Transplant first: Addressing inequality of access to renal transplantation across the West Midlands

Kerry Tomlinson on behalf of sponsor group

East Midlands KQUIP/UKRR regional day

Background: identifying the problem

Stoke 63% listed pre-emptively

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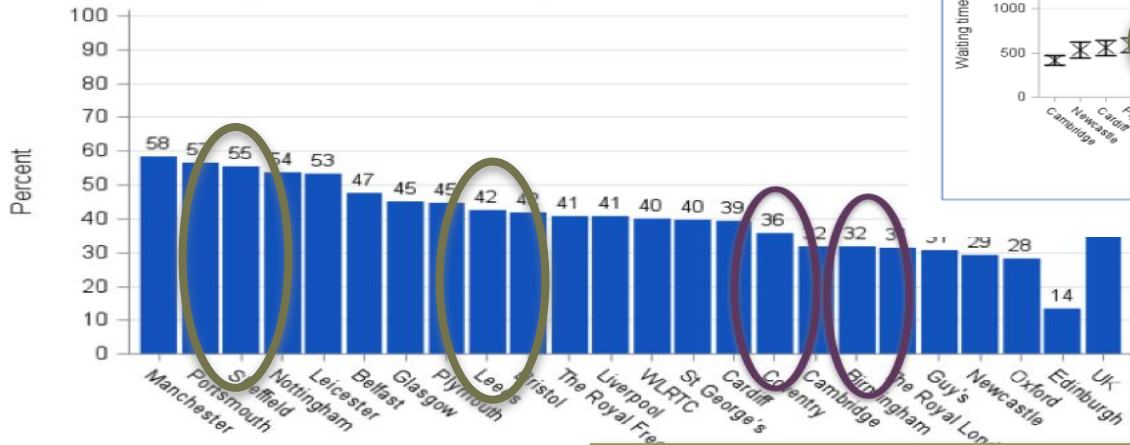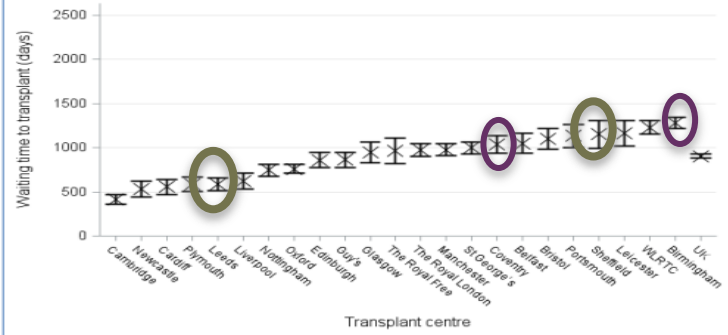

Figure 3.10 Median waiting time to deceased donor transplant for adult patients registered on the kidney transplant list, 1 April 2010 – 31 March 2013
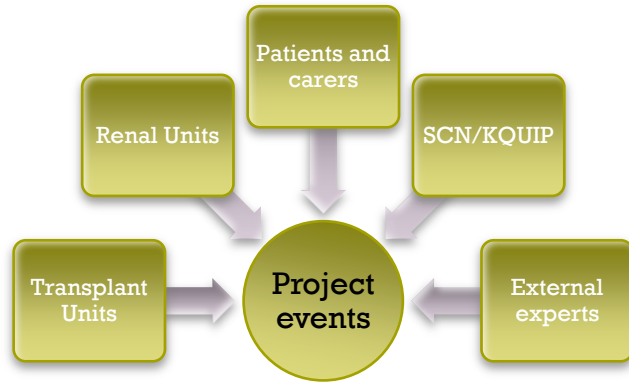
- UK RR 2014 report median time to listing
- 488, 598, 641, (683), 712, 765, 787, 867
- Y&H (147-1049)

+ Patient Voice

"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"

What did we do?

Patients and carers
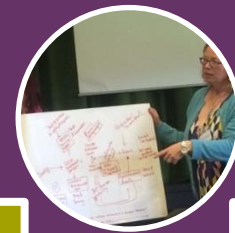
Renal Units

SCN/KQUIP

Transplant Units

Project events

External experts

Launch event July 2015

Pathway Redesign 1

Pathway redesign 2

Audit/Education event Jul 2016

Audit Education event July2017

Early agreement

Valuable time

BMI debate

Unit feedback

Launch event
July 2015

Pathway
Redesign 1

Pathway
redesign 2

Audit/Education
event Jul 2016

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

Project S...

