



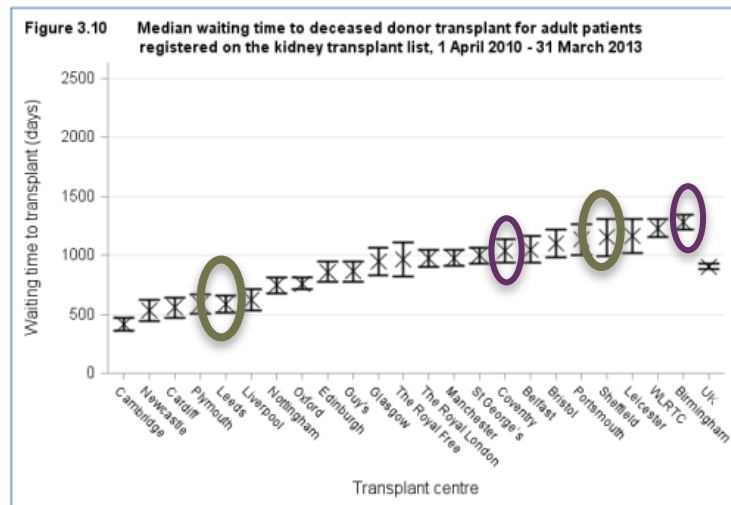
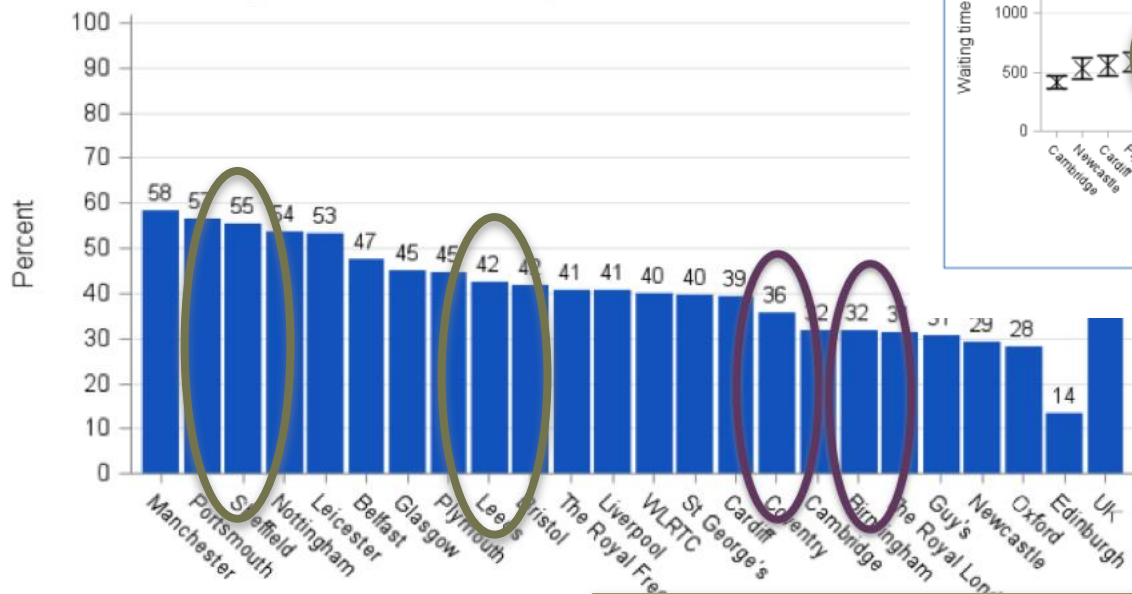
# Transplant first: Addressing inequality of access to renal transplantation across the West Midlands

