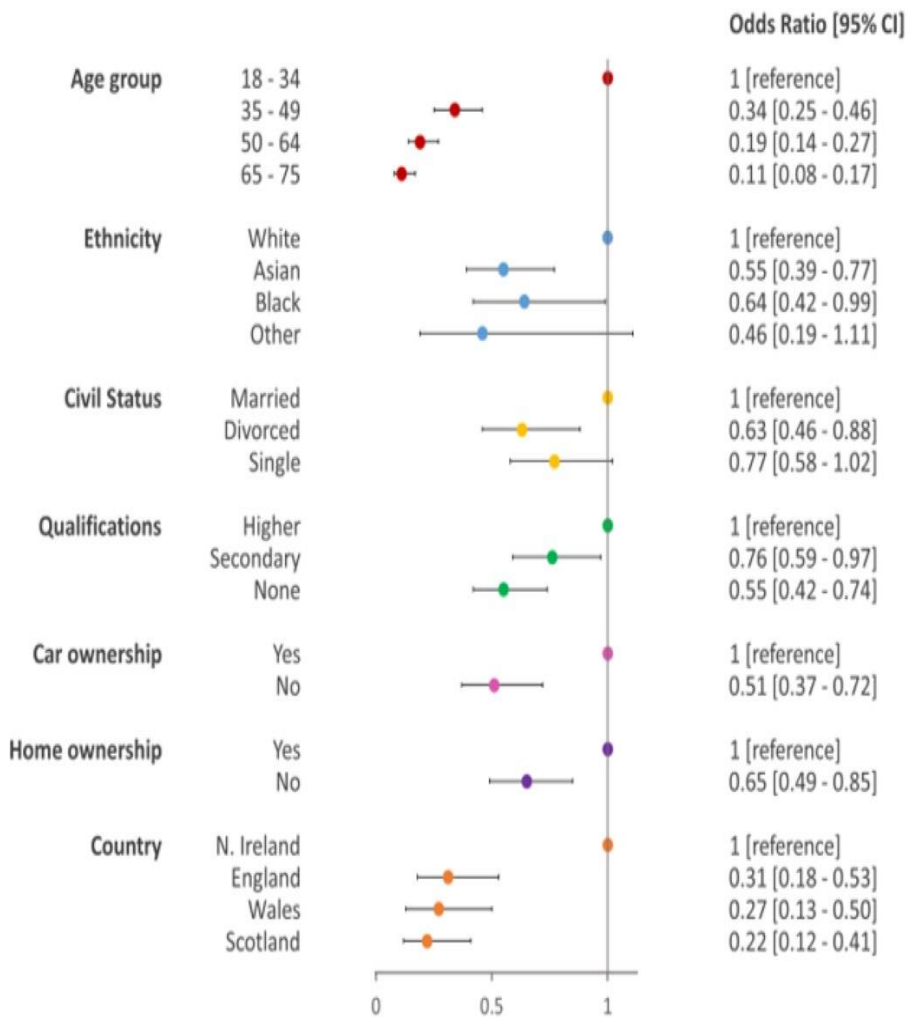
- Why might that be?

What we know
ATTOM: Patient factors associated with pre-emptive listing

- Age>50
- Ethnic group (Asian and Black)
- BMI(>35)
- Education
- Car Ownership
- Accommodation
- Employment
- Time First seen by nephrologist
- Diabetes
- Cerebrovascular disease
- Vascular Disease
- Malignancy
- Heart Disease
- Heart Failure
- Current Smoker

ATTOM: Factors associated with LDKT

Limited health literacy



Why does it matter to us?

- Better outcomes for limited resource
- Pride in doing a job well
- GIRFT and Peer review are on their way..

Why does it matter to us?

"When my kidneys failed, getting a kidney transplant became the most important thing that I had ever wanted in my life. I have never wanted anything more and never will. Each step of the way I was accompanied by a desperate longing for it to happen, and every setback and delay was something I felt acutely, and caused a lot of anxiety"

Breakout session 1

- Rules of engagement
- Be open (even if you think you know the answer)
- Be non-hierachical
  - Transplanting and non-transplanting
  - Consultants and MDT
- If you are talking all the time stop (particularly consultants)
- The silent member holds the key?

