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

Kerry Tomlinson on behalf of sponsor group

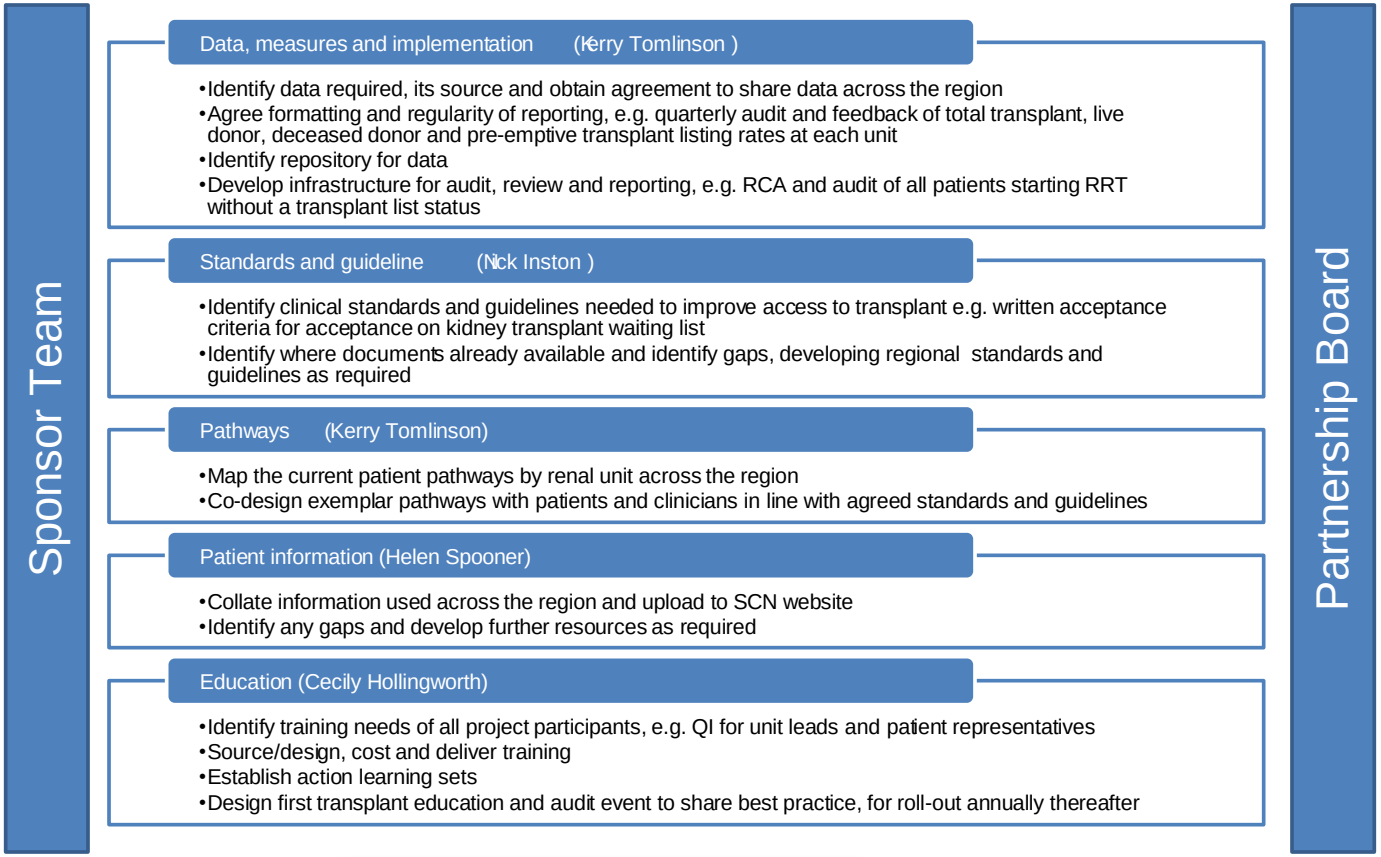
West midlands KQUIP day march 2017

Project Background

- Proposed to and adopted by West Midlands Cardiovascular Strategic Clinical Network (Renal Expert Advisory Subgroup)
- Aims to:-
  - lead to a progressive reduction in the excessive waiting times to renal transplantation in the West Midlands
  - Improve access to renal transplantation for all patients in the west midlands
- Full mandate and documents on website www.wmscnsenate.nhs.uk