Kerry Tomlinson on behalf of sponsor group  
Yorkshire and Humber

# 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



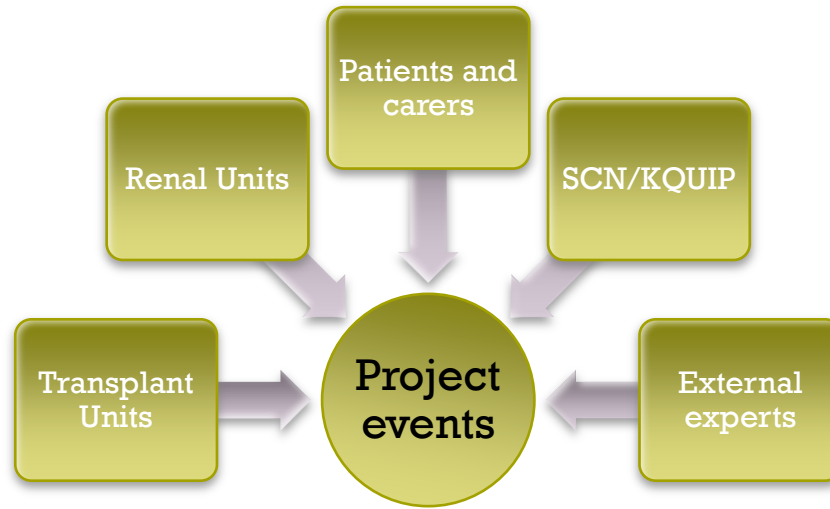
- UK RR 2014 report median time to listing
- 488, 598, 641, (683), 712, 765, 787, 867
- Y&H (147-1049)