Sponsor Team

Data, measu...
- Identify data
- Agree forma... donor, decea...
- Identify repo...
- Develop infra... without a tra...

Sta...
- Id... cr...
- Id... g...

Pa...
- M...
- C...

Patient inform...
- Collate infor...
- Identify any ...

Education (C...
- Identify train...
- Source/desig...
- Establish act...
- Design first t...

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

Donor Patient View

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.organdonation.nhs.uk/about-donation/living-donation/

transplantation to 2020

LDKT 2020

+ Data : Enhanced Dashboard

(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

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
					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
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	

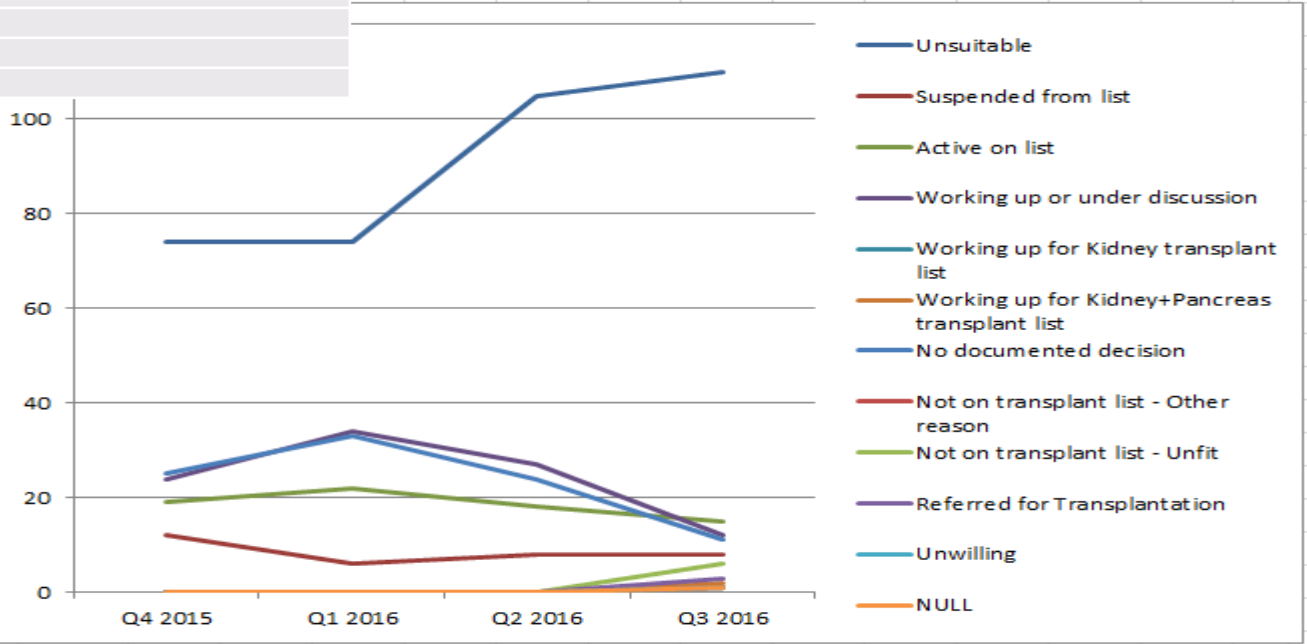# + Barriers to using data effectively

- Time

- It is **extremely** difficult to develop data set (anyone starting project now won't have to!)
  - Definitions (I am sure people will disagree with them!)
  - Collection
  - Collation (Discussions with RR but needs oversight)

- Tendency to justify exceptions (balance between wanting data to look good and using it to improve)

- Separation between people filing in data and those doing project

What are you doing with the data from the dashboard?		
Answer Options		**Response Count**
		3
answered question		3
skipped question		2

