



East and West  
Midlands Transplant  
First  
Living Donor  
Improvement Day



Kerry Tomlinson 26<sup>th</sup> May 2022

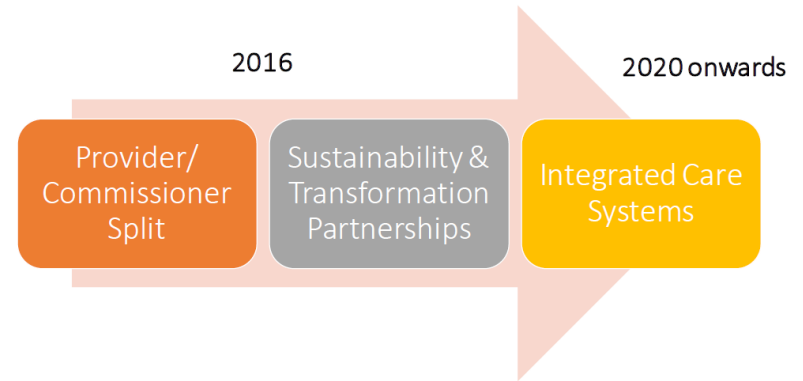


# + Why are we here?

- National Background
- Our region
- Why and how to collect data

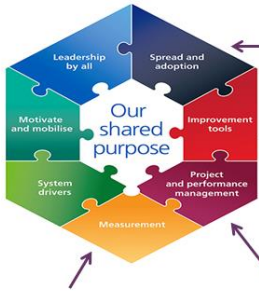


# + National picture



- Funding moving to ICS
- Obligation to work collaboratively
- Looking at patient groups and pathways rather organisations
- Value, Equity, Quality Improvement
- RSTP, GIRFT, NHSBT 2030
- Moving back to Networks

# + Transplant First and KQUIP



Shared lessons learned



KQUIP Home About KQUIP Hub

Transplant First Enhanced dashboard data

Enhanced dashboard data (2018 Q2)

**INCLUDE** All patients in UK who started haemodialysis or peritoneal dialysis for established renal failure in the quarter below.  
**INCLUDE** patients who start haemodialysis or peritoneal dialysis for established renal failure.  
**INCLUDE** patients with a listing transferred into first dialysis in the quarter.  
**EXCLUDE** from any patient who had first been seen by the nephrologist less than 90 days prior to starting dialysis (to include 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	Action on file		
3	No documented decision	Patient DMS 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 < 15	

Measurement for improvement and RCA

## 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 can be found below.

### Transplant First

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



Think Kidneys · 26/04/2018

Lots more sharing ideas about process/ transplant pathway #transplantfirst looking at the question What are the issues?

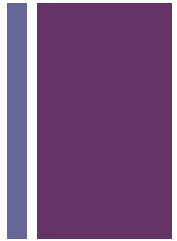


# The Midlands Kidney Network



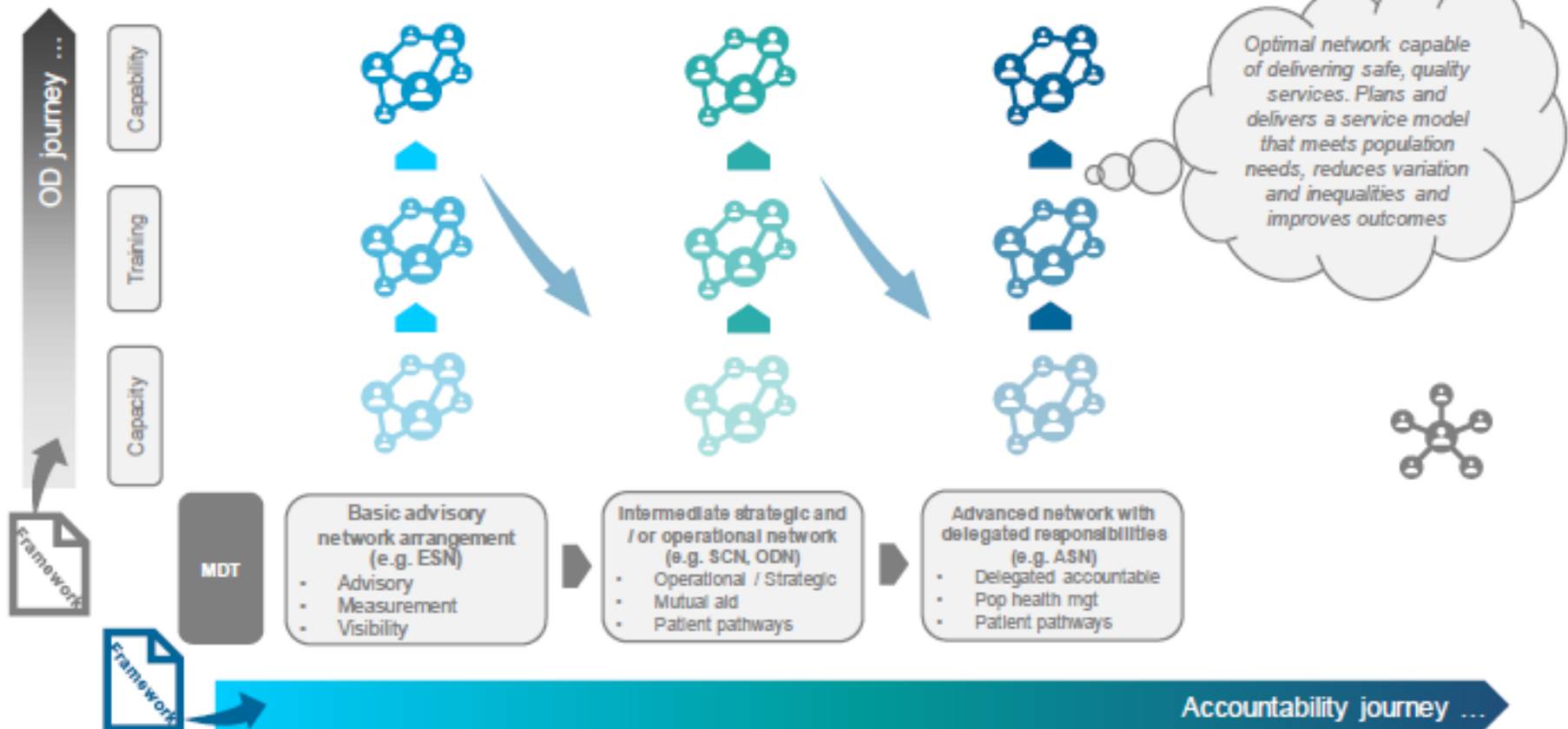


# Not all networks are equal



## Network (Networking) development journeys (the 'Readiness Framework') ...

DRAFT for discussion,  
does not represent  
policy



Recommendation	Actions	Owners	Timescale
4. Streamline renal transplant pathways to increase access and reduce unwarranted variation in deceased and living donor (DD and LD) transplantation.	a Discussions to be held in relation to options to improve the renal transplant commissioning pathway, as part of improved system-working. This should include equitable allocation of adequate resource for all steps in the recipient and LD pathways (assessment, surgery, follow-up) to all centres.	GIRFT/NHSE/I, NHSBT, RSTP, DHSC	Within 24 months of report publication
	b Renal National Service Specification (NSS) to require all providers to track patients with progressive CKD 4-5 using the Transplant First tool or local equivalent, to monitor timely work up of transplant candidates and their donors.	NHS England Specialised Commissioning	Within 24 months of report publication
	c Renal centres to have a dedicated specialist nurse transplant workforce.	Renal trusts	Within 12 months of report publication
	d Renal centres to ensure timely access to diagnostics and specialist opinions needed for transplant assessment.	Renal trusts	Within 12 months of report publication
	e Work up pathways of recipients and donors to the point of listing to be tracked using an 18-week timeline, which will require clinically appropriate 'clock rules'.	NHS England Specialised Commissioning and renal trusts	Within 12 months of report publication
	f Renal transplant NSS to require effective partnership within transplant networks, including local surgical assessment and representation of the referring team on the listing and LD MDTs.	NHS England Specialised Commissioning, RSTP and renal trusts	Within 12 months of report publication
	g NICE to develop a national guideline for suitability for transplant listing to be developed which is patient-centred and adopted in a consistent manner across all networks.	NICE, RA, British Transplantation Society (BTS), NHSBT, renal trusts, kidney patient groups	Approach NICE before April 2021
	h Access to transplant listing, organ allocation and LD transplants needs to be equal for patients of all ethnicities and socio-economic groups.	NHS England and NHS Improvement, RSTP, NHSBT	Ongoing