# + 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?



Launch event  
July 2015



Pathway  
Redesign 1



Pathway  
redesign 2

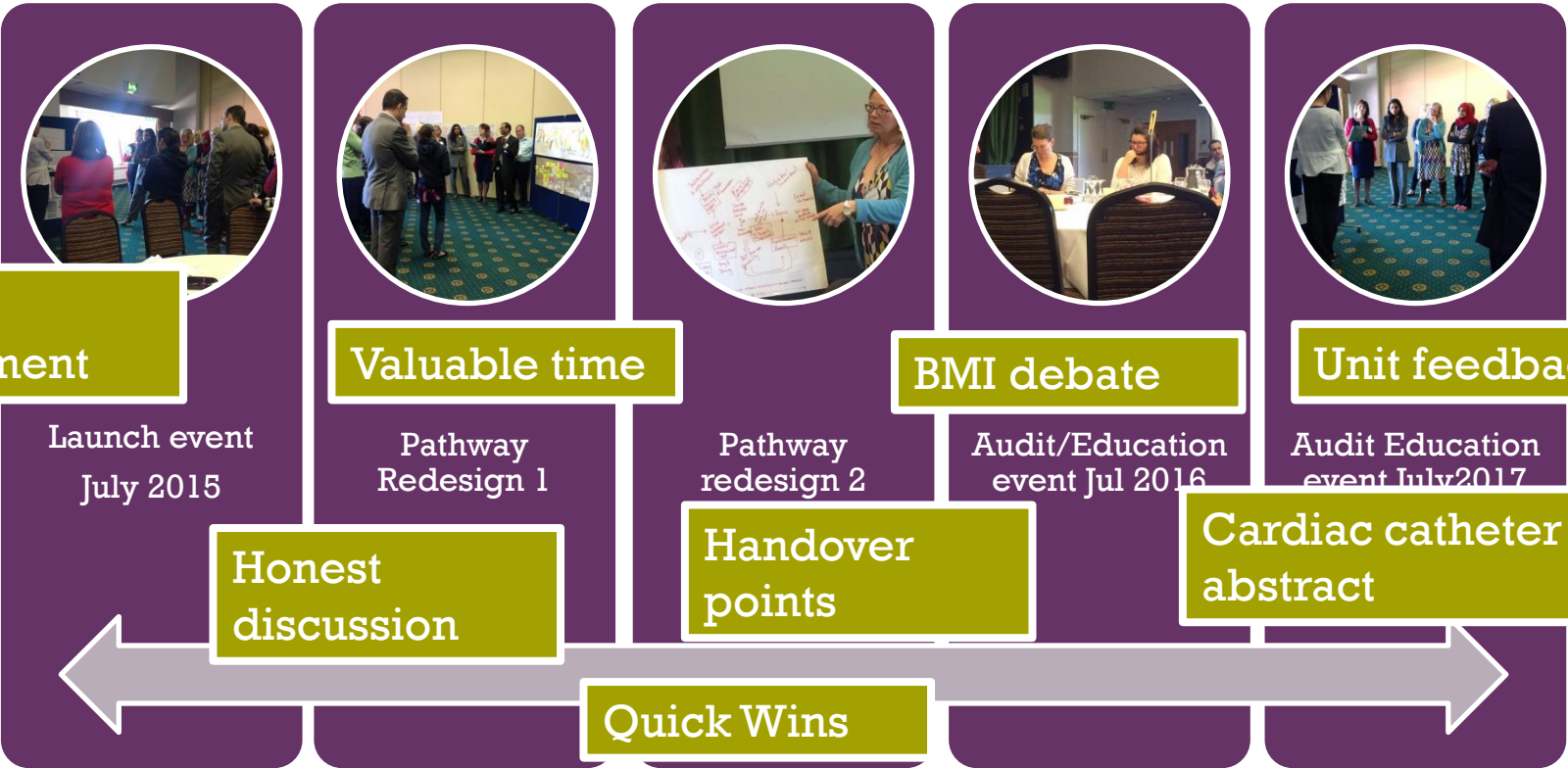


Audit/Education  
event Jul 2016



Audit Education  
event July 2017





**Patient Voice**

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

# + Project S

Sponsor Team

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- Identify any

- Education (C
- Identify train
- Source/desk
- Establish ac
- 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](http://www.britishkidney-pa.co.uk/information)

[www.kidneyresearchuk.org/health-information/kidney-transplantation](http://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/>

KQUIP

UKRR

ODT

NICE

transplantation to 2020

LDKT 2020

Partn





# 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 categories 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

List all patients who were registered on the renal transplant list in quarter no matter how long they 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	





# 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	
<i>answered question</i>		3	
<i>skipped question</i>		2	

Number	Response Date	Response Text	Categori es
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!!!