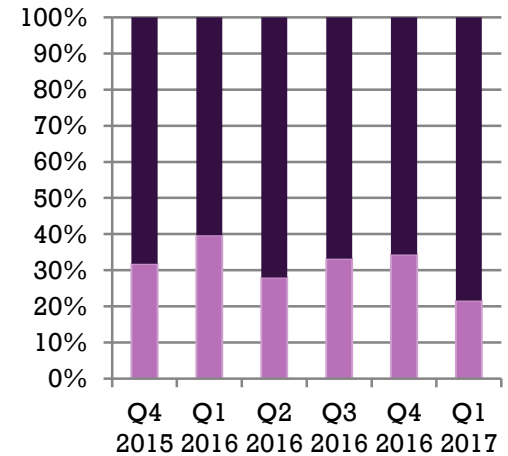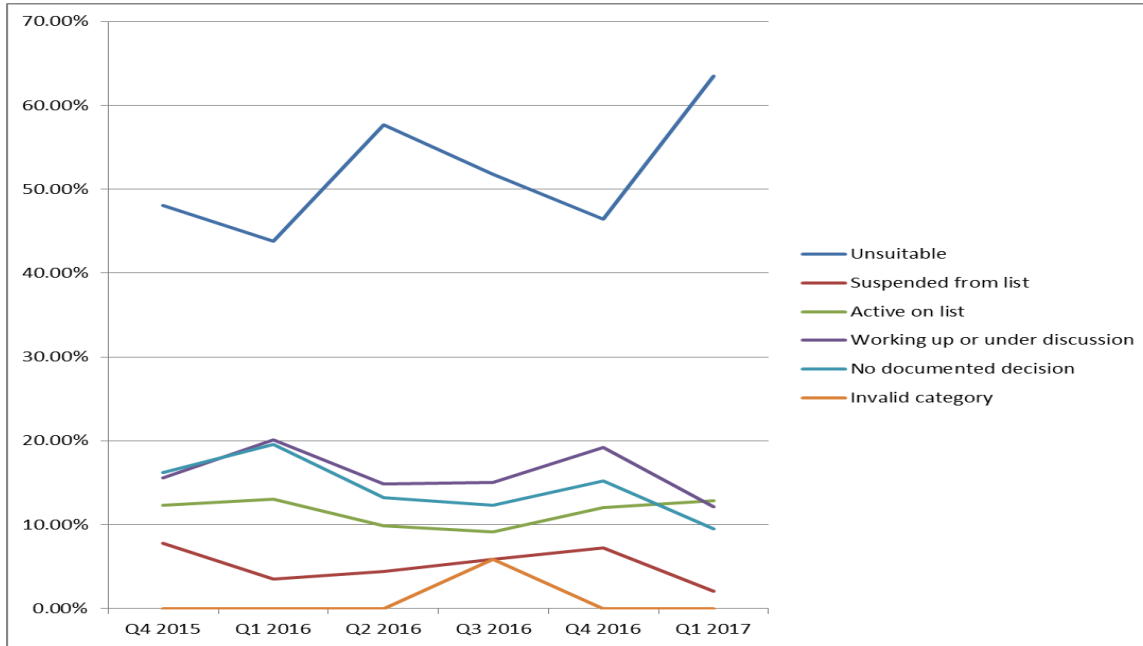| Number	Response Date	Response Text	Categories
1	Dec 2, 2016 10:56 PM	not using dashboard	
2	Dec 1, 2016 1:21 PM	i am not involved	
3	Dec 1, 2016 7:35 AM	look at it monthly and make small QI changes to see if we can improve listing process	

It only works if you use it locally

Cut and Paste: Argghhhh!!!