The project will not disadvantage existing dialysis or transplant listed patients

Project Structure



Data: What will we achieve? (What will success look like)

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

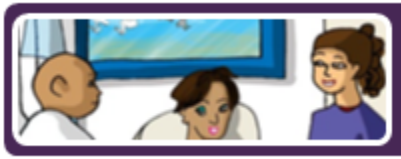
West Midlands will achieve >95% patients starting RRT with a transplant status

> 50% of patients will be listed pre-emptively

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

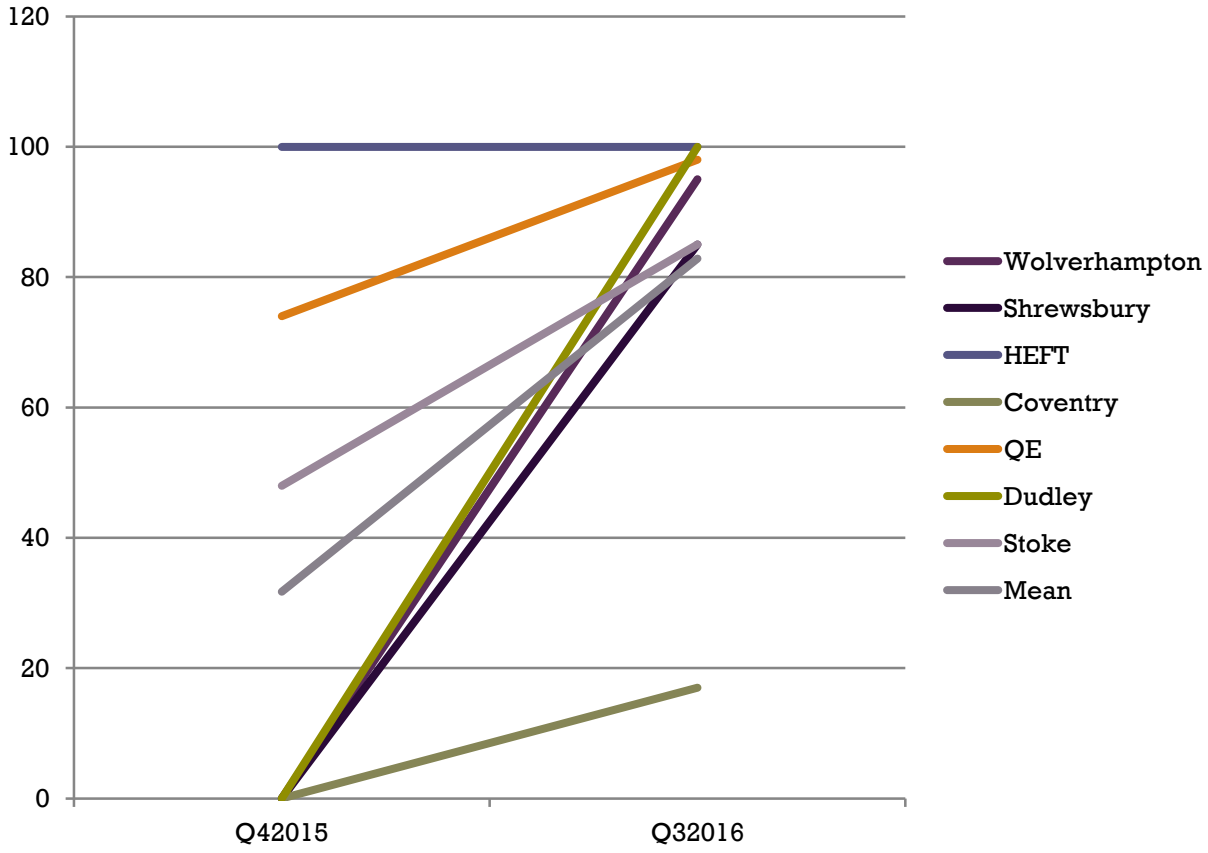
The wait for deceased donor kidneys in the West Midlands will be in line with the national average or better