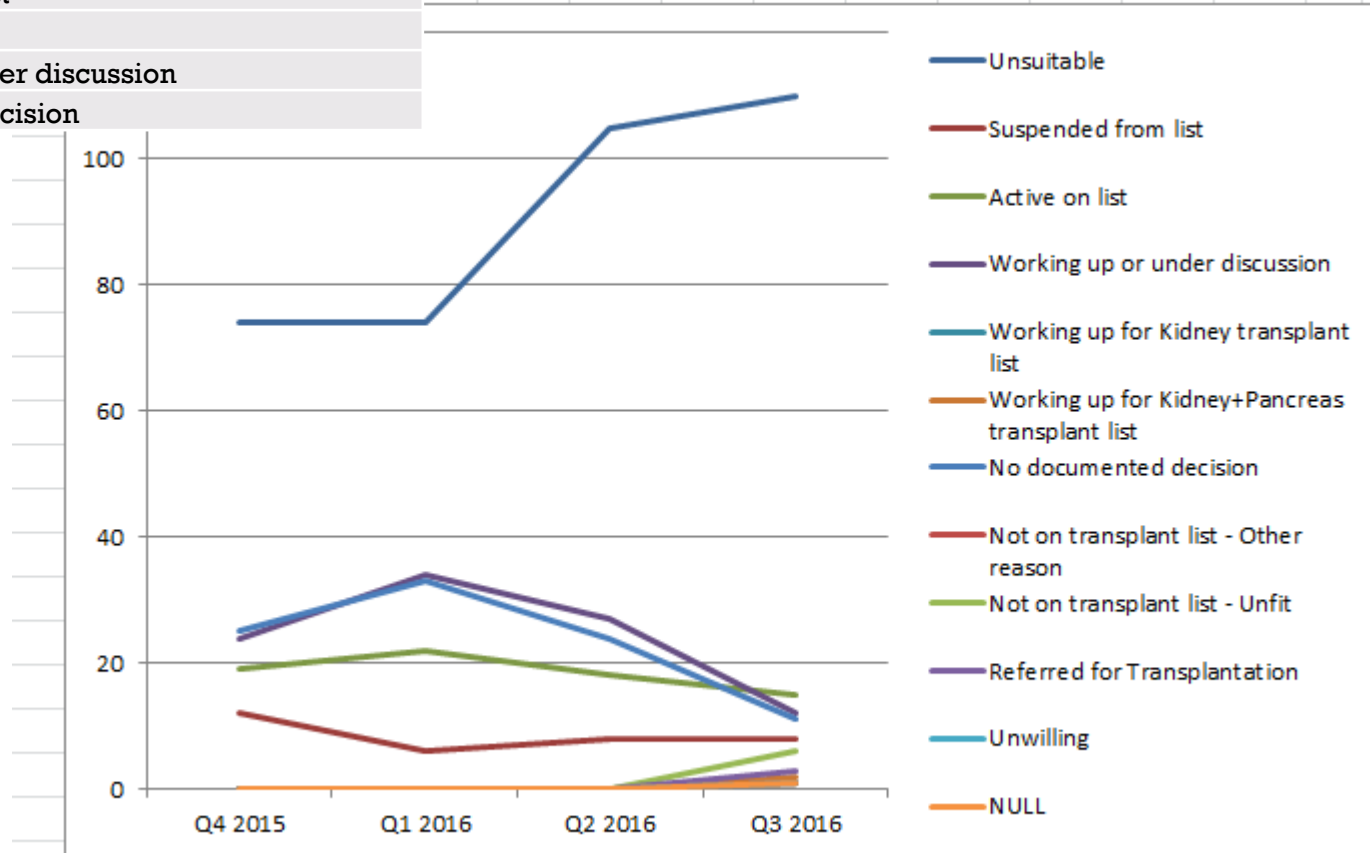
Active on list

Suspended from list

Unsuitable

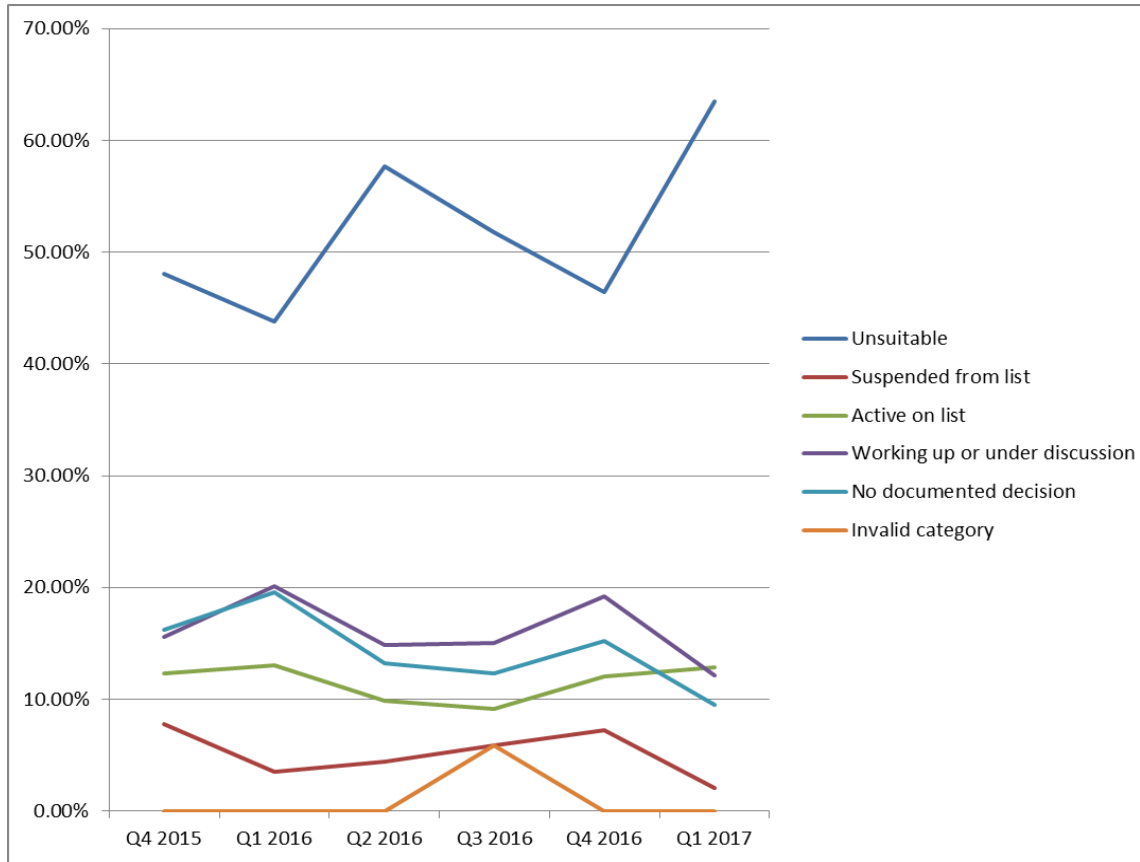
Working up or under discussion

No documented decision





# Transplant status from Enhanced dashboard



# + Lessons learnt from data

- 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 (e.g. diabetes multi-disciplinary)
  - Different feeder hospitals
  - Other reasons that will be apparent locally