Active on list
Suspended from list
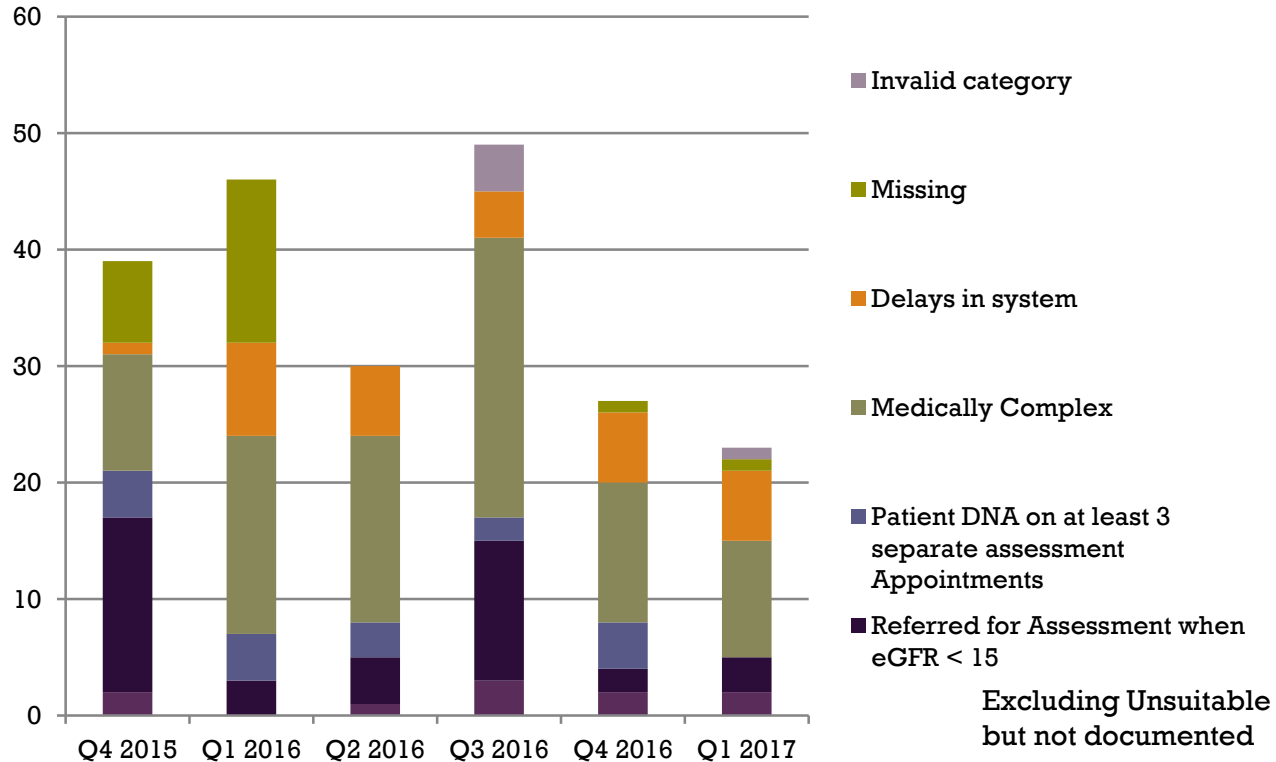Unsuitable
Working up or under discussion
No documented decision
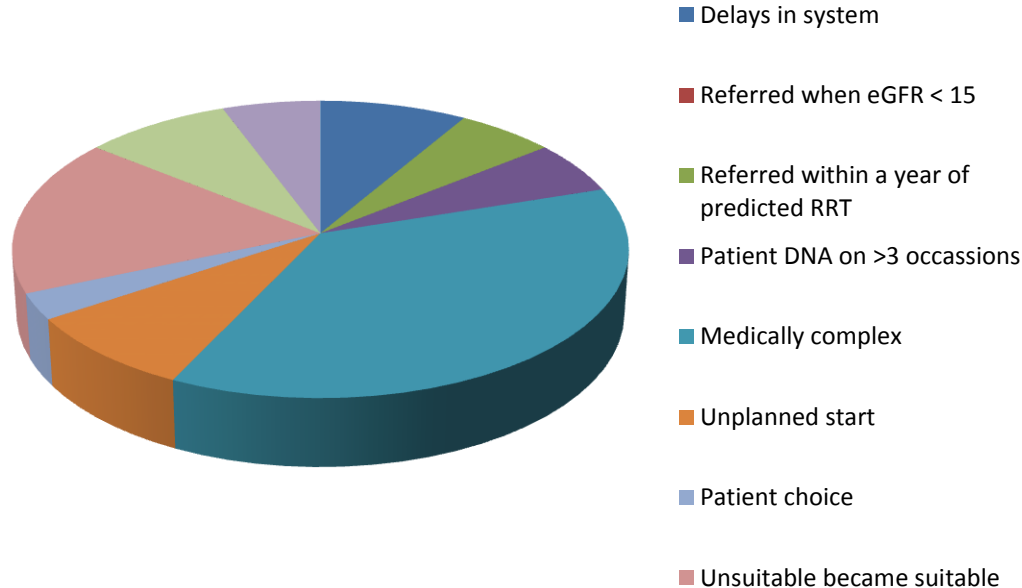
Transplant status from Enhanced dashboard

