



KQuIP

Improving access to pre-emptive and living kidney donation

Regional workshop

Monday 12th September 2-4pm



Agenda for today



Midlands Kidney Network



Time	Topic	Speakers
2pm – 2.15	Introduction and welcome	Liz Wallin
2.15 – 2.30	Patient experience	Paul Viola
2.30 – 3.45	Unit presentations on Transplant First audit tool completion and health equalities <ul style="list-style-type: none">- Hear from each other about local approaches to the audit, learning so far- Share ideas and opportunities for collaboration to overcome locally identified health inequalities.	All
3.45 – 4pm	Summary and next steps	Catherine Stannard



Midlands Kidney Network



Unit presentations

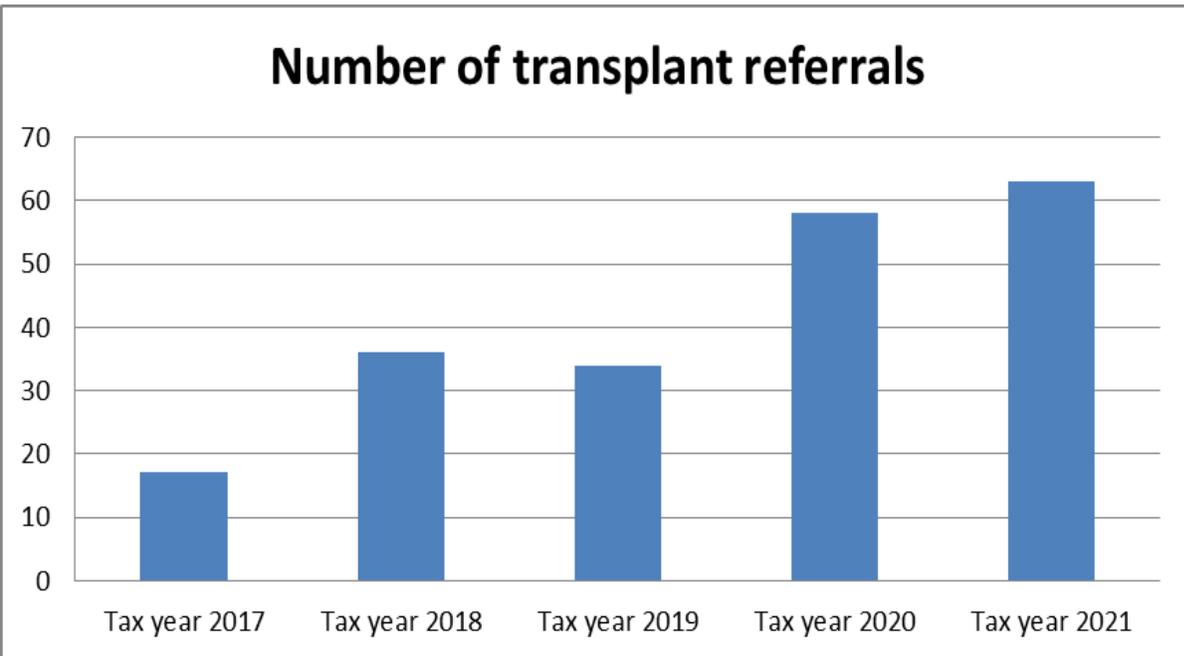
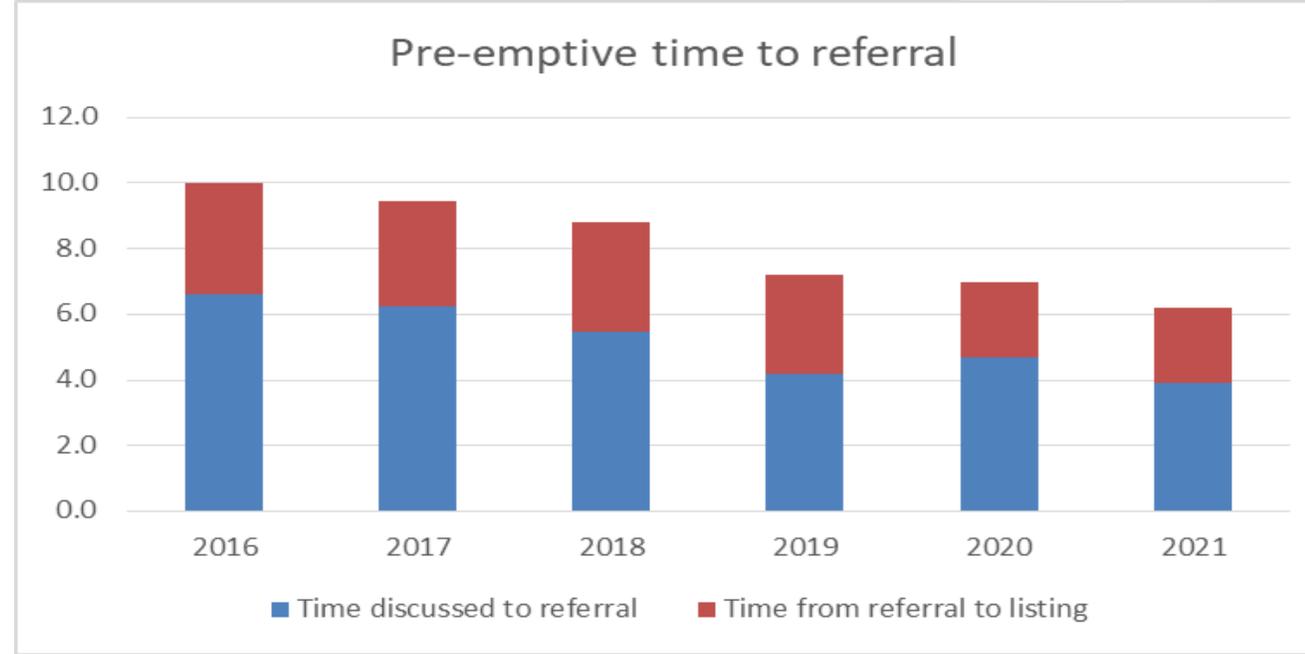
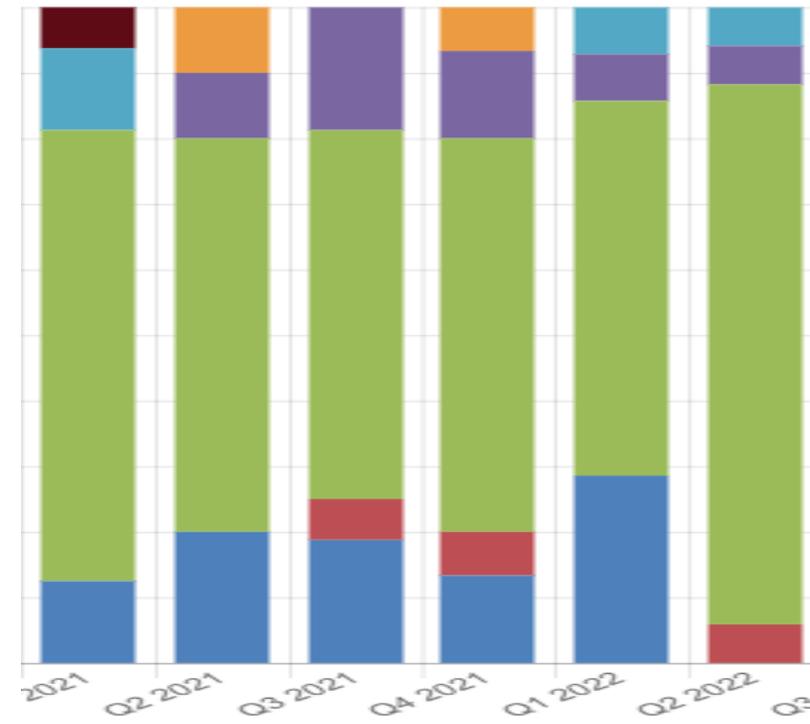
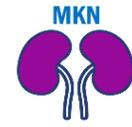
KQuIP