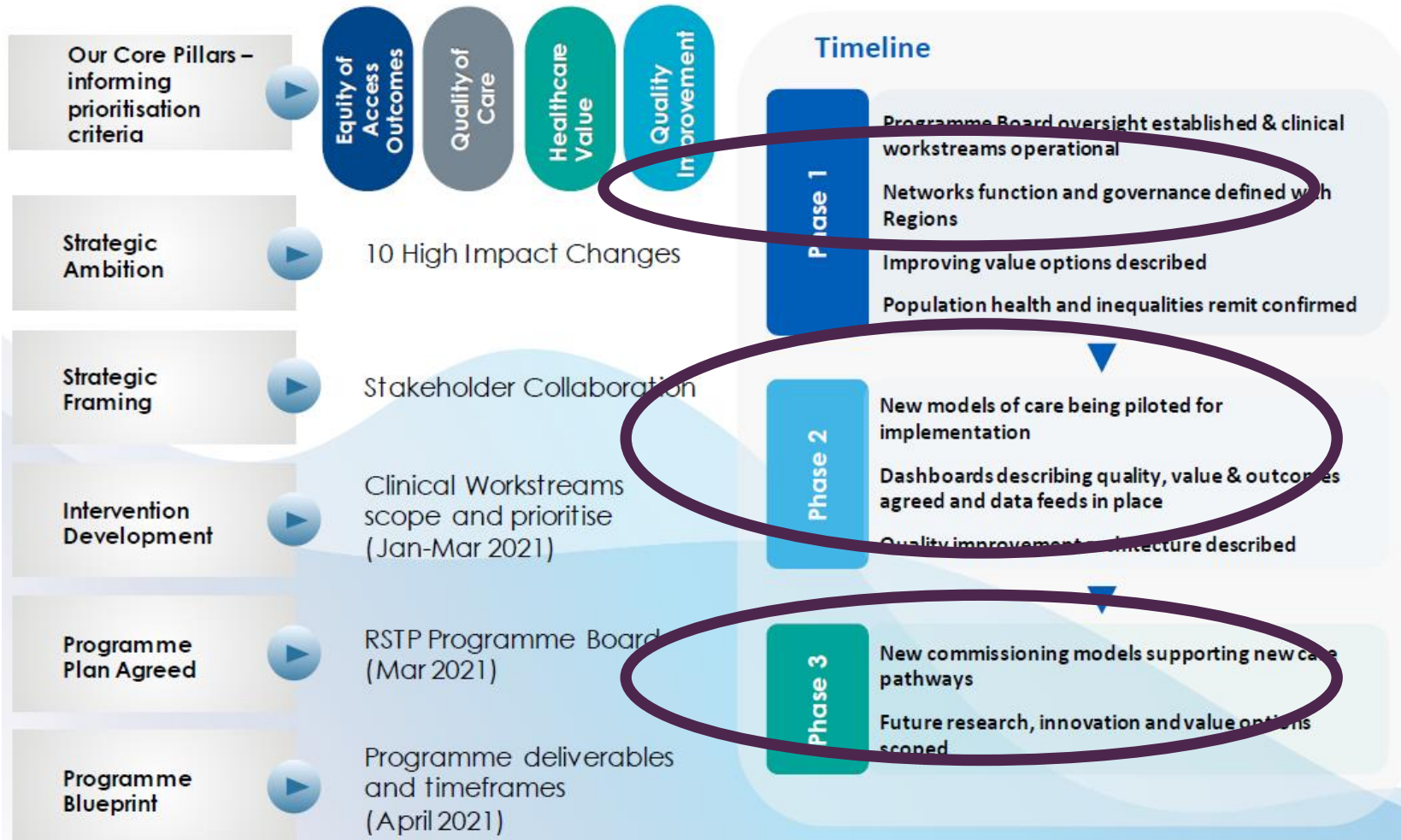


# GIRFT

recommendations

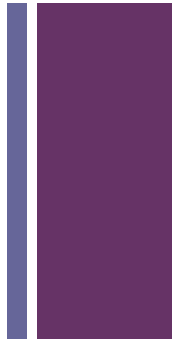
# Delivering the RSTP

## Development and prioritisation of programme interventions





# Renal Services Transformation Programme



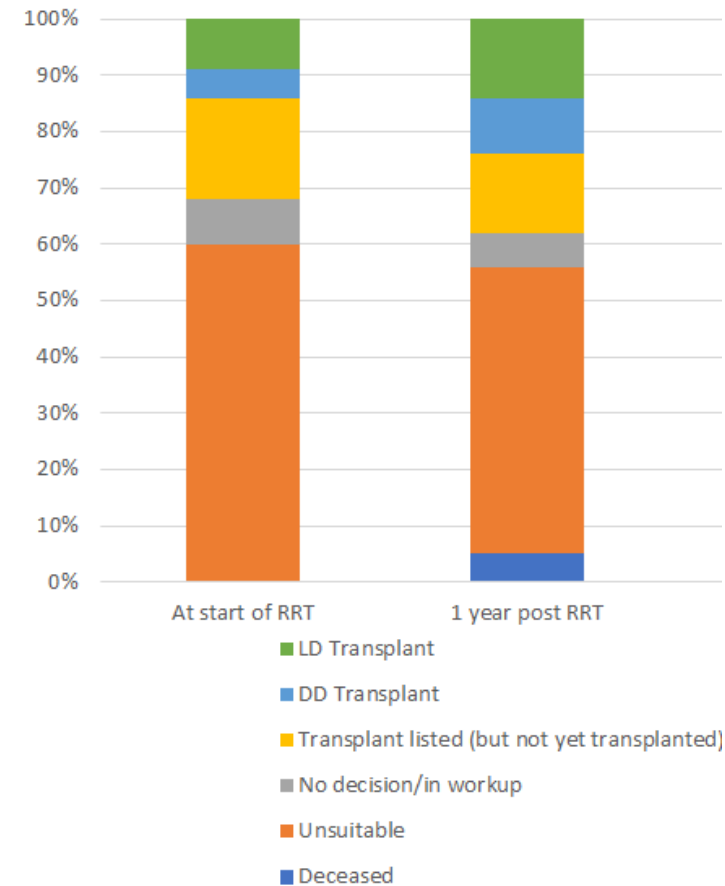
## ■ Data Dashboard

- Access to transplantation
- LD rates

Transplant status at start of RRT	Live Donor Transplant
Includes all patients starting RRT known to unit for >90 days and exclude acute starters	Deceased donor transplant
	On transplant list (suspended or active) - show both separately
	Unfit for transplant (needs definition)
	Everyone else =missed patients