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

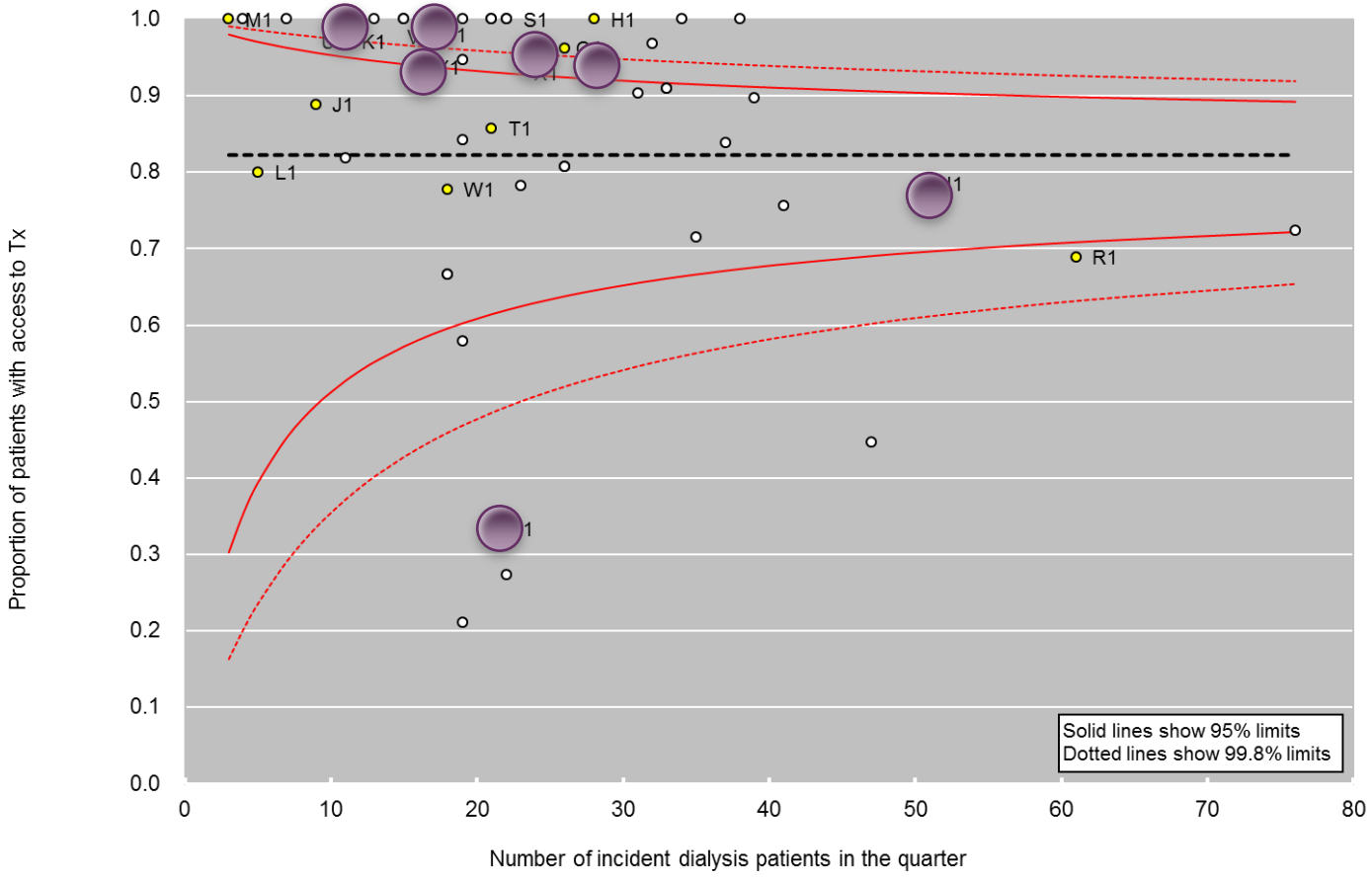


95% of all CKD 5 patients will have a documented transplant decision

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

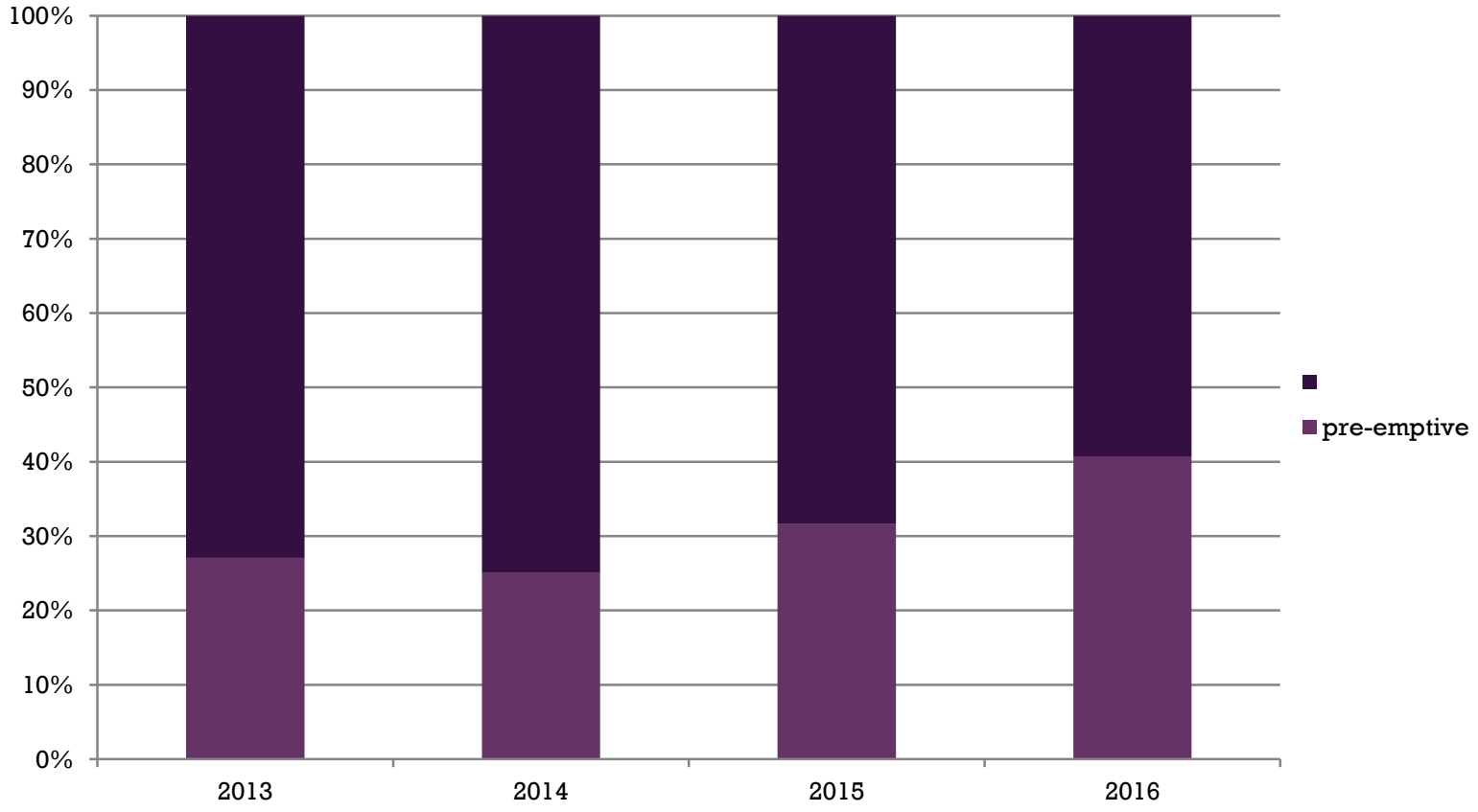


West Midlands will achieve >95% patients starting RRT with a transplant status



> 50% of patients will be listed pre-emptively

UHB listings from all units



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

Table 4.2 **Adult extended criteria DBD donor kidney offer decline rates by transplant centre, 1 April 2013 and 31 March 2016**

Centre	Code	2013/14		2014/15		2015/16		Overall	
		N	(%)	N	(%)	N	(%)	N	(%)
Belfast	A	35	(57)	18	(39)	26	(46)	79	(49)