Living Donor Updates Shrewsbury & Telford NHS Trust

Monday 12th September 2022

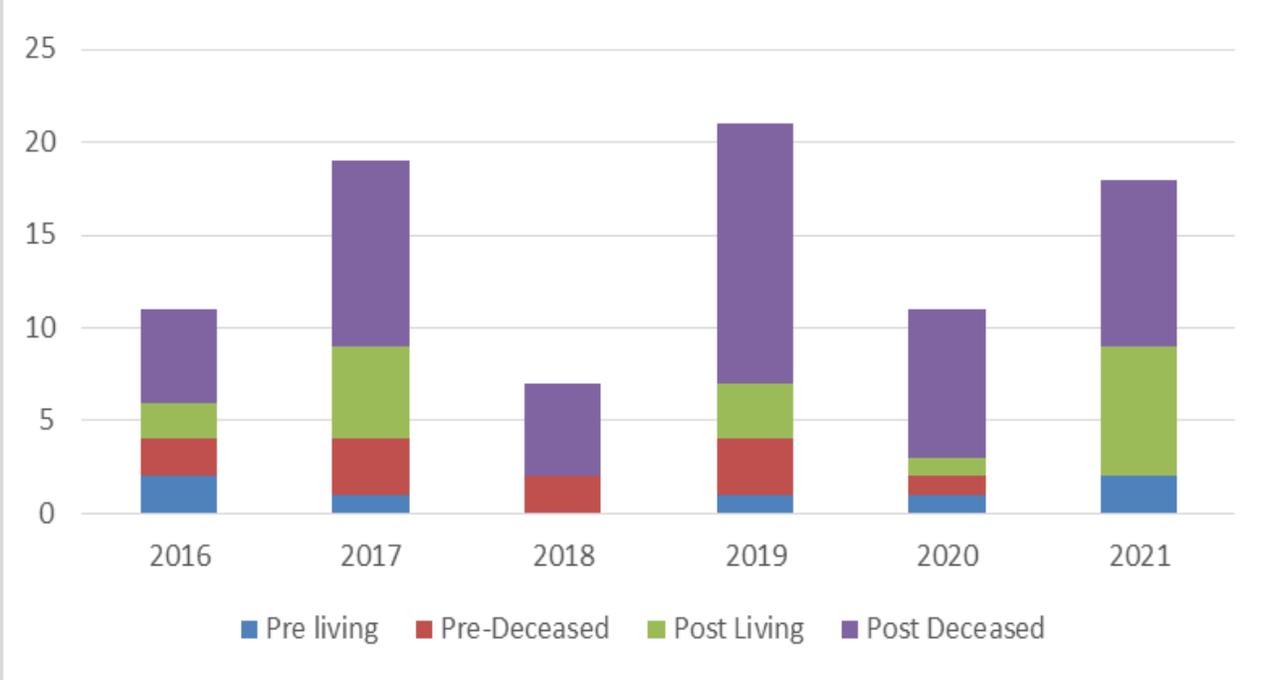




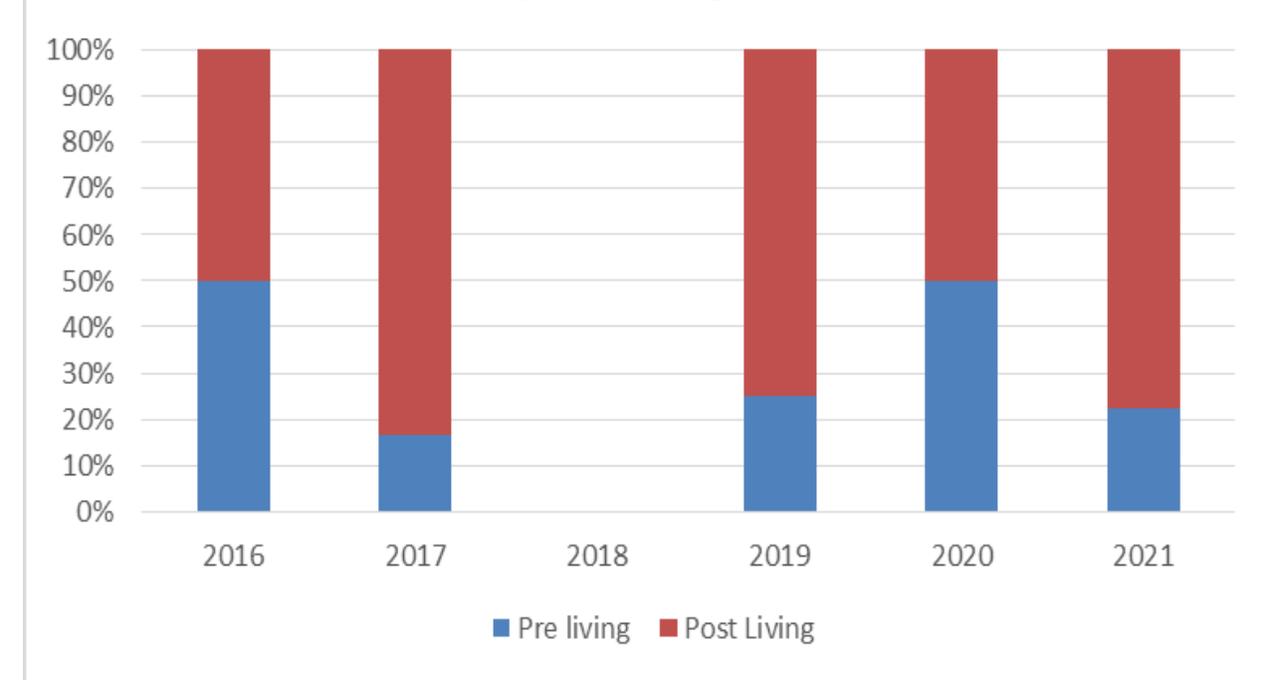
2021-2022 data on transplant status for RRT starters for Shrewsbury & Telford NHS Trust.