## ■ Service Specifications

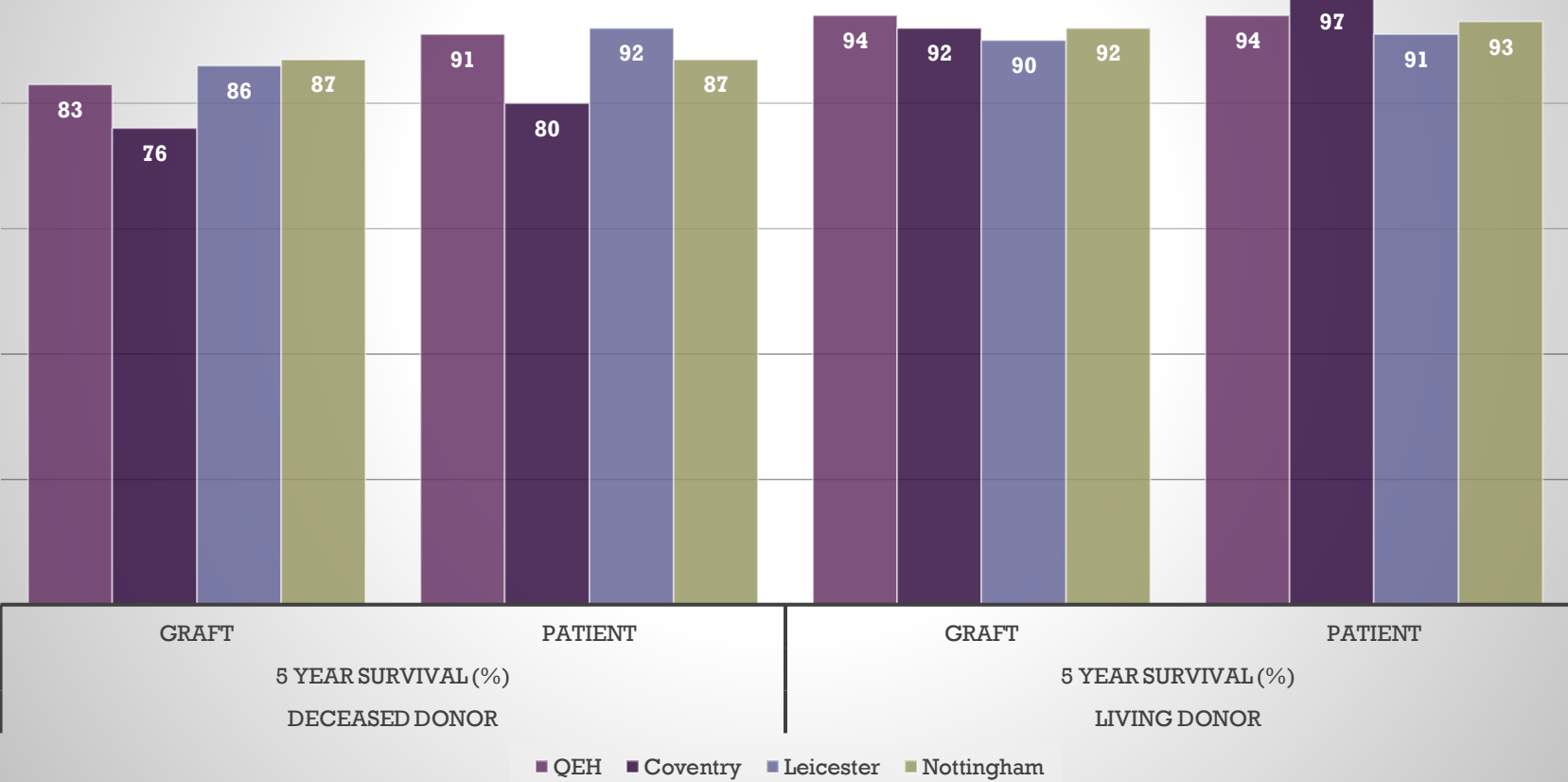
## ■ Toolkit





<b>Transplantation Sub Group Work Plan</b>	<b>Timescale</b>	<b>Due Date</b>
<b>Short term goal</b>		
<b>Workforce and improving this</b>		
Gap analysis of workforce	4 months	Jun-22
Working with individual renal units on business proposal for additional workforce	6-9 months	Dec-22
Renal centres to have a dedicated nurse specialist transplant workforce	12-18 months	Jul-23
<b>Medium term goal</b>		
<b>Improving data and dashboard submissions</b>	8 months	Sep-22
Agree key metrics for collection	6 months	Jul-22
Identify data sources (e.g. Trusts/Renal Units, Renal Registry, NHSBT)	4 months	May-22
Develop a system for obtaining, collating and presenting the data on a regular basis to maximise value	8 months	Sep-22
<b>Long term goal</b>		
<b>Improving living donor rates and improving access to early transplantation</b>	12 months	Feb-23
Renal centres to ensure timely access to diagnostics and specialist opinions needed for transplant assessment	12 months	Feb-23
Work up pathways of recipients and donors to the point of listing to be tracked using an 18-week pathway, which will require clinically appropriate 'clock rules'	12 months	Feb-23
Renal transplant National Service Specification (NSS) to require effective partnership within transplant networks, including local surgical assessment and representation of the referring team on the listing and Living Donor MDTs	12 months	Feb-23
Introduce and trial a T-PREM	12 months	Feb-23