Breakout session 1

- What are the barriers to improving access to pre-emptive transplant listing in your unit

- What are the barriers to improving access to Living Kidney Donor transplantation in your unit

ATTOM: Centre factors associated with transplant listing

- Centre variables linked to pre-emptive listing were
  - Being a transplant centre
  - Number of consultant nephrologists
  - Whether transplantation is discussed with all patients
- Centre variables linked better access to listing after dialysis were
  - Number of consultant nephrologists
  - Written protocol

Barriers to LKDT

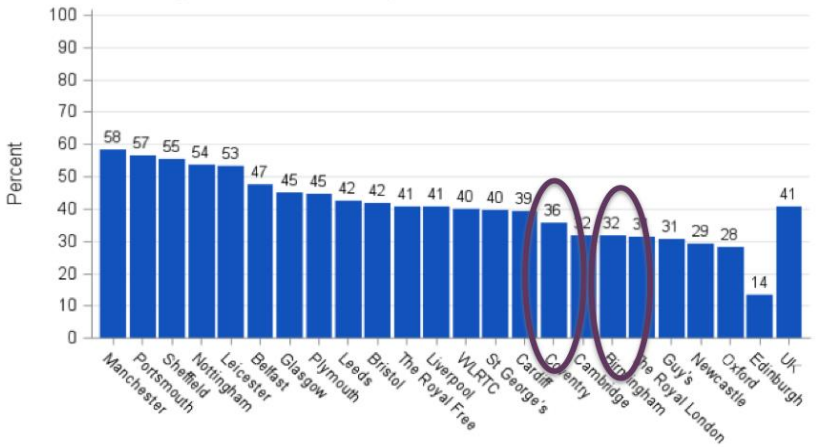
- Lack of accessible information
  - GP lack of knowledge
  - Uncertainty about information resources
  - Donors coming forward unaware how to access teams
  - Uncertainty about information resources
- Pathway issues
  - Not giving information upstream e.g. in low clearance clinic
  - Not being able to do all workup locally
  - Radiology department schedules
  - Batching donors
  - Complexity/length of pathways
  - Ability to personalise (e.g. out of hours appointments)
  - Matching donor and recipient timelines- especially if done across two centres
- Resources/Finance
  - Location of HTA assessors and Psychologists
  - GP responses to queries delayed
  - Limited resource (staffing or money for tests)
  - Living Donor Co-ordinator (LDC) time
  - LDCs often single handed- back up for donors when they are away
  - Parts of pathway not funded in non-transplant units
- Skills/Knowledge
  - How to discuss recipient concerns for donors
  - Transplant expertise in low clearance settings
  - Accessing UK Living Donor kidney Sharing Scheme
- Uncertainty
  - Perception of risk and how to convey it meaningfully
  - Whether to contact donors

Transplant First in the West Midlands

NHS England
West Midlands Clinical Network

NHS Blood and Transplant

Figure 3.11 Adult pre-emptive listing rates by centre, registrations between 1 April 2013 and 31 March 2014

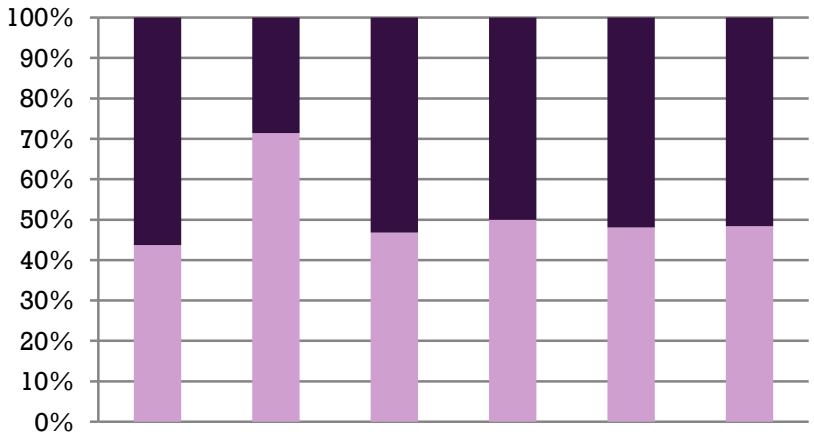


Think Kidneys · 26/04/2018
Lots more sharing ideas about process/ transplant pathway #transplantfirst looking at the question What are the issues?