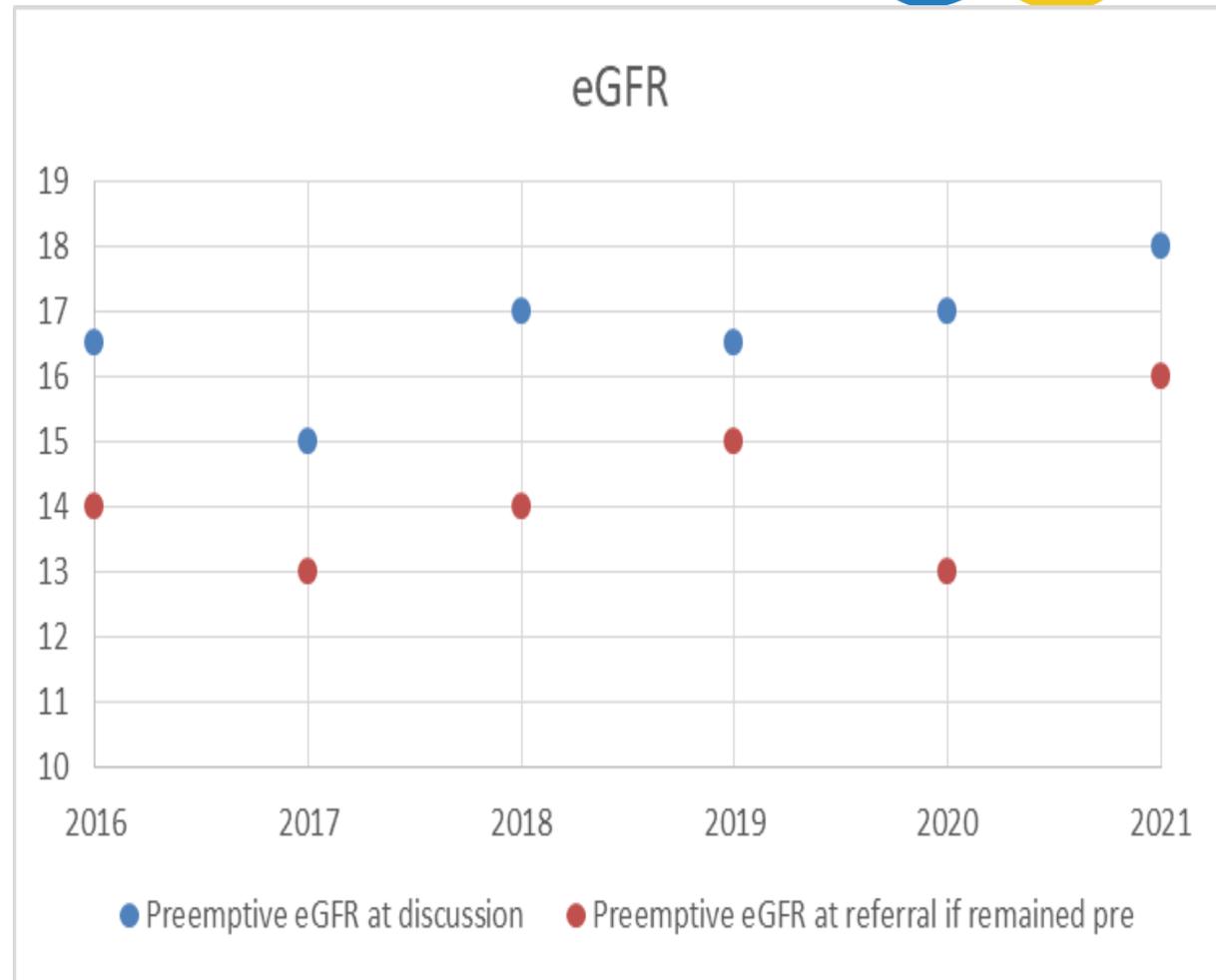
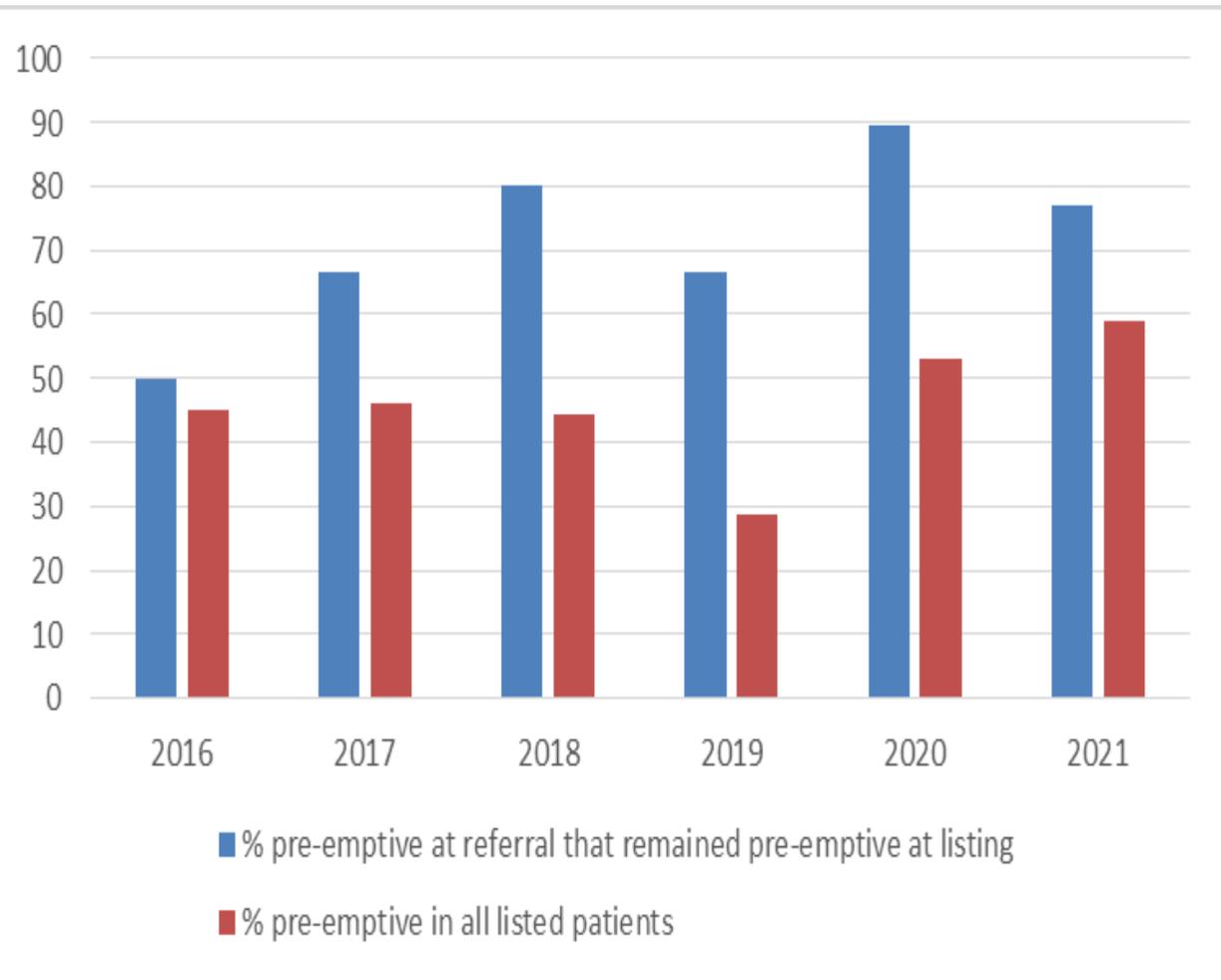