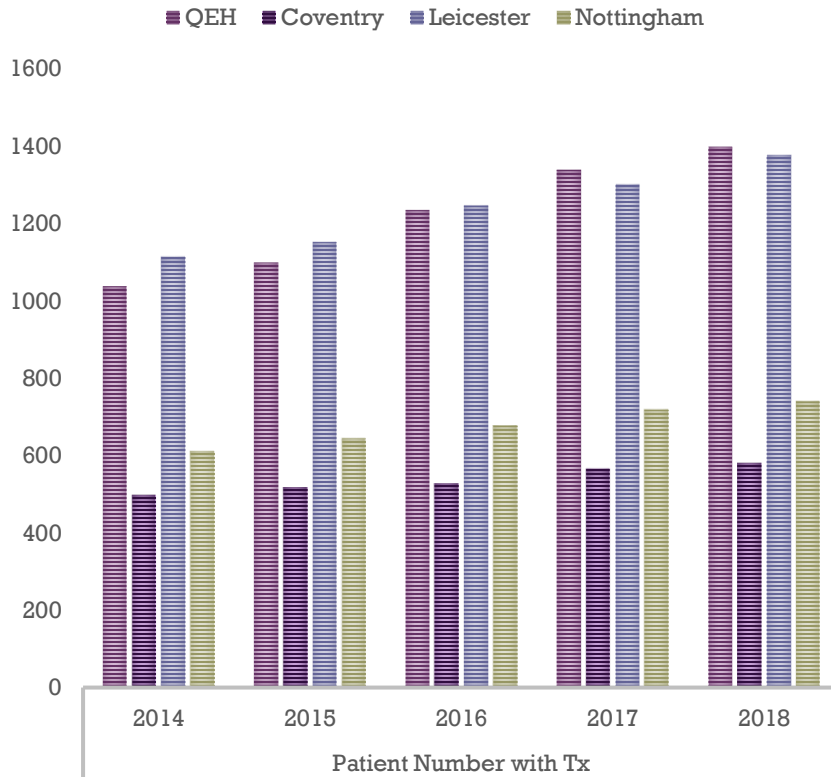
# Early Kidney Tx Outcomes WM



# Number of Prevalent Adult Tx Patients by Year in West Midlands



## WM PATIENT TX ACTIVITY



## # TX PATIENTS AS PROPORTION OF CATCHMENT POPULATION

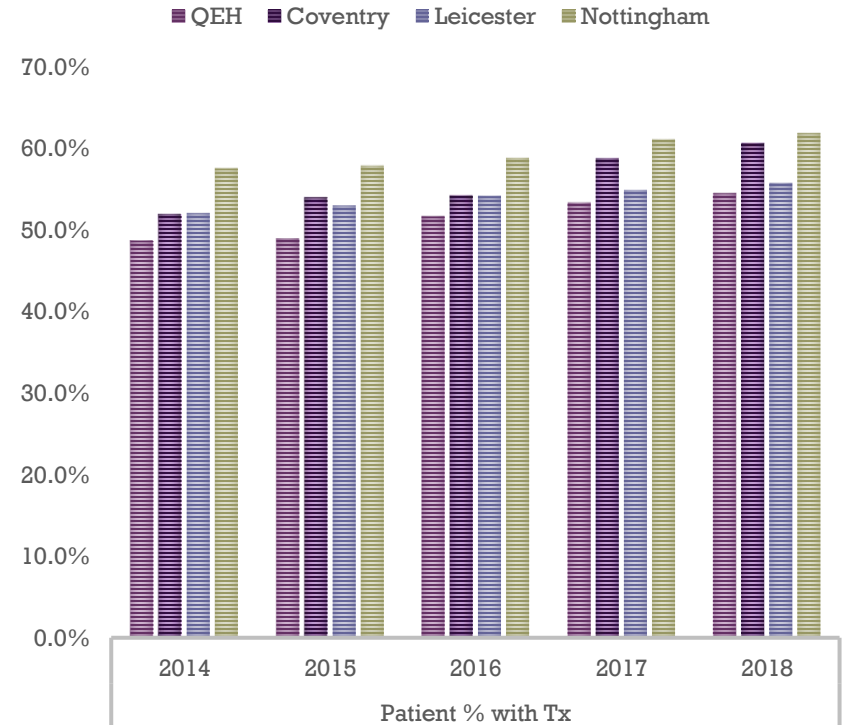
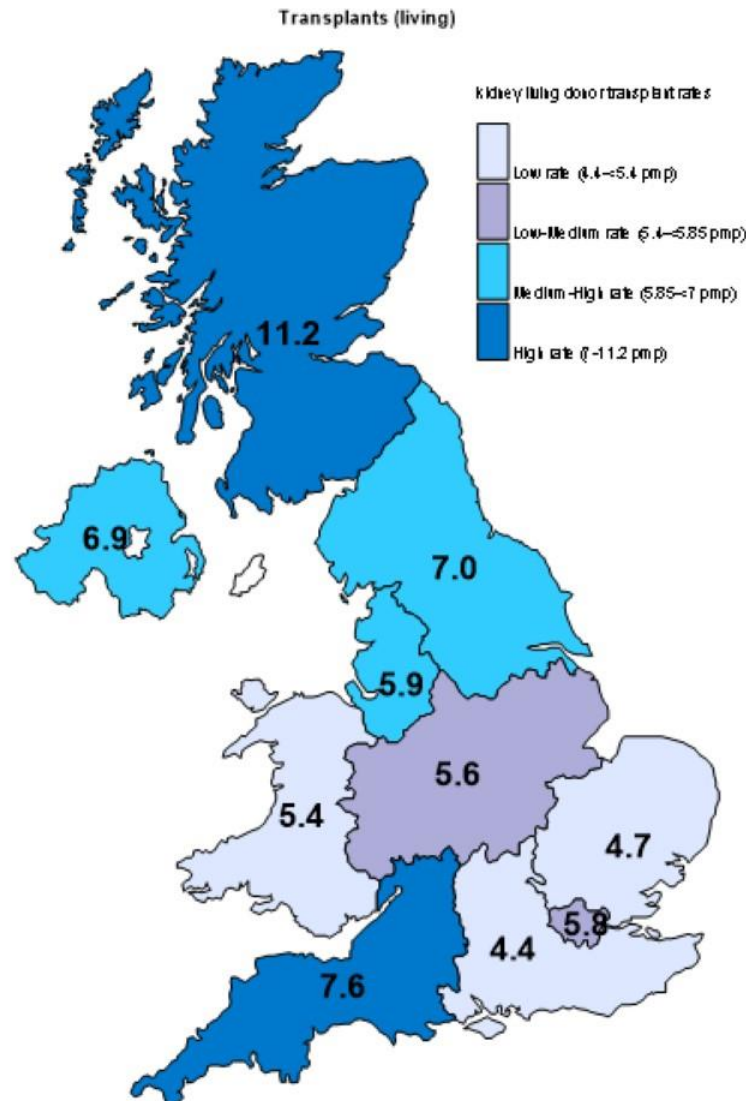
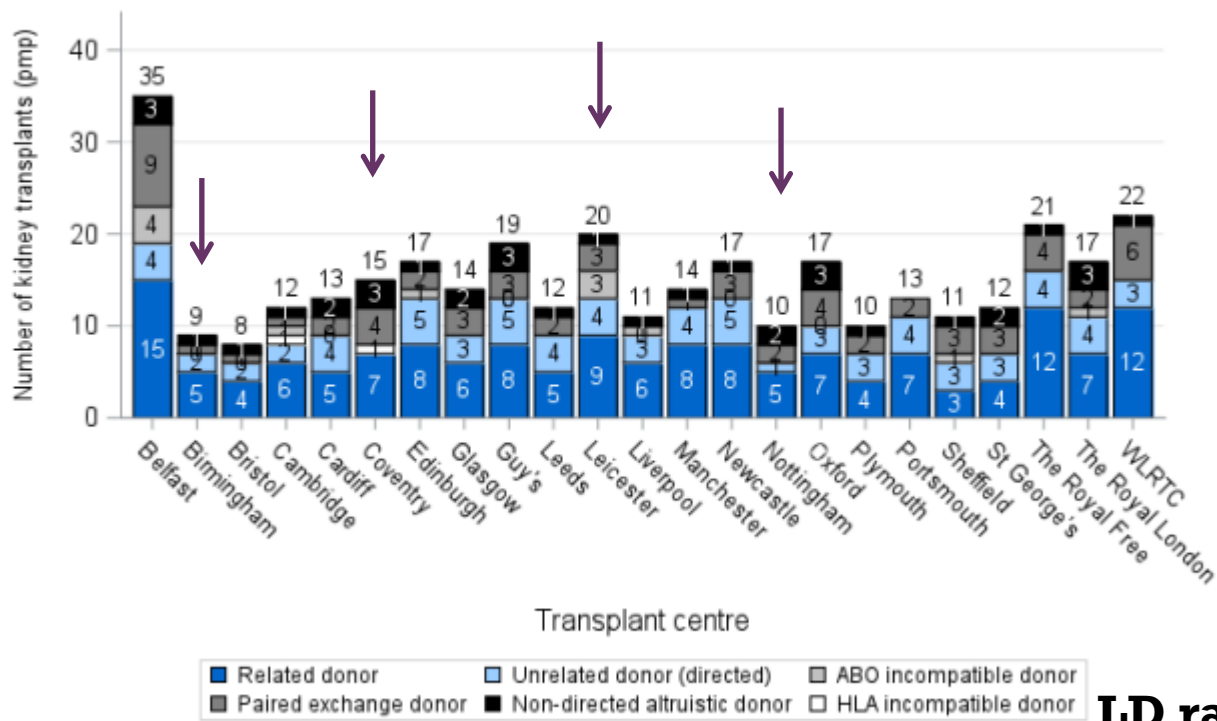