Birmingham	B	133	(80)	94	(71)	93	(53)	320	(69)
Bristol	C	62	(61)	45	(51)	85	(66)	192	(61)
Cambridge	D	20	(50)	33	(58)	23	(52)	76	(54)
Cardiff	E	22	(77)	11	(64)	19	(68)	52	(71)
Coventry	F	15	(40)	17	(65)	11	(45)	43	(51)
Edinburgh	G	31	(52)	28	(64)	31	(74)	90	(63)
Glasgow	H	31	(39)	35	(49)	57	(53)	123	(48)
Guy's	J	35	(57)	29	(52)	54	(46)	118	(51)
Leeds	K	18	(28)	27	(41)	29	(38)	74	(36)
Leicester	L	99	(81)	89	(80)	40	(60)	228	(77)
Liverpool	M	21	(33)	28	(68)	32	(63)	81	(57)
Manchester	N	77	(45)	62	(60)	102	(41)	241	(47)
Newcastle	O	20	(70)	18	(56)	28	(57)	66	(61)
Nottingham	P	38	(68)	16	(69)	23	(48)	77	(62)
Oxford	Q	18	(50)	17	(47)	33	(61)	68	(54)
Plymouth	R	13	(69)	11	(36)	11	(27)	35	(46)
Portsmouth	S	47	(43)	44	(34)	38	(55)	129	(43)
Sheffield	T	41	(61)	41	(66)	37	(68)	119	(65)
St George's	U	41	(37)	38	(45)	56	(59)	135	(48)
The Royal Free	V	22	(64)	24	(46)	32	(59)	78	(56)
The Royal London	W	54	(72)	44	(55)	52	(73)	150	(67)
WLRTC	X	78	(56)	73	(59)	84	(51)	235	(55)
UK		**971**	**(60)**	**842**	**(58)**	**996**	**(55)**	**2809**	**(58)**

Centre has reached the upper 99.8% confidence limit
Centre has reached the upper 95% confidence limit
Centre has reached the lower 95% confidence limit
Centre has reached the lower 98.8% confidence limit

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

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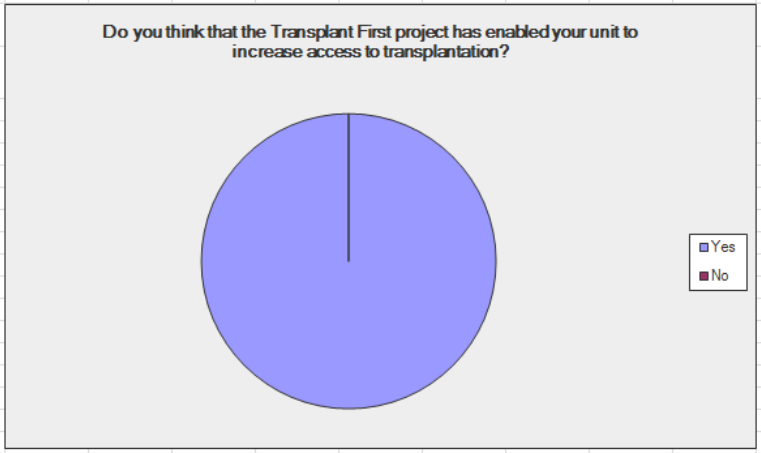
Positive stories