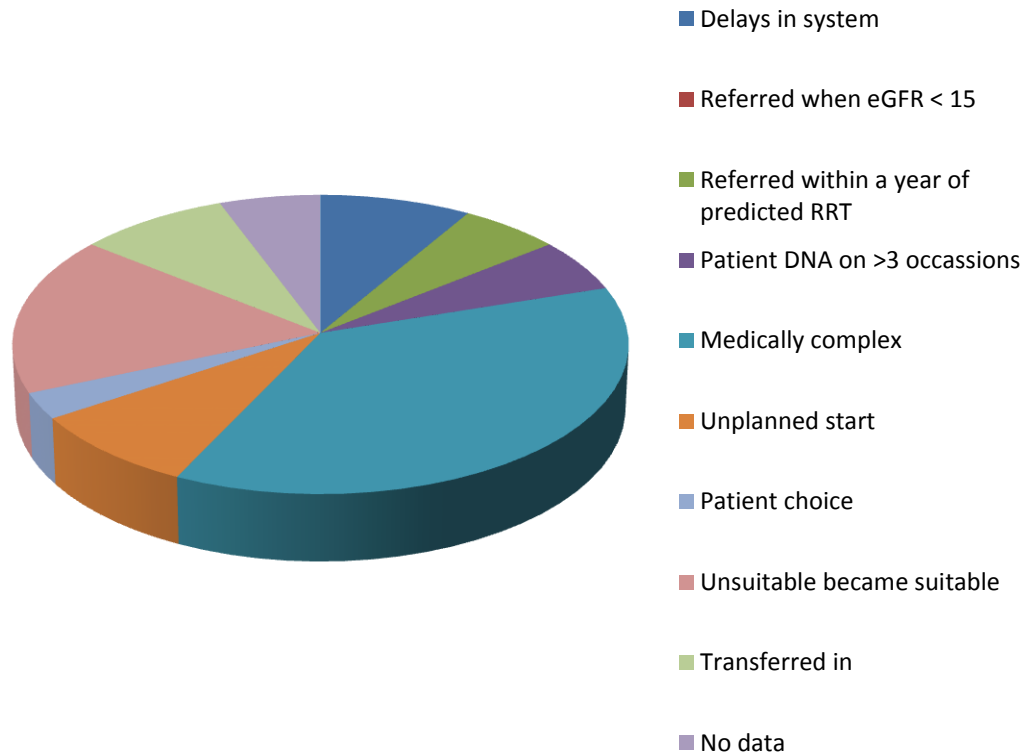
Bradford Timely  
listing project:  
Dental reviews for  
Leeds

It only works if you use it locally



# Reason given why patients were not listed pre-emptively

Q12017



# + eGFR at referral to seminar 2012

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

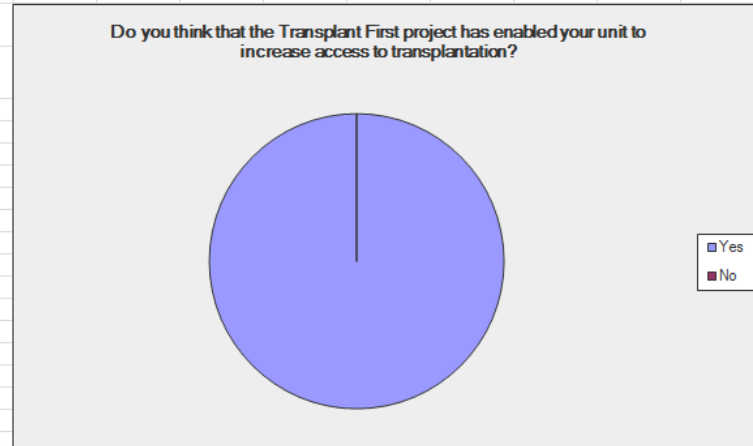
Approximately 50% late referral avoidable