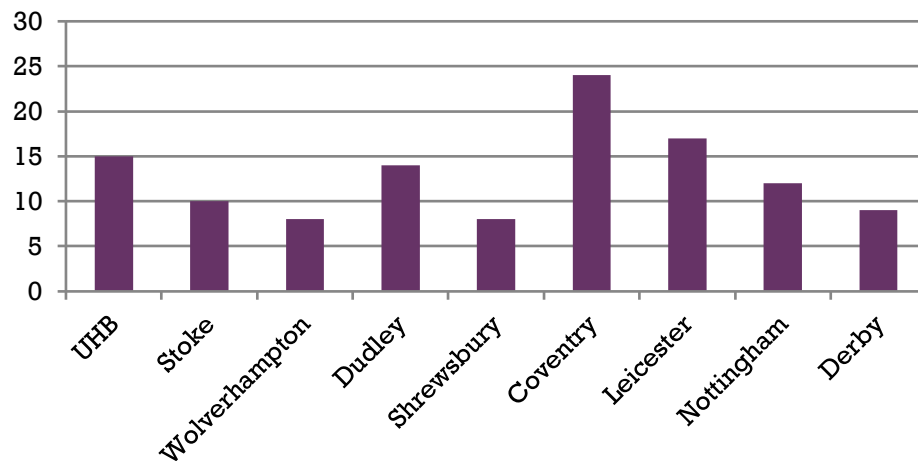
Figure 2.7 Living donor kidney transplant rates (pmp) by recipient country/NHS region of residence



**Figure 2.1 Adult Living donor kidney transplants (pmp) in the UK, 1 April 2019 - 31 March 2020**



**LD rate pmp 2017-20**



# + Pre-emptive listing

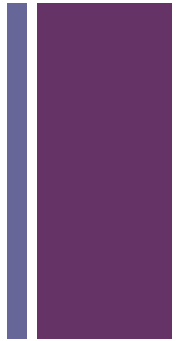
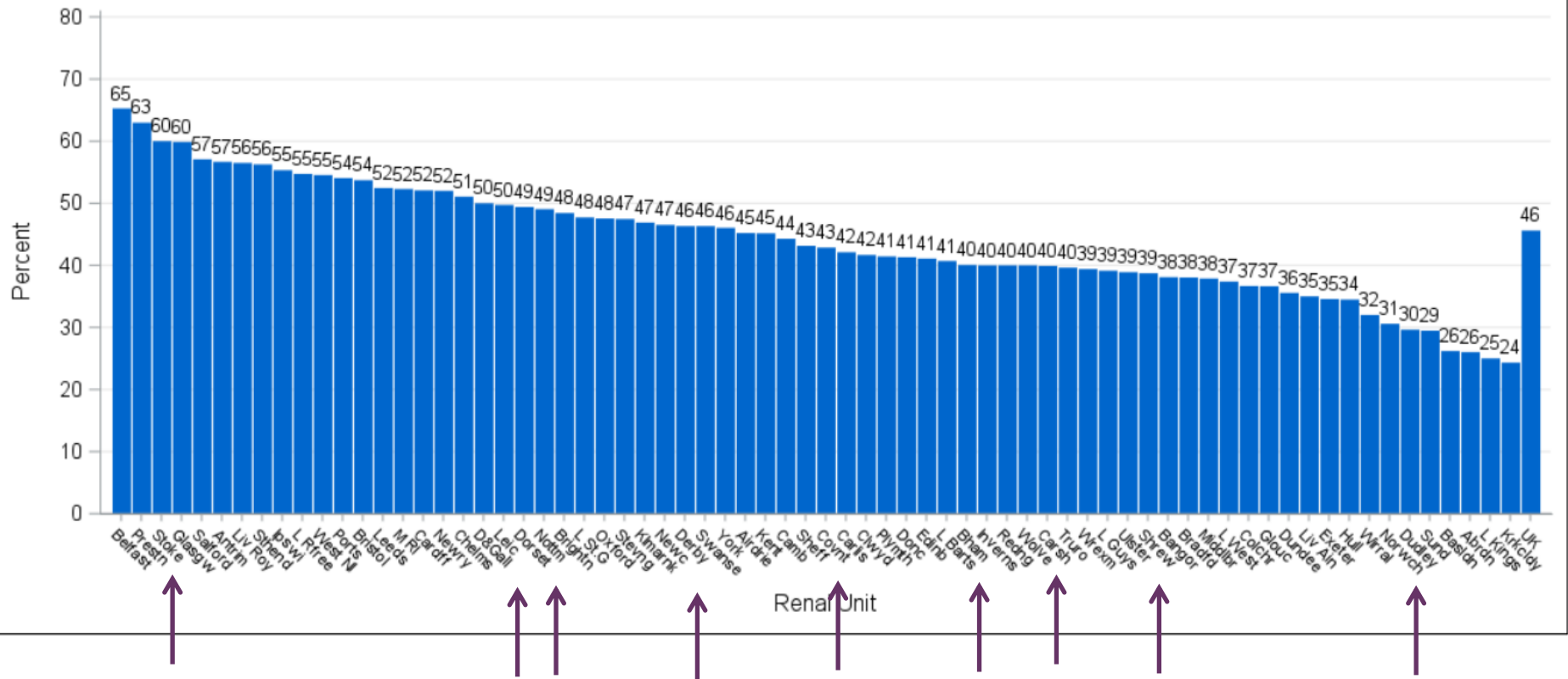


Figure 1.7 Adult pre-emptive listing rates by centre, registrations between 1 April 2016 and 31 March 2019