SaTH Transplantation Tax Year



% Pre-emptive living donor rates





Reasons identified for 'Missed' patients at UNIT



Only one Transplant Nurse for service until October 2021.
Complex medical issues including urology, cardiology, nephrectomy, respiratory issues delaying things.
Patients not having tests done in adequate time frame-eg blood group and ecg despite reminding them.
Issues with patients engaging with renal team.
Obesity previously couldn't be listed and now we use Coventry for higher BMI patients.
Previously unfit for transplant and then deemed suitable.
Different Consultant taking over their care.
Pandemic.
Walk in services decreased due to covid.
Small number of status not documented compared to some time ago but still address this issue on a regular basis.



If collected: What % of patients have a living donor who has reached at least phase 1



Out of 70 patients listed from 2020 onwards 27 donors got to Phase 1 tests = 38.6%.

Of these donors

- 6 live donors transplants went ahead-1 pre emptive.
- 3 have planned operation dates-no pre emptive.
- 1 donor signed off and await recip to loose weight, currently pre.
- 2 donors found unsuitable to donate.
- 1 donor changed their mind.
- 2 donors stopped as pt changed their mind.
- 2 patients transplanted from transplant list.
- 6 donors in testing at UHB.
- 1 donor in paired exchange.
- Some patients had more than 1 donor.

All our Renal Team are not afraid to ask any patient about living donation.



Patient experience results (*paper questionnaire*)



We sent five questionnaires out and only got one back-good feedback on this.



Locally identified health inequalities:



Social economic status

We have a Renal Social Care coordinator in post-our Jewel in our Crown for all patients.

Cultural issues

Gift of Life book now in Polish, Urdu, Punjabi and Somali-off NHS BT website – to reflect the minority of our population (~10% CKD patients). Have access to an interpreter if needed.

BMI and Geography overlap

Differing access to potential obesity services

Differing units (however also positive for local expertise to resolve) (SPK in Cardiff with own protocols)

Psychology

Currently awaiting Psychology post to be advertised for Renal Services.

Patients can refer themselves to Shropshire Psychological Therapies service themselves in Shropshire.

Leaflet given to patients. Very rural area and high number of suicides in Shropshire.

Transplant nurses drop in service if needed for support. 1hr pre transplant OPD review.



Next steps for our unit:



Main Aim:

Increase pre-emptive living donation to 20% of incident transplant patients by April 2024.

Drivers:

Increase pre-emptive listed transplant status to 60% of all listed by April 2024.

Patients “missed” patients (i.e. in workup or no decision at start of RRT) to be less than 20% if timely referred to nephrology

How?

Talk earlier eGFR based on risk of progression

Introducing idea of transplantation and living donation – cultural specific data from NHSBT videos esp what it is being a donor

- Tangri (>20% RRT risk at 2 years)
- 3 monthly review of eGFR <30 report (example next slide)

Next steps for our unit:

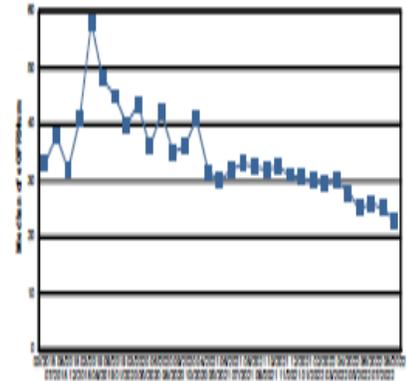


Clinical vision
eGFR<30, age
<70 initially
report

Age 55
GFR 23.00 ACR 310.00

Tx plan

Diabetic nephropathy in type I diabetes - no histology



Next steps for our unit:



- Increased Transplant Nurses support to 3 to manage case load
 - with NHSE post to promote living donation
- Plan for Transplant notice boards to be updated throughout the Trust as well as in clinic areas. ? As well into Phlebotomy areas.
- 3 monthly meeting
 - all Renal Consultants transplant list and those at risk
 - MDT with UHB on all transplant patients and advise on other patients as well. Live donor team on meeting as well.
- Attending UHBs Transplant waiting list MDT weekly and live donor MDT via teams.
- Access to Healthy lifestyles service for Telford area only currently.
- Access to Tier 2 and 3 weight management system for our patients and donors early in CKD
 - Preferably 2 years before workup as takes time

Stakeholders



- NHSE nurse post to promote living donation
- Trust permission (Hummingbird) for access to notice boards to be updated throughout the Trust as well as in other clinic areas
 - Phlebotomy areas, dialysis units, PRH and RSH OPD areas
 - OPD area video to highlight websites for information
 - ?with clinic letters as more virtual clinics
- Advanced kidney care, CKD and dialysis teams
 - All grades
- Bariatric service (RSH) and Healthy Lifestyle Teams (PRH)
- Transplanting centres
 - Cardiff, Coventry, QEHB