Transplant First · 26/04/2018
Really proud of the West Midlands kidney transplant community today. Showing changes they have made and plan to make to improve transplantation and living donation. Working together ! 👍 @ThinkKidneys @westmidskidney #Transplantfirst

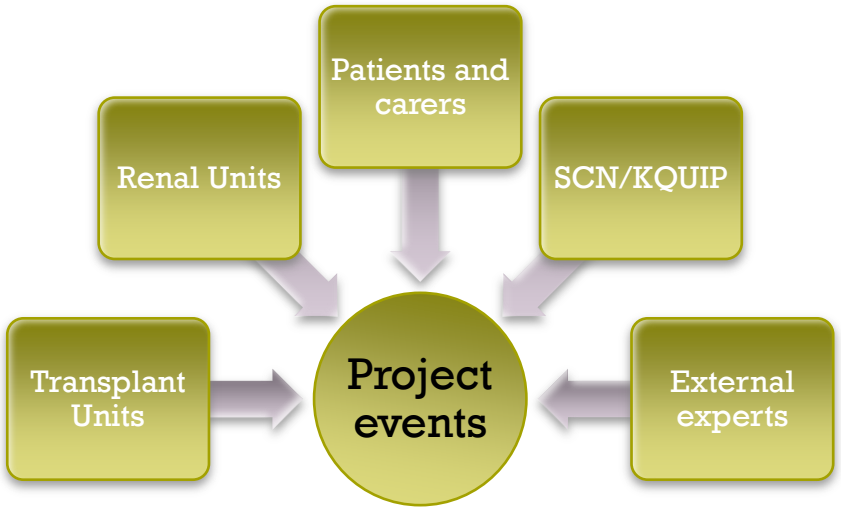
4 10

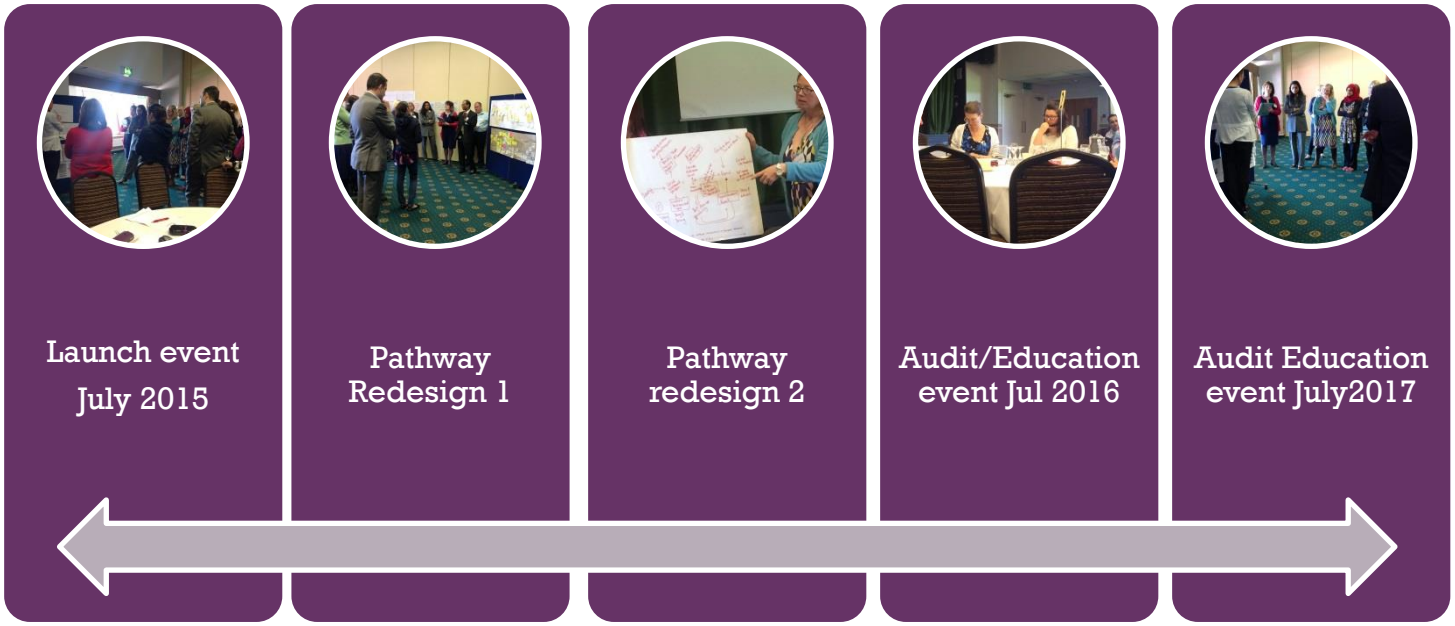
Pre-emptive transplant listing from each renal unit April 17-Dec17



Renal Units

What did we do?