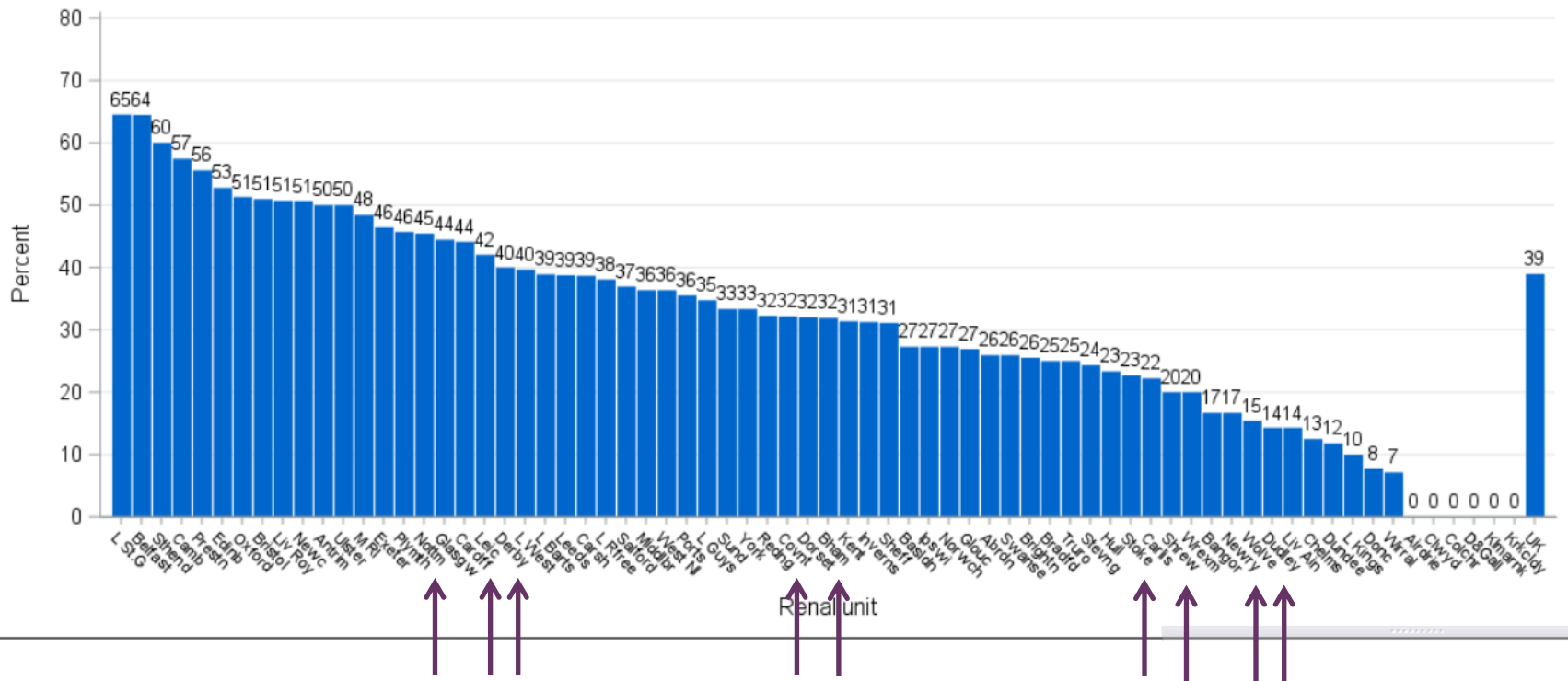




# Pre-emptive LD

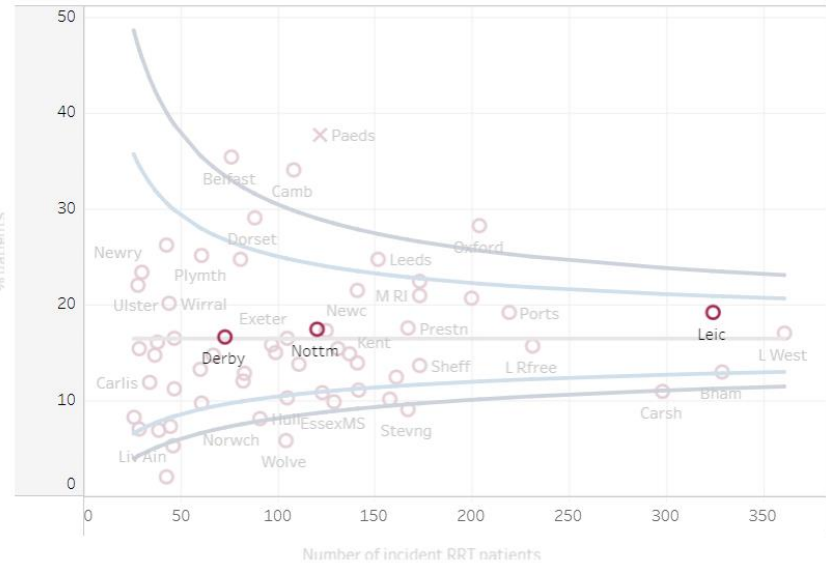
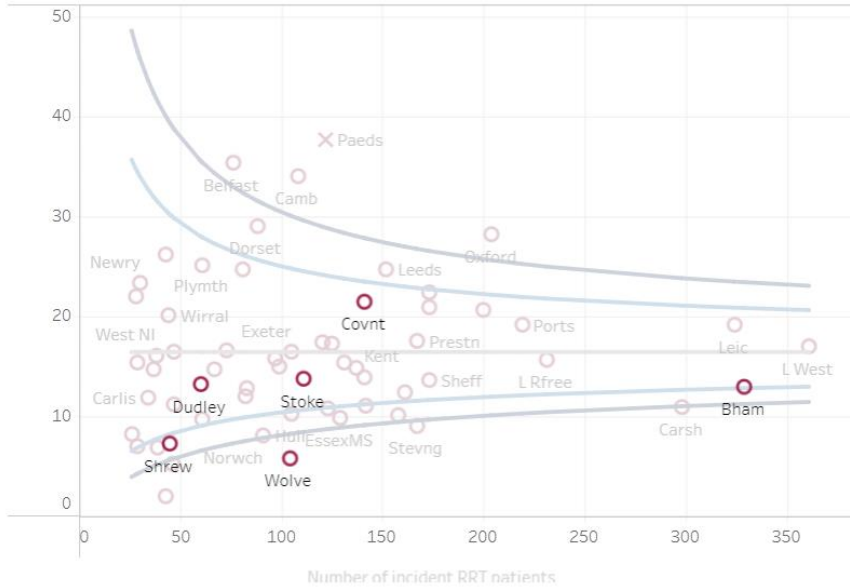


Figure 2.6 Adult living donor pre-emptive transplant rates by renal unit, 1 April 2017 - 31 March 2020



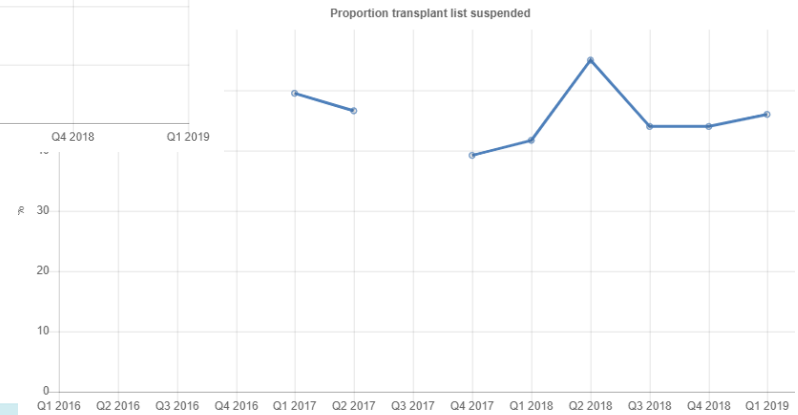
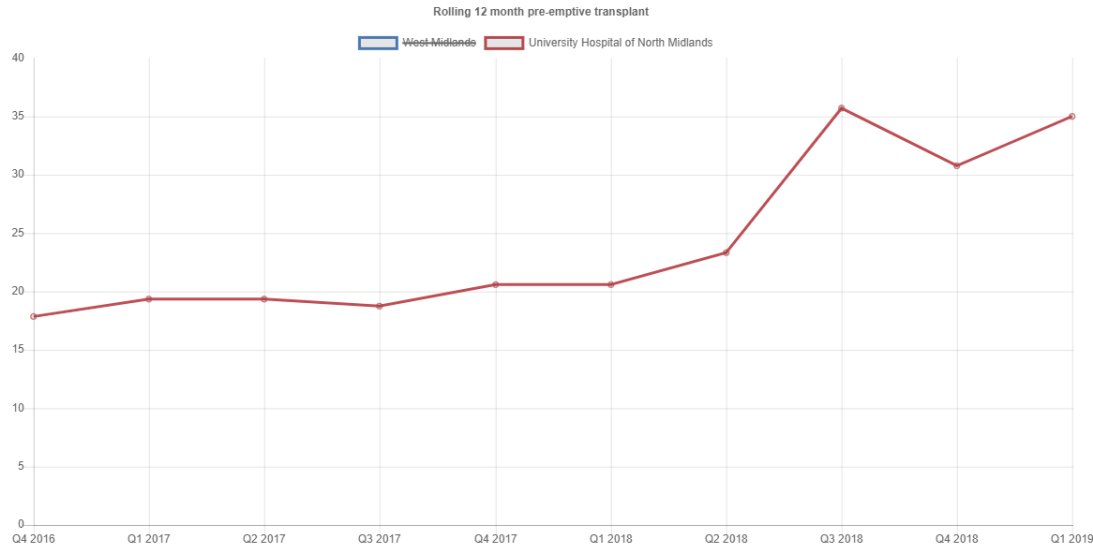