Living Donor Updates

University Hospitals North Midlands

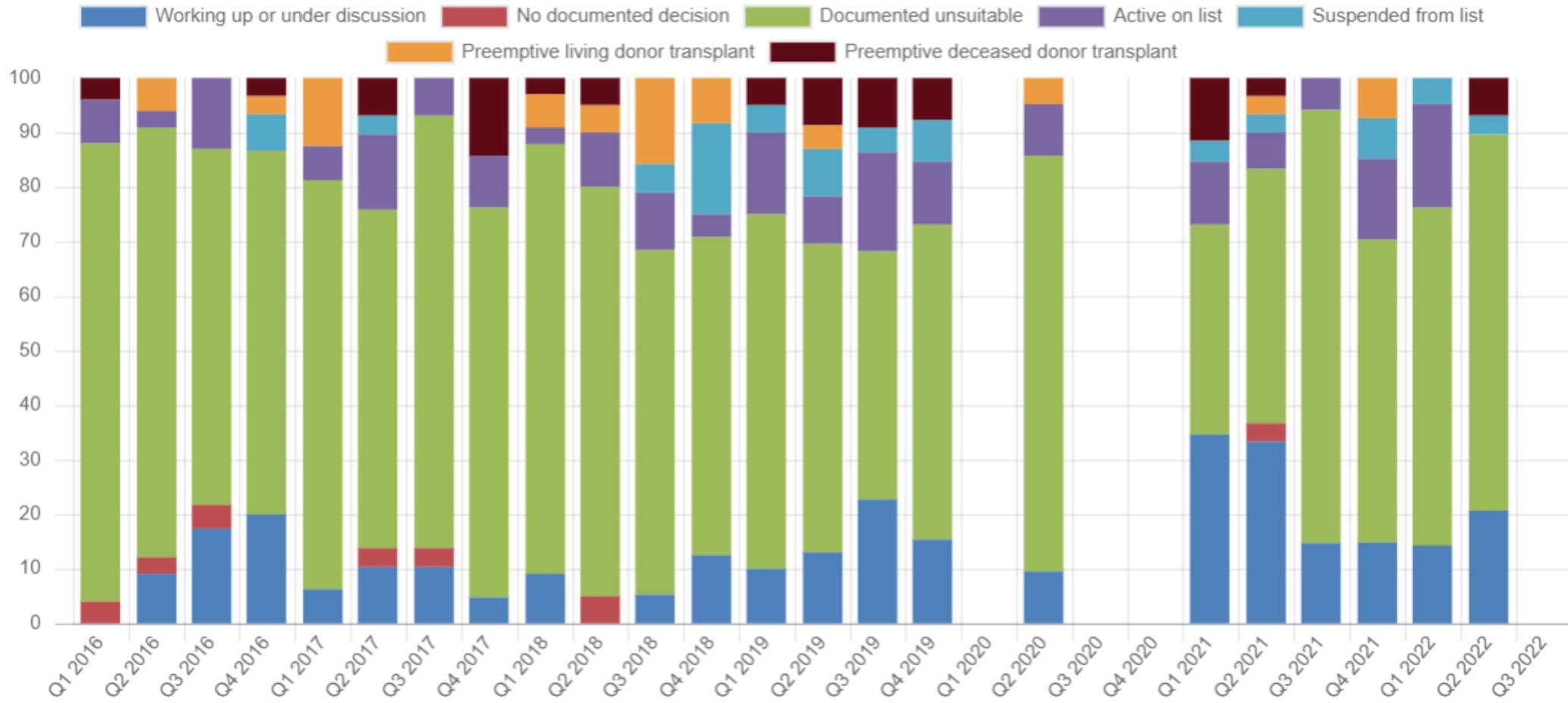
Monday 12th September 2022



2021-2022 data on transplant status for RRT starters



Renal Replacement Therapy Starters data:

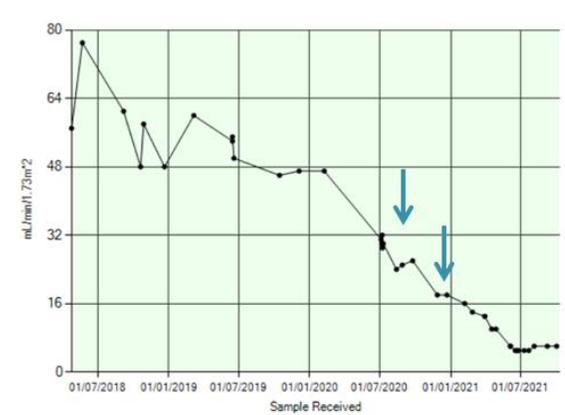


Reasons identified for ‘Missed’ patients at UNIT

[Reasons why patients were still in category “working up or under discussion” or “not documented” at time of starting dialysis]



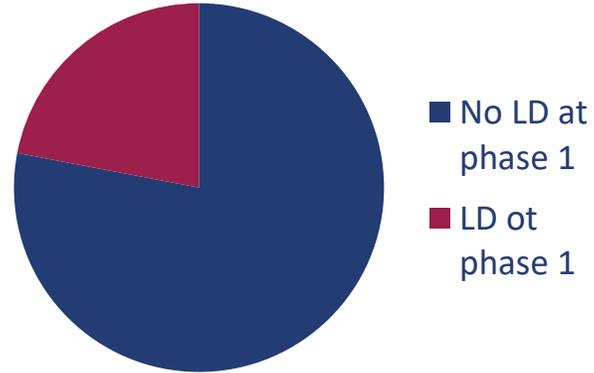
- Delays due to Covid (pause in service, staff shortages)
- Indirect delays due to capacity (3-8 months from referral to transplant unit to listing)
- Late referral for rapid but predictable decline
 - Not in AKCC
 - DM or other proteinuric renal disease
- Not moving assessment forward at each visit
 - Not seen by consultant
 - Not doing things in parallel
 - Not addressing patient concerns
 - Learning disabilities
- High BMI
 - Dietetic support not systematic
 - “surprise” turndowns



If collected: What % of patients have a living donor who has reached at least phase 1



- 2021 data



Patient experience results (*paper questionnaire*)



- Sorry – still a work in progress





Locally identified health inequalities:

In particular focussing on those identified in the KRUK report

(https://www.kidneyresearchuk.org/wp-content/uploads/2019/09/Health_Inequalities_lay_report_FINAL_WEB_20190311.pdf) and any

others you have found to be an issue locally, for example:

Social deprivation

Ethnicity/language barriers

Gender

Age

Sexual orientation

*Disability – physical or mental- **one patient with learning disabilities had delayed listing as a result***

Mental health

Geography

Health literacy/education

BMI





Next steps for our unit:

- Introducing KFRE (but would not have been more predictive than eGFR fall)
- Trainings and education between LD co-ordinator and KC nurses
- Update patient information for use in AKCC
- Early US request (tests in parallel/nurse requests)
- Nurses training in Health Care assessment
- Some consultant expansion
- Agreed communication parameters with recipients
- Monthly team MDT
- Patient knows best
- Continued feedback to team