Legend:
- Unsuitable
- Suspended from list
- Active on list
- Working up or under discussion
- No documented decision
- Invalid category

"Missed" patients

Reason patients are "missed"

Legend:
- Invalid category
- Missing
- Delays in system
- Medically Complex
- Patient DNA on at least 3 separate assessment Appointments
- Referred for Assessment when eGFR < 15

Excluding Unsuitable but not documented

Reason given why patients were not listed pre-emptively

Q12017

- Delays in system
- Referred when eGFR < 15
- Referred within a year of predicted RRT
- Patient DNA on >3 occassions
- Medically complex
- Unplanned start
- Patient choice
- Unsuitable became suitable

+ Lessons learnt from data

- **Transferable causes for missing listing:**

    - **Failing transplants**

    - **Predictable but rapidly declining patients**

    - **Different approaches to cardiac angiography pre-dialysis**

    - **Referral to other specialties slows listing**

- **Local causes for missing listing :**

    - **Specific clinics (e.g. diabetes multi-disciplinary)**

    - **Different feeder hospitals**

    - **Other reasons that will be apparent locally**

It only works if you use it locally

eGFR at referral to seminar 2012

	Listed within 90 days of RRT	Listed > 90 days post RRT
Stoke	19	8
Leighton	17	9

Approximately 50% late referral avoidable

Positive stories

Transplant First - West Midlands Strategic Clinical Network

Do you think that the Transplant First project has enabled your unit to increase access to transplantation?		
Answer Options	**Response Percent**	**Response Count**
Yes	100.0%	5
No	0.0%	0
answered question		**5**
skipped question		**0**

Do you think that the Transplant First project has enabled your unit to increase access to transplantation?

- Yes
- No
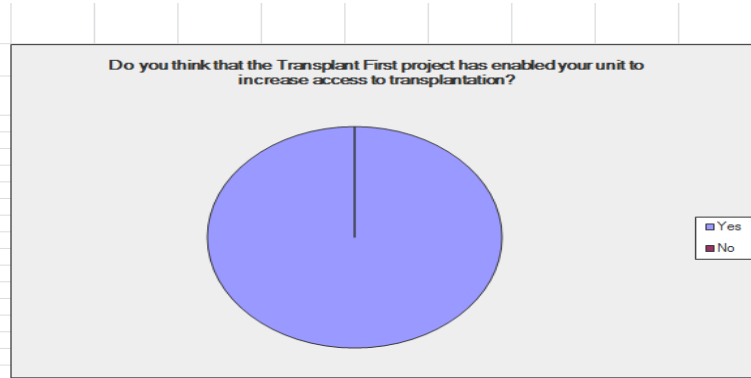
Working with other units to improve transplantation and work together for a better patient experience

Better collaborative working to improve patient experience

Highlighted pathway delays and led to re-design

We now have a Transplant Coordinator in post

Improving transplant profile for staff and patients

Better data to influence decisions

How sponsor team have found it

- Time needed can't be overestimated

- Project support is key (Changed from SCN to KQUIP half way through)

- Different Transplant Unit approaches to involvement

- Have to rely on engagement of units and work hard to keep enthusiasm

- Patient engagement is difficult both in breadth and sustainability

- Data collection is very difficult

- Getting feedback can be difficult

- On-going need for human interactions and mediation

Barriers from Unit perspective

Lack of time for individual units to discuss changes

Consultants

Would like more personalized input

Software barriers

Change in unit personnel

Would like more interaction

Staffing shortages

Role of ongoing QI education

What will we achieve? (Is it working?)