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**



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 Co-ordinator in post

Improving transplant profile for staff and patients

Better data to influence decisions

Other Successes

Donor Patient View

- Quick Wins
  - Mobile numbers on referral letters
  - Transplant unit to tell referring units about appointments
- Agreement
  - Finish tests before referral
  - Start Donor workup sooner
  - Single point of referral
  - Work towards limited or lead consultants

West Midlands Cardiovascular Clinical Network

Transplant First

Standards & Guidelines for Renal Transplantation in the West Midlands - 130916

Contributors:

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Lessons learnt from data

- Over the first three quarters of the project the proportion of patients who were being referred late for workup fell from 7/19 to 4/27

- 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

Barriers to using data effectively

- Me
- It is **extremely** difficult to develop data set and collection and collation (final version just about ready!)
- Time
- Separation between people filing in data and those doing project

What are you doing with the data from the dashboard?

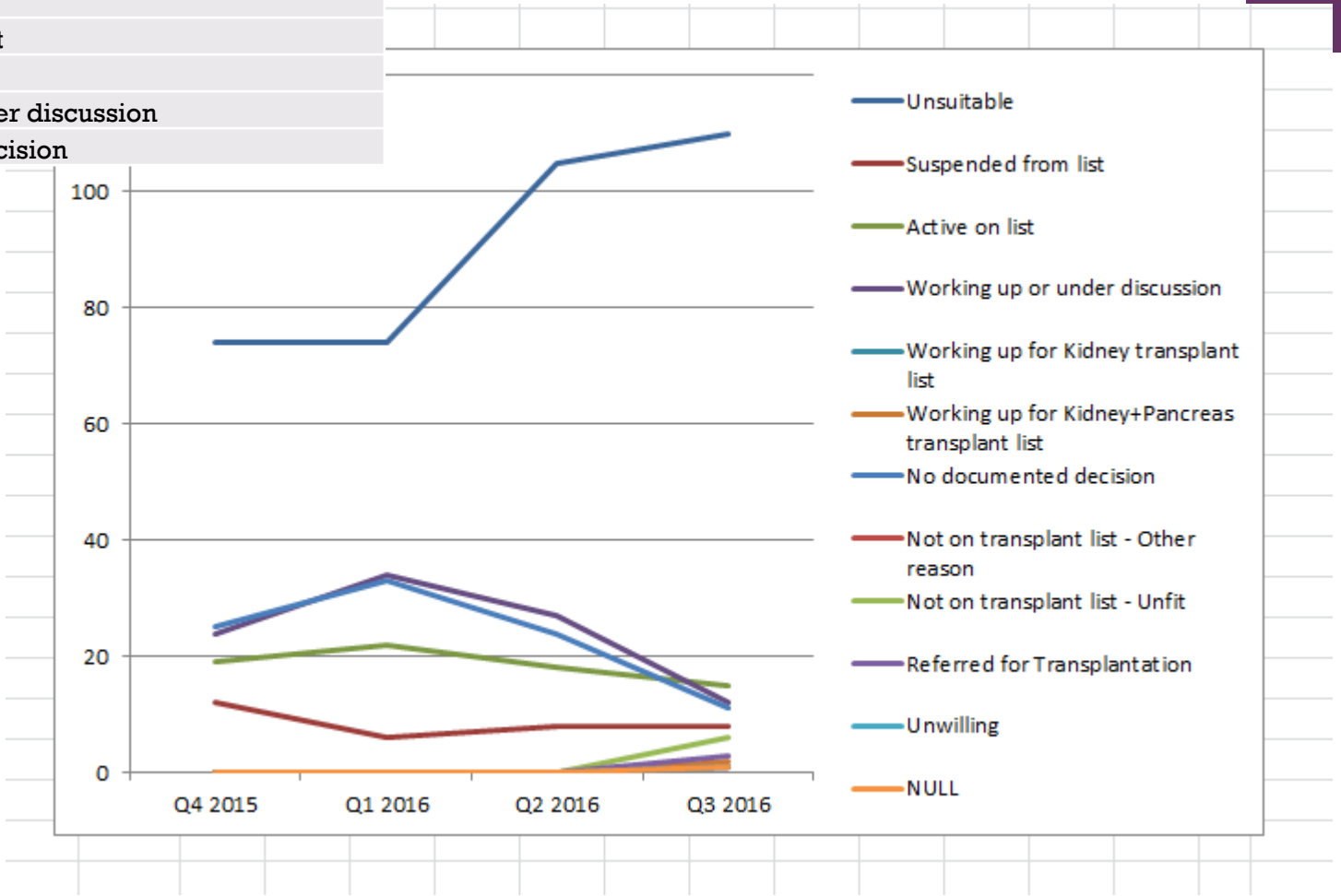
Answer Options	Response Count
	3
answered question	3
skipped question	2