Early agreement

Launch event July 2015

Valuable time

Pathway Redesign 1

BMI debate

Pathway redesign 2

Audit/Education event Jul 2016

Unit feedback

Audit Education event July2017

Honest discussion

Handover points

Cardiac catheter abstract

Quick Wins

Patient Voice

Sponsor team meetings, conference calls, working with RR, subgroup meetings, contact with units etc

Transplant First and KQUIP

THINK KIDNEYS

KQuIP Home About KQuIP Hub Latest

Transplant First! Enhanced Dashboard Data Transplant listing data Summary Charts 2018 Q2

Enhanced dashboard data (2018 Q2)

INCLUDE All patients in unit who started Haemodialysis or Peritoneal Dialysis for established renal failure in the quarte
Failure.
INCLUDE patients who start haemodialysis or peritoneal dialysis for established renal failure.
INCLUDE patients with a failing transplant who start dialysis in the quarter

EXCLUDE from any patient who had first been seen by the Nephrologist less than 90 days prior to starting dialysis (for
EXCLUDE patients who start haemodialysis or peritoneal dialysis for acute kidney injury.

ID no	Status	Reason	Comment
1	Working up or under discussion	Referred for Assessment when eGFR < 15	
2	Active on list		
3	No documented decision	Patient DNA on at least 3 separate assessment Appointments	
4	Working up or under discussion	Medically Complex	
5	Working up or under discussion	Referred for Assessment when eGFR <	

KQuIP National Projects

Following input from the renal community KQuIP will be focusing on three priority areas for national quality improvement projects. These projects are all at different stages of development and further details on each one ca be found below.

Transplant First

Improving access to kidney transplantation. Pre-emptive transplant listing and kidney transplantation rates vary across the UK. Transplant First has been developed in the West Midlands by the West Midlands Clinical Network. Read more about Transplant First here.

Measurement for improvement and RCA

Data : Enhanced Dashboard RCA

(It's taken ages so I am telling you about it whether you like it or not!)

West Midlands Strategic Clinical Network *Transplant FIRST*

Renal Unit	Stoke - North Midlands
Contact Email	

List all patients who started Dialysis , HD or PD in quarter who fit inclusion criteria - ending 31/12/15 (nb total should be same as denominator for dashboard return)

ID no Renal unit use only (do not include hosp or NHS no)	Transplant status (choose one for each patient)	Reason patient still "working up or under discussion" or "no documented decision" (if you have chosen one of these catagories in previous column please choose category from drop down list)	Comment
1	Active on list		
2	Suspended from list		
3	Unsuitable		
4	Working up or under discussion	Referred for Assessment when eGFR < 15	
5	No documented decision		
6	Unsuitable		
7	Working up or under discussion		
8	Unsuitable		
9	Suspended from list		
13	No documented decision	Unsuitable for transplant but NOT documented	
14	Working up or under discussion	Referred for Assessment when eGFR < 15	
15	Working up or under discussion	Referred for assessment within 1 year of predicted date of reaching ESRF	
16	Working up or under discussion	Patient DNA on at least 3 separate assessment Appointments	
17	Working up or under discussion	Medically Complex	
18	Working up or under discussion	Delays in system	