# + 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
<i>answered question</i>		5
<i>skipped question</i>		0



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

## Consultants

Lack of time for individual units to discuss changes

Would like more personalized input

Software barriers

Change in unit personnel

Would like more interaction

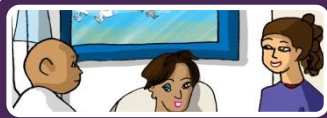
Staffing shortages

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

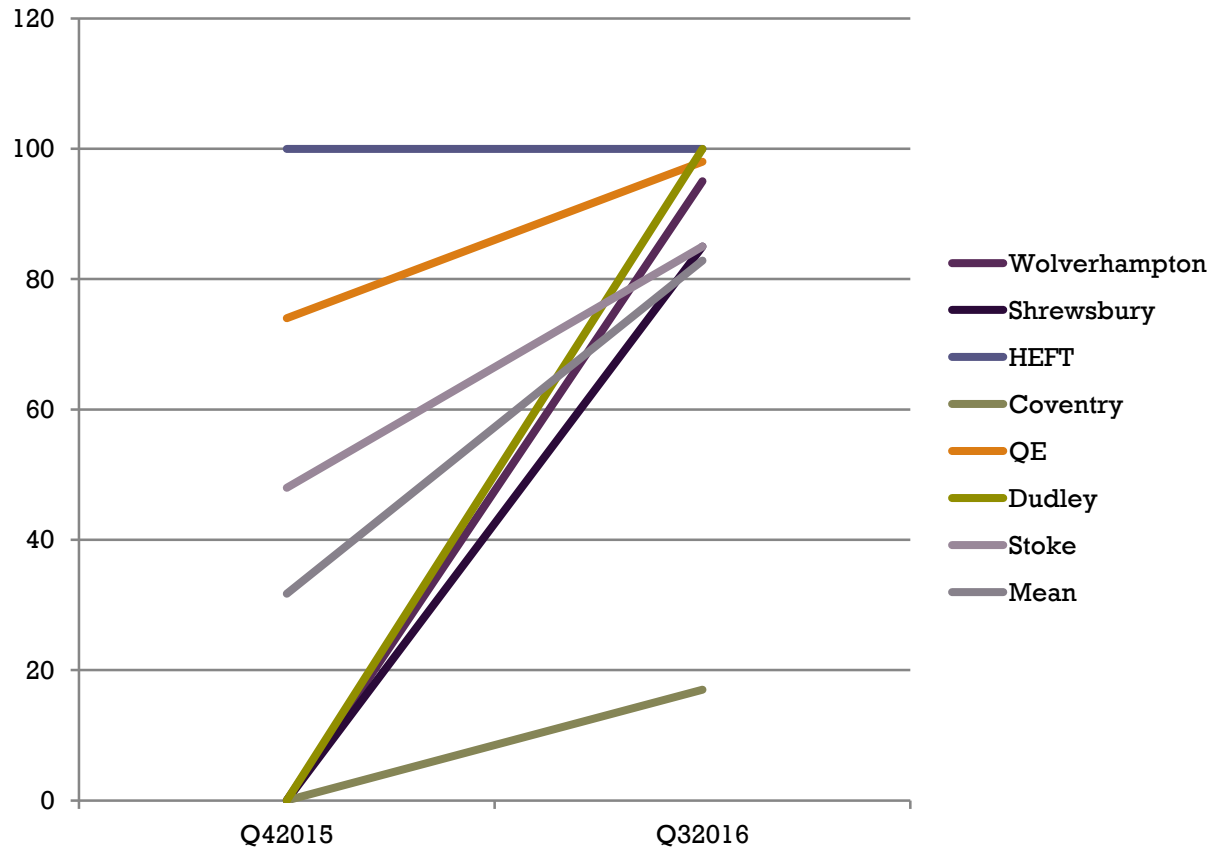


We will be in the top 50% of transplant units for pre-emptive transplants



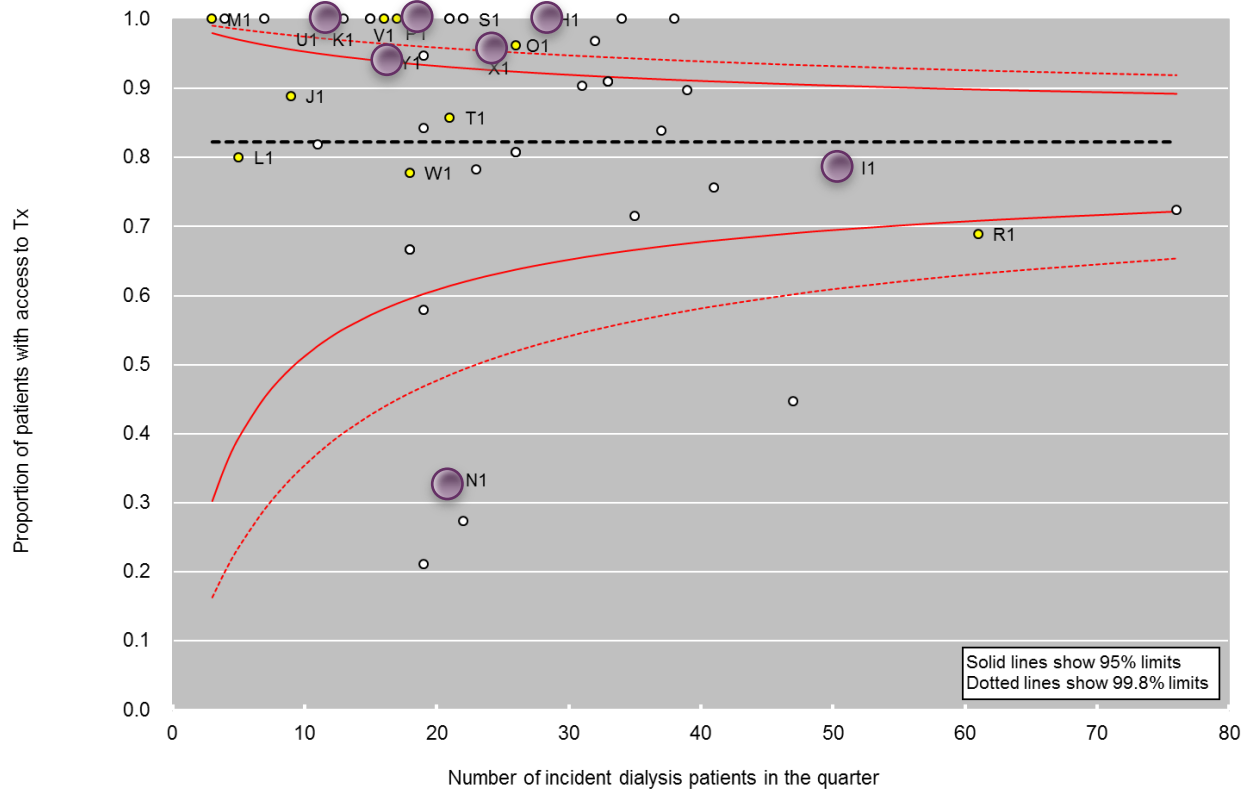
95% of all CKD 5 patients will have a documented transplant decision