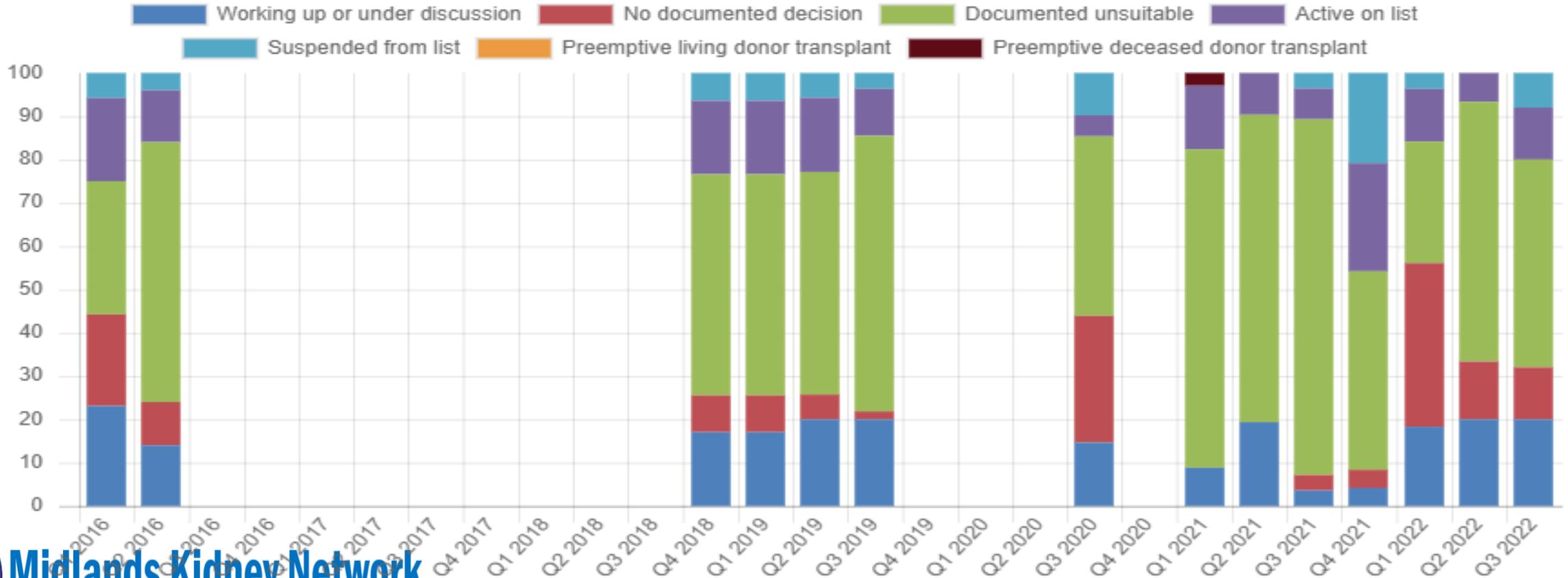
Living Donor Updates
[Heartlands Hospital]
Dr Eqbal/Dr Ahmed Hassan
Monday 12th September 2022



2021-2022 data on transplant status for RRT starters for Heartlands Hospital [2021 and first half of 2022]



Renal Replacement Therapy Starters data:



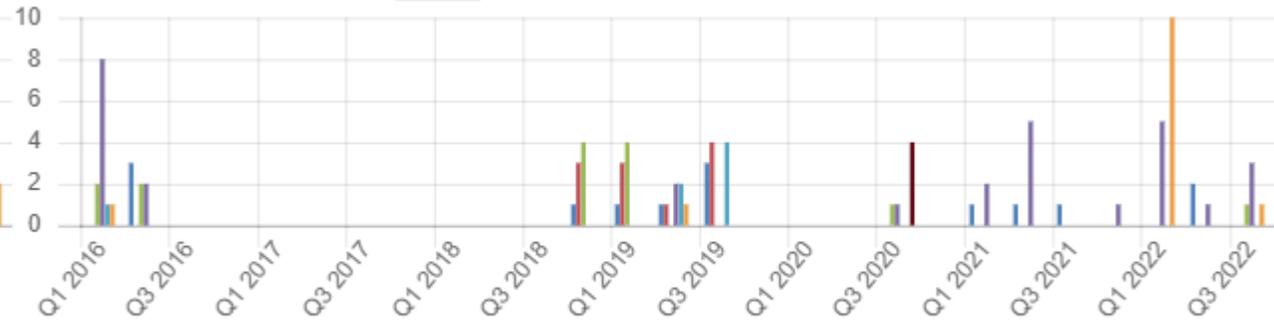
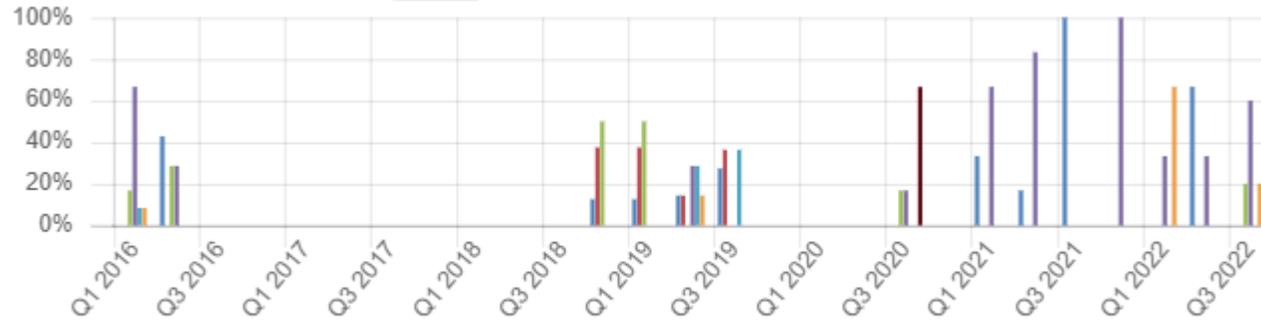
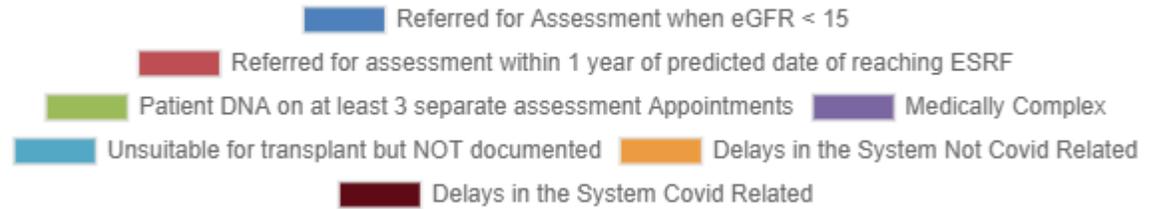
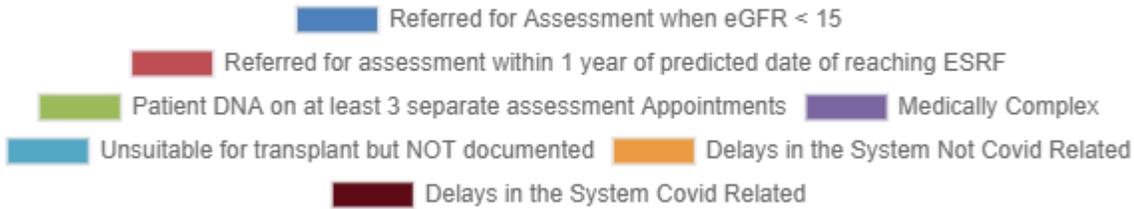
Reasons identified for 'Missed' patients at UNIT

[Reasons why patients were still in category "working up or under discussion" at time of start of dialysis]