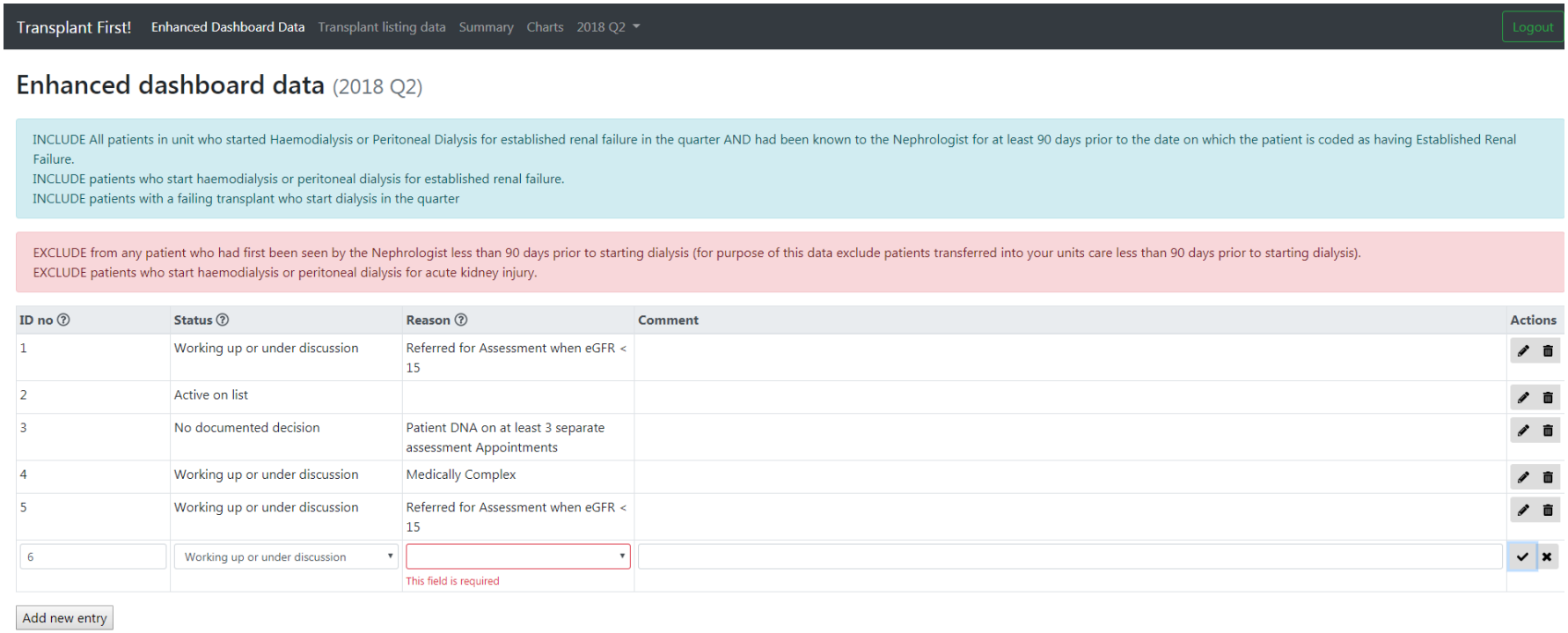
Must complete if 'Working up or under discussion' or 'No decision documented' in previous column - Transplant status

Data: Transplant listing RCA

List all patients who were registered on the renal transplant list in quarter no matter how long the had been on dialysis or if they were pre-emptive

ID no Renal unit use only (do not include hosp or NHS no)	Date patient started dialysis	Date patient was transplant listed	Number of days from start of RRT to listing	Adjusted with pre-emptive listing =0	For all patients who have not been listed pre-emptively please give reason from drop down list
1		30/01/2017	0	0	
2	07/07/2015	18/01/2017	551	551	Medically complex
3		14/03/2017	0	0	
4	15/12/2016	20/02/2017	65	65	Referred for assessment within 1 year of predicted date of reaching ESRF
5		20/03/2017	0	0	
6		15/04/2017	0	0	
			0	0	
			0	0	Referred for assessment when eGFR <15
			0	0	Referred for assessment within 1 year of predicted date of reaching ESRF
			0	0	Patient DNA on at least 3 separate assessment appointments
			0	0	Medically complex
			0	0	Previously unsuitable but became suitable
			0	0	Unplanned start
			0	0	Transferred in
			0	0	Delays in System
			0	0	
			0	0	
			0	0	
			0	0	
			0	0	

In development



Lessons learnt from data

- Transferable causes for missing listing:
  - Late referrals (Predictable but rapidly declining patients)
  - Failing transplants
  - Different approaches to cardiac angiography pre-dialysis
  - Referral to other specialties slows listing

It only works if you use it locally

- Local causes for missing listing :
  - Specific clinics (e.g. diabetes multi-disciplinary)
  - Different feeder hospitals
  - Other reasons that will be apparent locally e.g. variable unit practise