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	

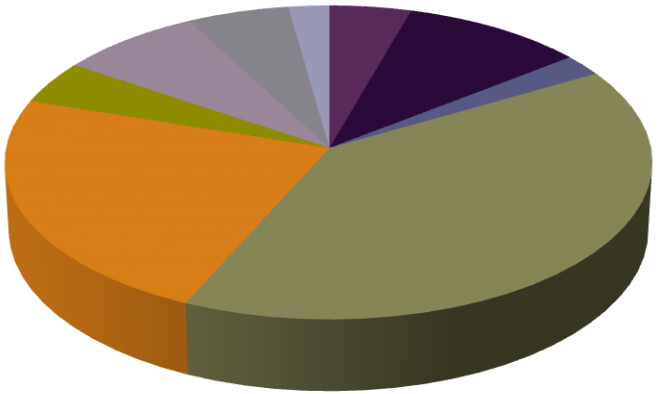
- Tendency to justify exceptions (balance between wanting data to look good and using it to improve)

Cut and Paste: Argghhhh!!!

Active on list
Suspended from list
Unsuitable
Working up or under discussion
No documented decision



Reason given why patients were not listed pre-emptively



- 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
- Transferred in
- No data

Nearly all from one unit

No unit reported delays in system

No unit asked where to put the delays in system

How sponsor team have found it

- Time needed can't be overestimated
- Project support is key
- 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

Barriers from Unit perspective

Lack of time for individual units to discuss changes

Consultants

Software barriers

Wanting more support and face to face meetings

Staffing shortages

Other Barriers

- Me
- Different Transplant Unit approaches to involvement
- Changing personnel (units and project team)
- Resource
- Time, Time, Time
- On-going need for human interactions and mediation
- Role on on-going QI education

Where do we go from here?

- Suggestions from Survey
  - The project needs continued administrative support, particularly to communicate data between units in the region
  - Regular meetings and joint clinics with Transplant units
  - Possibly come and present the data locally so frontline staff who do the work in the unit to ensure timely listing can actually hear about it

Last few months of project

- Final version of data collection
- More work to access national data more easily
- TF rollout through KQUIP
- Please feedback
  - Useful lessons
  - What you want next from project team
- Plan Summer Audit/Education meeting
- On-going reporting of data and outcomes through WMSCN Renal EAG

Discussion

NHS England
West Midlands Clinical Network

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