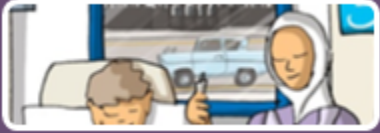
# % of CKD 5 patients with recorded transplant status on IT system





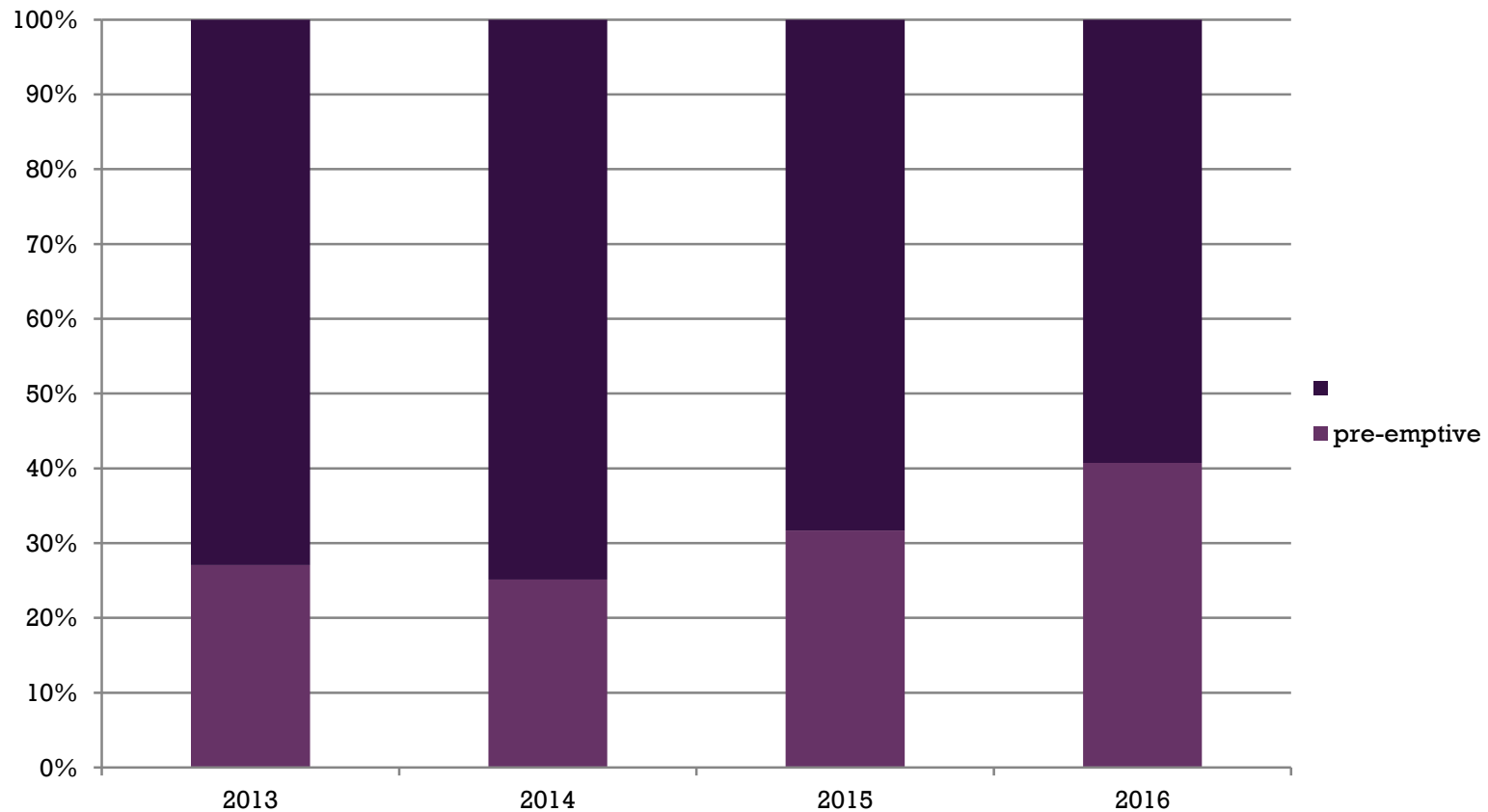
# West Midlands will achieve >95% patients starting RRT with a transplant status