ATTOM: Patient factors associated with pre-emptive listing

- Age>50
- Ethnic group (Asian and Black)
- BMI(>35)
- Education
- Car Ownership
- Accommodation
- Employment
- Time First seen by nephrologist
- Diabetes
- Cerebrovascular disease
- Vascular Disease
- Malignancy
- Heart Disease
- Heart Failure
- Current Smoker

Transplant First: Improve understanding of barriers to transplantation in your unit and remove them

ATTOM: Centre factors associated with transplant listing

- Centre variables linked to pre-emptive listing were
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www.thinkkidneys.nhs.uk/kquip/wp-content/uploads/sites/5/2017/04/Transplant_First_Standards_and_Guidelines_Final_version_091116.pdf

Breakout session 2

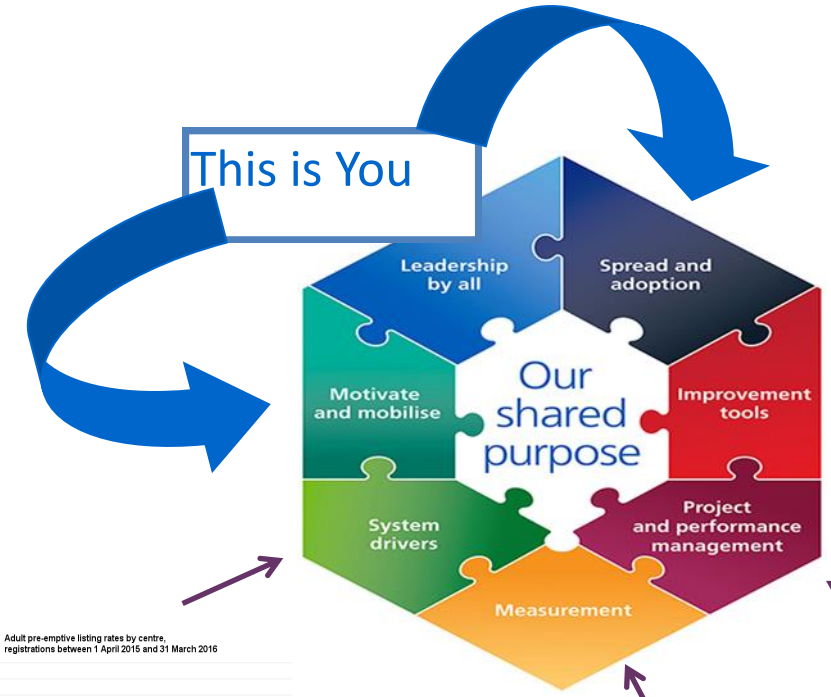
- What actions can you take to improve access to pre-emptive transplant listing in your unit?

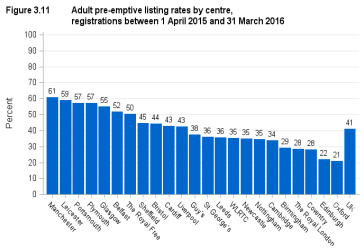
- What actions can you take to improve access to Living Kidney Donor transplantation in your unit?

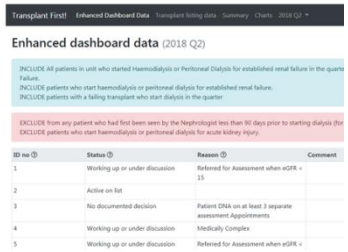
Changes, ideas and learning from Transplant First project (see handout)

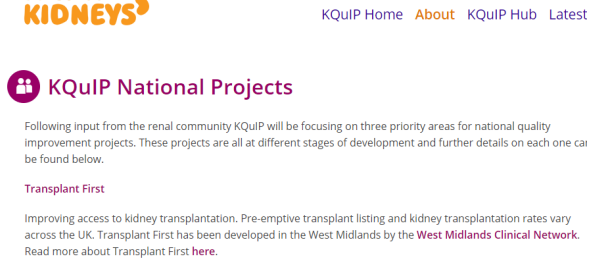
- Appointing lead nurse and doctor for transplantation in each renal unit (now mandated)
- Appointing transplant co-ordinator
- Centralising referrals to transplant centre via one e mail address
- Sending patients mobile with referrals so they could be texted to avoid DNA
- Joint assessments clinics 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 practice (e.g. early cardiology assessment) to encourage adoption

Go forth and multiply!









Transplant First: Thanks to everyone working to improve access to transplantation