Proportions

Absolute numbers

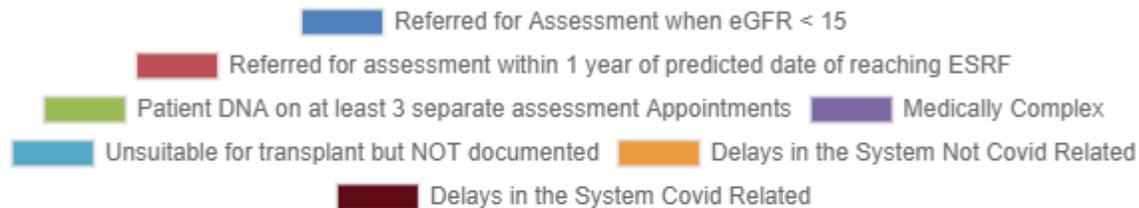


Reasons identified for 'Missed' patients at UNIT

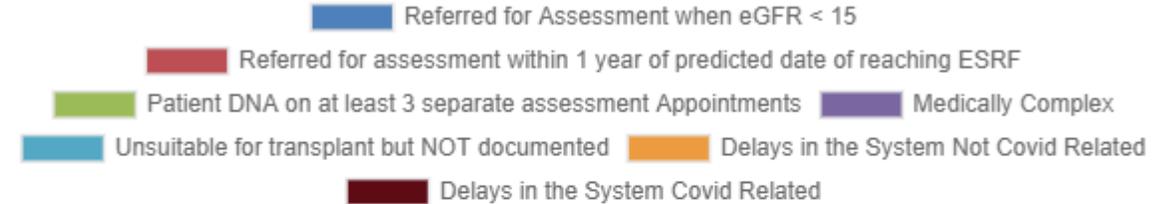
[Reasons why patients were still in category "not documented" at time of starting dialysis]



Proportions



Absolute numbers



If collected: What % of patients have a living donor who has reached at least phase 1



50 % of patients with living donors have donors who reached at least phase 1 (6 out of 12)





Patient experience results (*paper questionnaire*)

It has been sent by our nurses to the patients. Not received back yet.



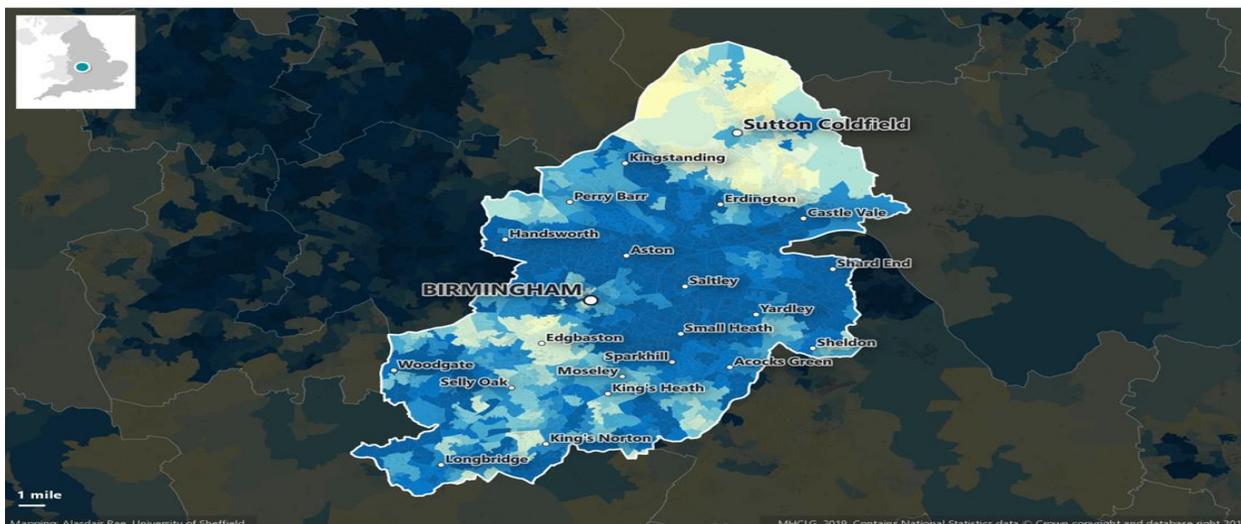


Locally identified health inequalities:

Social deprivation: (still a barrier for getting benefit from the services provided in general, and it is associated with risk factors for CKD. Unfortunately it is highest in the area covered by Heartlands Hospital.

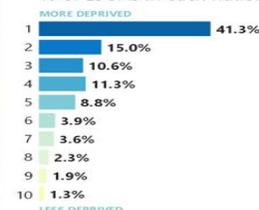
English Indices of Deprivation 2019

BIRMINGHAM



Local deprivation profile

% of LSOAs in each national deprivation decile



What this map shows

This is a map of Indices of Deprivation 2019 data for **Birmingham**. The colours on the map indicate the deprivation decile of each Lower Layer Super Output Area (LSOA) for England as a whole, and the coloured bars above indicate the proportion of LSOAs in each national deprivation decile. The most deprived areas (decile 1) are shown in blue. It is important to keep in mind that the Indices of Deprivation relate to small areas and do not tell us how deprived, or wealthy, individual people are. LSOAs have an average population of just under 1,700 (as of 2017).





Ethnicity/language barriers: Large population of Ethnic Minority in this region with language barrier. Need for Peer Support Service (ideally from same ethnic group with no language barrier)

Age: High percentage of elderly population. Almost 65% patient of our pre dialysis clinic are not suitable for Transplant(due to age and multiple comorbidities)

Health literacy/education : Lots of cultural and religious beliefs need to be dealt with honestly



Next steps for our unit:

LD Coordinators- QE LD coordinators are managing patients from HGS site remarkably well. Currently 12 patients are being assessed for LD.

Funding from the renal network for a B6 nurse for Heartlands Hospital to promote awareness and increase uptake of LRD from the pre-dialysis and dialysis population-
Currently in Process



Thank you



Living Donor Updates [DUDLEY – RENAL UNIT]

Monday 12th September 2022



2021-2022 data on transplant status for RRT starters for UNIT NAME
[Ideally 2021 and first half of 2022, otherwise Jan 2022 to end of August 2022. Please use example format below to allow comparisons:]



Jan 2022 to Aug 2022

9 transplants done – LD none, DCD 6, DBD3

RRT STARTERS = 34(HD =31, PD = 3)

Unsuitable(Medical) = 16

Unsuitable(under review) = 3

Working up = 9 (Referred for Tx = 4)

Under discussion = 2

Active = 3

Suspended = 1

Nil record = 0



Reasons identified for 'Missed' patients at UNIT

[Reasons why patients were still in category "working up or under discussion" at time of starting dialysis]



- Unplanned start (Crashlanders after multiple DNAs)
- Medically Complex
- Delays in the system - MPS scans at Nuclear Med
- Patient undecided



If collected: What % of patients have a living donor who has reached at least phase 1



33% (3 out of 9)



Patient experience results (*paper questionnaire*)



Sent out to patients and awaiting return



Locally identified health inequalities:



In particular focussing on those identified in the KRUK report (https://www.kidneyresearchuk.org/wp-content/uploads/2019/09/Health_Inequalities_lay_report_FINAL_WEB_20190311.pdf) and any others you have found to be an issue locally, for example:

Elderly patient population





Next steps for our unit:

- Band 6 post for a specialist transplant nurse will be out soon – part-time
- New IT administrator started in post recently (vacant for > 3 months)
- Will be putting up clinic for Hep B vaccinations for patients who are under transplant work-up before RRT.