95% of all CKD 5 patients will have a documented transplant decision

West Midlands will achieve >95% patients starting RRT with a transplant status

> 50% of patients will be listed pre-emptively

The West Midlands will have the highest rate of pre-emptive listing in the UK

The wait for deceased donor kidneys in the West Midlands will be in line with the national average or better

We will be in the top 50% of transplant units for pre-emptive transplants

% of CKD 5 patients with recorded transplant status on IT system

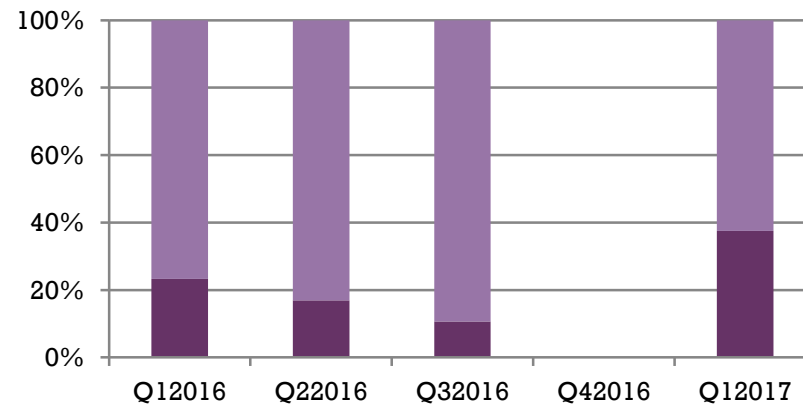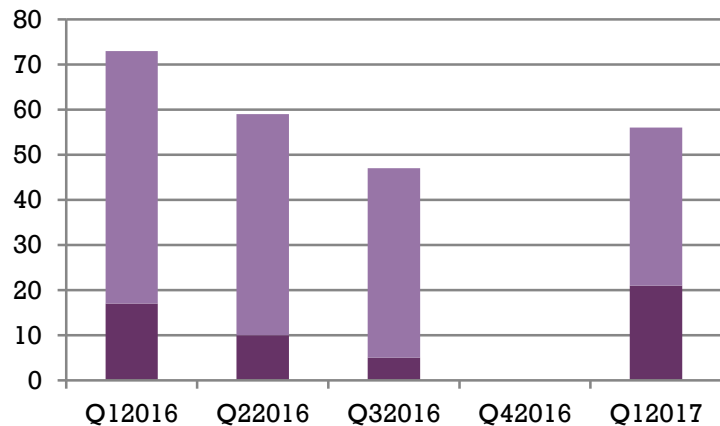West Midlands will achieve >95% patients starting RRT with a transplant status