# Adjusted % of incident RRT patient with pre-emptive listing or LD





# + What the TF data tool collects: Performance



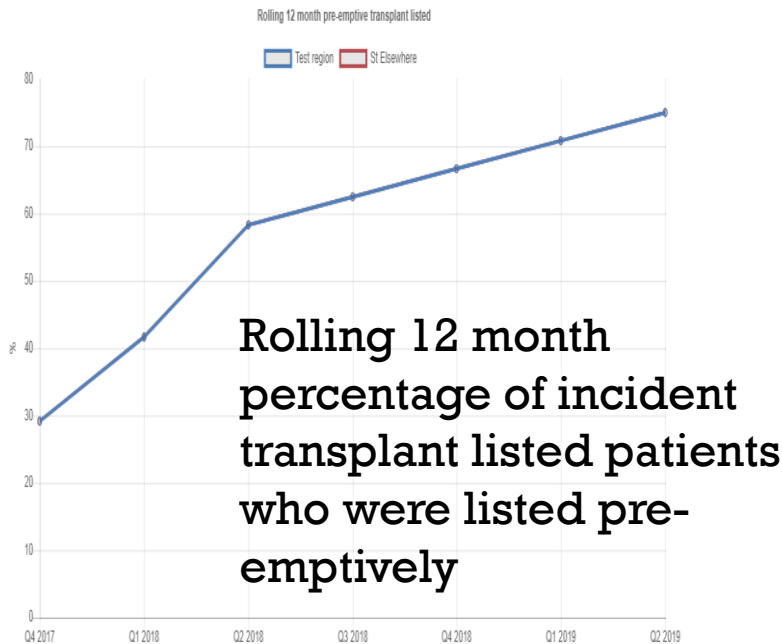
Proportion of CKD5 patients who have a Transplant Status on Renal IT System  
(Optional - if region choose to report this data)

	Total number of patient	Number of patients with transplant status	Percentage of patients with transplant status
HD	280	248	88.57%
PD	86	69	80.23%
Transplant with eGFR < 15	15	14	93.33%
CKD5 not yet on dialysis	165	134	81.21%
<b>Total</b>	<b>546</b>	<b>465</b>	<b>85.16%</b>

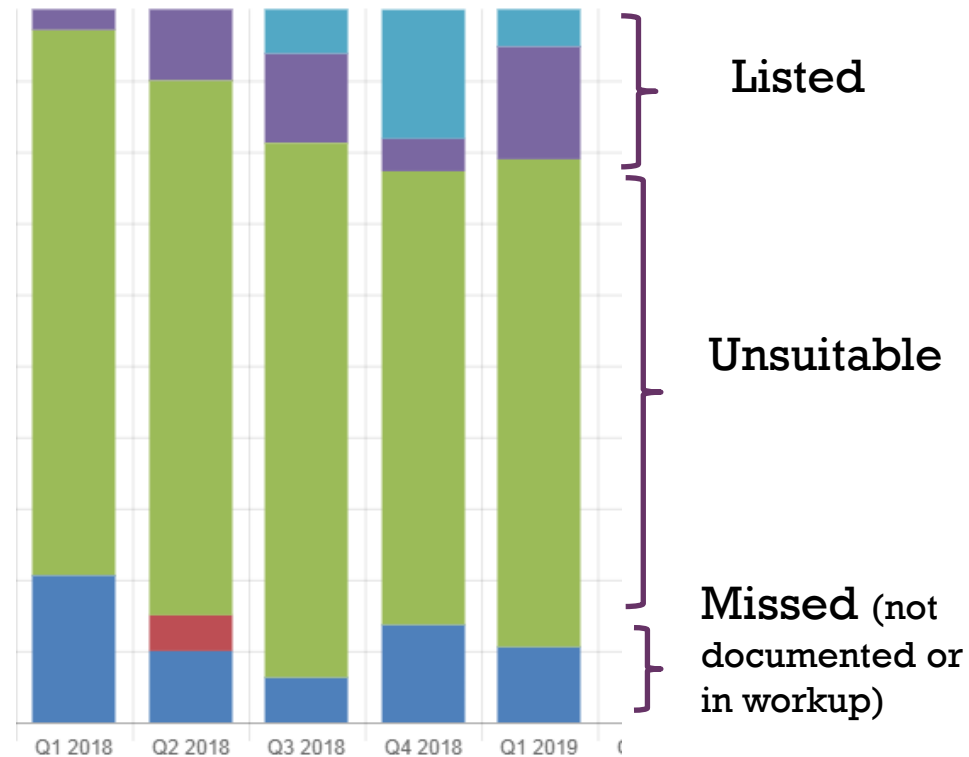
# + What the tool collects: performance at two time points in the patients journey



## ■ TRANSPLANT LISTING



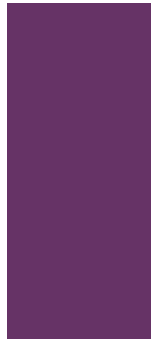
## ■ DIALYSIS STARTERS



Data made up in these graphs



# Dialysis starters: not acute starts, known to unit



**NHS England**

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**NHS commissioning**  
**Specialised services**

National Programmes of Care and Clinical Reference Groups  
 Internal Medicine  
 Cancer  
 Mental Health  
 Trauma  
 Women and Children  
 Blood and Infection

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### Specialised services quality dashboards

Specialised Services Quality Dashboards (SSQD) are designed to provide assurance on the quality of care by collecting information about outcomes from healthcare providers. SSQDs are a key tool in monitoring the quality of services, enabling comparison between service providers and supporting improvements over time in the outcomes of services commissioned by NHS England.

For each SSQD, there is a list of agreed measures for which data is to be collected. These measures are included in a 'Metric Definition Set'.

No	Status <sup>?</sup>	Reason <sup>?</sup>	Comment	Actions
1	Active on list			
2	Suspended from list			
3	Documented as unsuitable			
4	Working up or under discussion	Select Reason		
		<i>This field is required.</i>		
5	Working up or under discussion	Referred for Assessment when eGFR < 15	Missed in peripheral clinic	
6	Working up or under discussion	Referred for assessment within 1 year of predicted date of reaching ESRF		
7	Working up or under discussion	Patient DNA on at least 3 separate assessment Appointments		
8	Working up or under discussion	Medically Complex		
		<i>This field is required.</i>		
9	Working up or under discussion	Delays in system		
		<i>This field is required.</i>		
10	No documented decision	Unsuitable for transplant but NOT documented		

[Export data](#)



# Data entry: Transplant listing data

Enter date of transplant listing and dialysis start

Tool works out days to listing

If listing not pre-emptive a reason is required



List all p

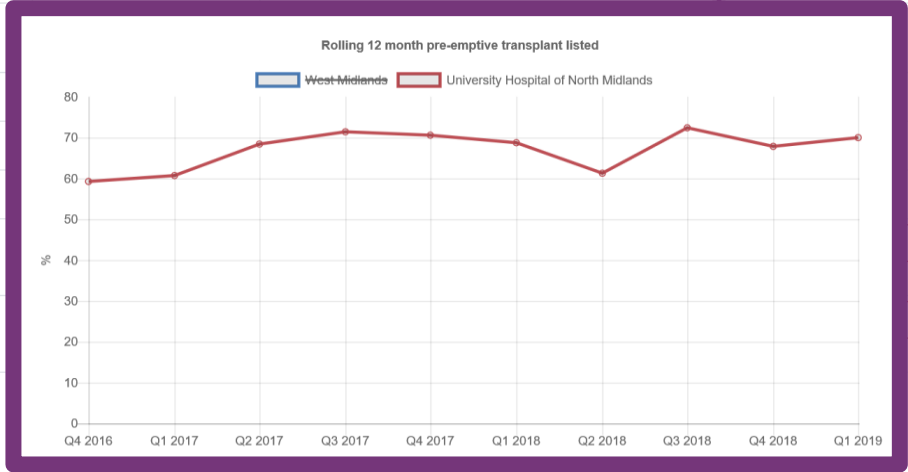
had been on dialysis or if they were pre-emptive