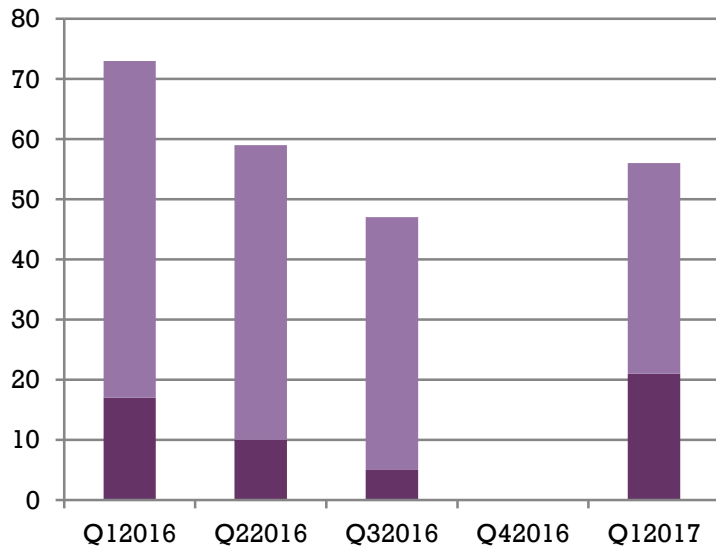
> 50% of patients will be listed pre-emptively

## UHB listings from all units

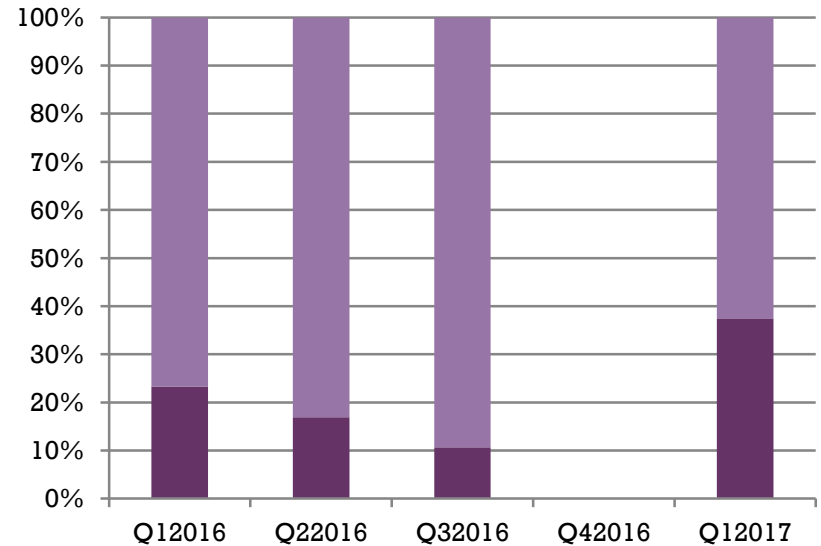




## We will be in the top 50% of transplant units for pre-emptive transplants



■ On Dialysis  
■ Pre-dialysis



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
- More work to access national data more easily
- 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'  
KQuIP**



**NHS**  
*England*  
West Midlands  
Clinical Network

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