UHB listings from all units
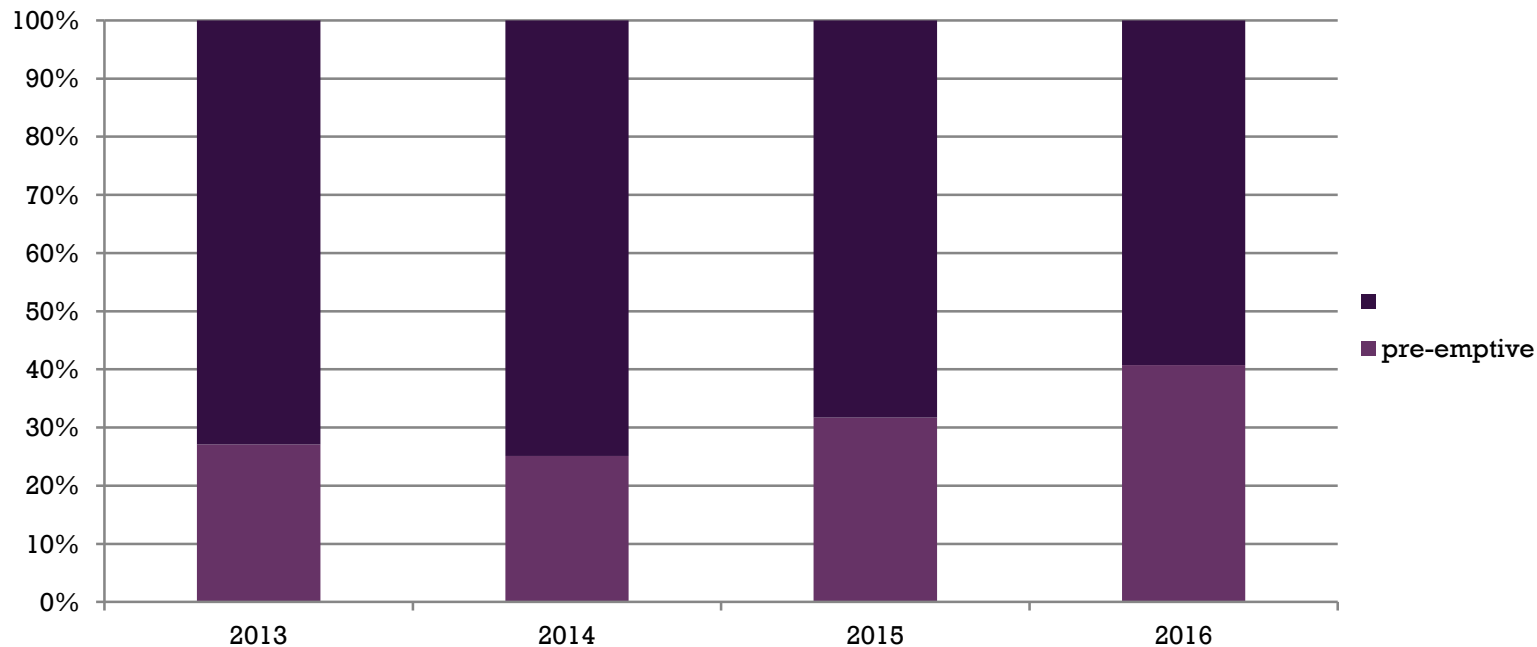
We will be in the top 50% of transplant units for pre-emptive transplants

Self reported pre-emptive kidney alone transplant rates (note includes transplants outside the region)

KQUIP rollout

- TF rollout through KQUIP

- Producing "How to Guide"

- Access to data collection tool
  - (support from RR being determined)

- More work to access national data more easily

- Strengthening links with LD 2020

- Dovetailing with other sources of information
  - ATTOM
  - Renal Registry

Transplant First, How to Guide

Overview

- Background – In 2015, West midlands region formed the Transplant First Project to:
  - Increasing live and deceased donor kidney transplantation rates
  - Increasing pre-dialysis (pre-emptive) kidney transplant wait-listing and transplantation rates

- NHS Change Model
  - Our shared purpose – Stakeholder group with committed Clinical Director, MDP by-in. Shared vision and objectives to drive forward quality improvements.
  - Leadership by all - Sponsorship, Partnership board, Steering group,
  - Motivate and mobilise - Regional stakeholder network events, regular briefings to Renal Unit Leads to cascade
  - Influencing factors - Low live donor and decreasing transplant rates in the West Midlands compared to National data.
  - Measurement – Consistent data returns, increase in pre-emptive listing and transplants
  - Project and performance management – Robust project management support to plan, manage and progress
  - Spread and adopt – Medical and Nursing by-in – Clinical Directors commitment to steer forward change
  - Improvement tools – UKRR data, BT, NHS blood and transplant annual report, National and Local data

THINK KIDNEYS   Kidney Quality Improvement Partnership | Title | Author   00.00.0000 | 1

Thank you to all patients, carers, kidney unit staff, registry staff etc. who are working on the project

+ Time to listing: Historical

- 2007-8 Median 170 days

- 2008-9 Median 0 days

- 2009-10 Median 0 days

- 2010-11 Stoke 84 Leighton 347

- 2011-12 Stoke 93 Leighton 407 (incomplete data)

- 2012-13 Stoke 0 Leighton 89

- 2014 Stoke 0 Leighton 0 (63% pre-emptive)

Note post 2012 introduction of separate listing clinic in Leighton to parallel Stoke system, no other change made at same time

KQuIP/UKRR Regional Day
East Midlands

15:00- 16:00 - Breakout Sessions

Consider the following questions, write on flipchart and agree who is feeding back :-

1. What does the data and national project mean for?
- **Our unit**
- **Our region**

2. Why the East Midlands region should take on one of the KQuIP projects as a region?