Number of patients listed in quarter	9
Number of patients pre-emptively listed	6
Percentage of patients pre-emptively listed	66.67%
Median time to listing (in days)	0
Mean time to listing (in days)	107

Comment may be required

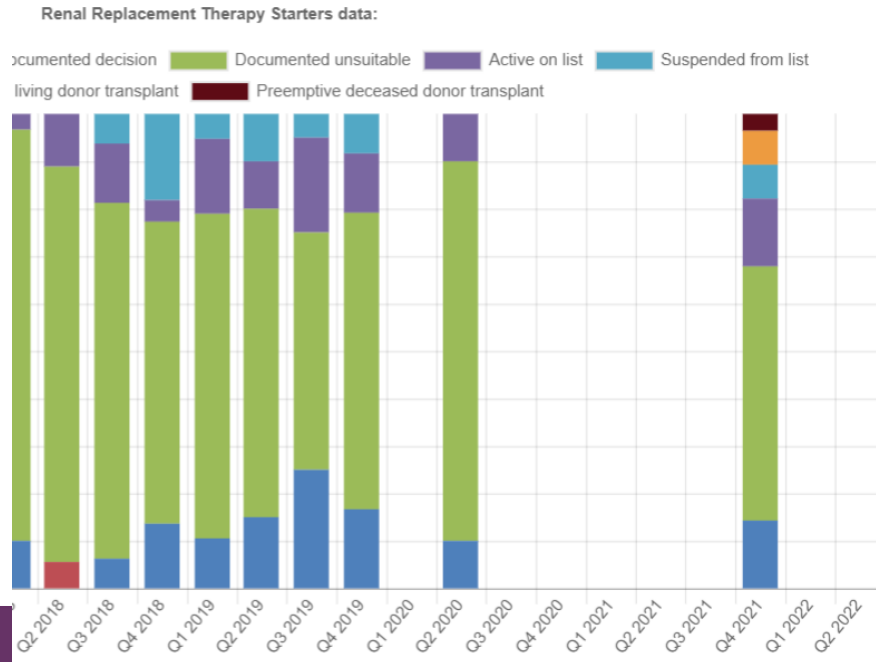
No				
1				
2	05/05/2016	01/01/2016	402	0
3	01/01/2014	01/01/2016	720	720
4	01/02/2015	01/01/2016	330	330
5	03/06/2015	01/01/2016	208	208
6	05/07/2015	01/01/2016	176	176
7	<input type="text" value="11/09/2015"/>	<input type="text" value="01/01/2016"/>	110	110
8	<input type="text" value="12/10/2015"/>	<input type="text" value="01/01/2016"/>	79	79

Add new entry



# + Further developments

- Addition of pre-emptive LD and DD transplants to RRT starters



## Living donor status

**At least 1 potential living donor has reached stage 1 tests**

Select this option even if the donor was subsequently unable to proceed

**No potential living donors have reached stage 1 tests**

This audit measure is designed to show early identification of donors. If donors have been identified but not yet proceeded to stage 1 they are not recorded here

# + How we have used the data



- This information can be used to target areas for change and QI. For example:-
  - change structure of clinics
  - looking at how we communicate with other specialties
  - exploring causes of DNAs
  - regionally- cardiology practices



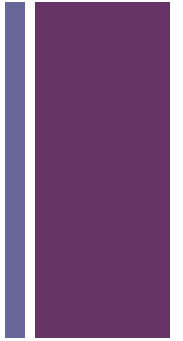
Thanks to everyone working to  
improve access to  
transplantation





## ■ **Barriers identified**

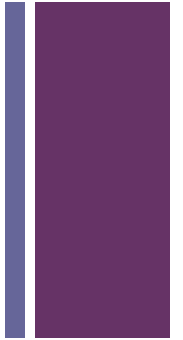
- Psychology testing
- Time off work for donor
- Unmanageable numbers in Facebook campaigns (then not proceeding)
- Radiology dept schedules
- Not being able to do all workup locally
- Perception of risk and how to convey it meaningfully
- Not giving information upstream e.g. in low clearance clinic
- Donors coming forward unaware how to access teams
- Recipient concerns for donors
- Batching donors
- Complexity of pathways
- Ability to personalise (e.g. out of hours appointments)
- Overweight donors

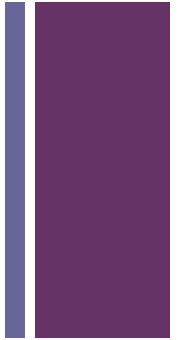






- Matching donor and recipient timelines- especially if done across two centres
- Specific units issues (e.g. fortnightly meetings)
- Location of HTA assessors and Psychologists
- Some donors are waiting to be contacted. Can we contact them?
- GP responses to queries delayed
- GP lack of knowledge
- Uncertainty about information resources
- Staff turnover
- Limited resource (staffing or money for tests)
- Hospitals blocking referrals to other units
- Overseas donors and visas
- For Children's hospital –teenage recipients
- LDCs often single handed- back up for donors when they are away





## ■ **Unit Actions**

- Reduce numbers of visits (reduce consultations and batch tests)
- Consider Donor group talk
- Change timing of Xmatch
- Review batching (note- the updated LD guidelines suggest not to batch donors)
- Wolverhampton- share CKD/GP information pack?
- Audit Donors about their experience (UHB) (note- NHSBT developing Patient experience measures)
- Closer work with low clearance teams to give them power to educate potential donors and identify most at risk patients
- Consider local GP campaigns (inform them of films above)



# Data from pilot work at University Hospitals North Midlands: Q4 2016-Q3 2018



- Average sized Renal Unit
- This unit had already done QI work in transplant listing and the rate of late referral for transplant assessment was relatively low and pre-emptive listing high
- Patterns were noted e.g. late referrals from joint diabetic clinic
- Constant feedback to team (included on low eGFR MDT)



# + Reasons why transplant listing was missed



	“Missed” dialysis starters	Transplant listed after dialysis	
Referred when eGFR<15			
Referred within 1 yr of predicted RRT		3	Referred within 1 yr of predicted RRT
Complex	8	9	Complex or unsuitable became suitable
Multiple DNA	4	1	Multiple DNA
Delays	4	1	Delays
		2	Transferred in
		1	Unplanned start
		1	Patient choice





# Reasons why transplant listing was missed

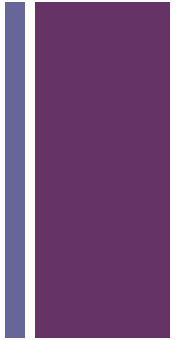


- Taking all the complex patients, the single most common unavoidable reason was waiting for a nephrectomy
- The commonest avoidable reason was waiting for other specialty opinions
- System delays included
  - random practical problems such as losing letters
  - appointment capacity
  - protracted decision making between transplant centres and multiple specialties





# ATTOM: Patient factors associated with pre-emptive listing

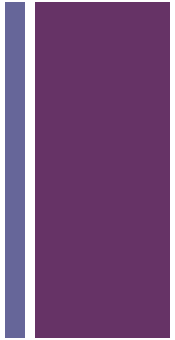


- Age > 50
- Ethnic group (Asian and Black)
- BMI (> 35)
- Education
- Car Ownership
- Accommodation
- Employment
- Time First seen by nephrologist
- Diabetes
- Cerebrovascular disease
- Vascular Disease
- Malignancy
- Heart Disease
- Heart Failure
- Current Smoker

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
  - 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