Living Donor Updates

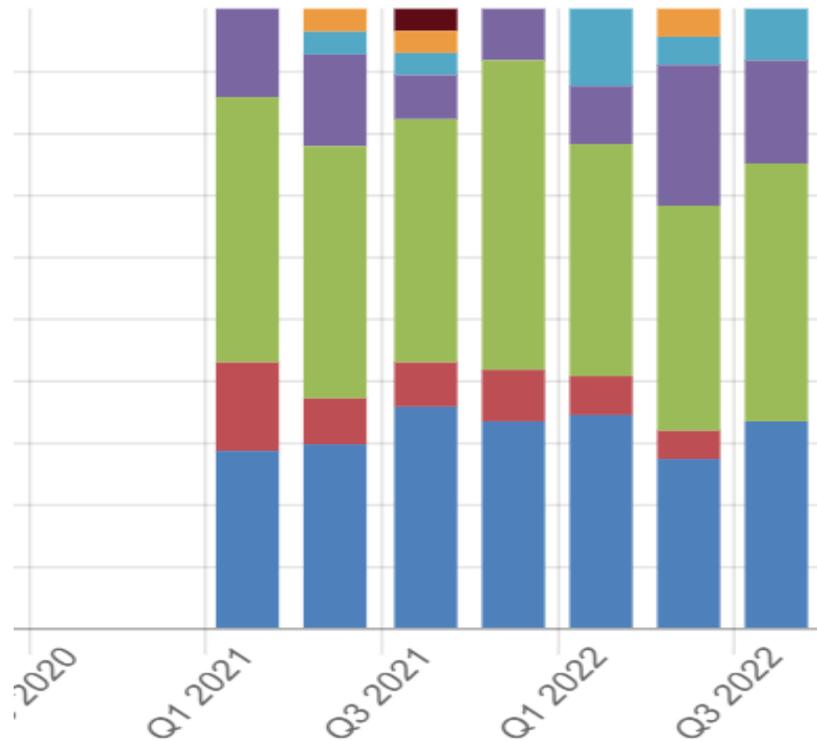
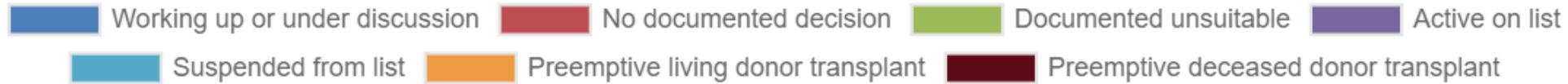
University Hospitals Derby and Burton NHS

Foundation Trust

Monday 12th September 2022



2021-2022 data on transplant status for RRT starters for UNIT NAME
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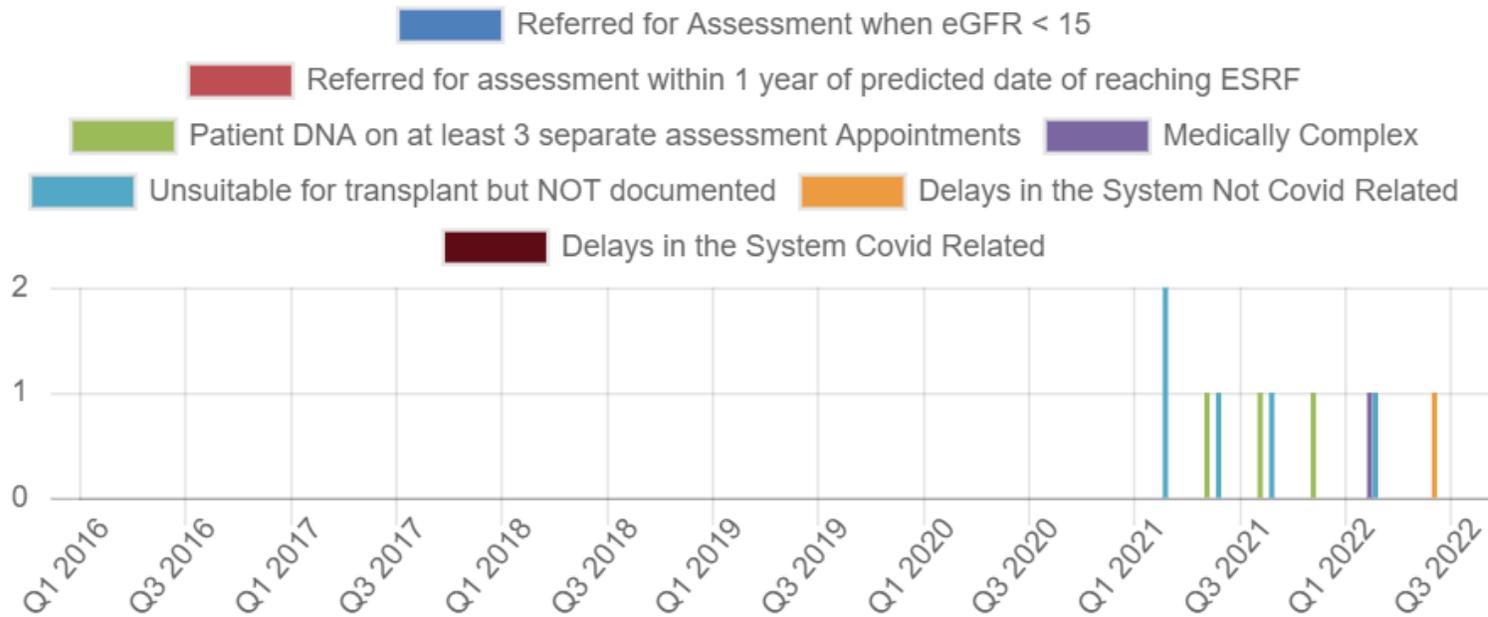


Reasons identified for ‘Missed’ patients at UNIT

[Reasons why patients were still in category “working up or under discussion” or “not documented” at time of starting dialysis]



Absolute numbers



If collected: What % of patients have a living donor who has reached at least phase 1



- Nottingham live donor team keep this data



Patient experience results (*paper questionnaire*)



- No data returned from the registry yet





Locally identified health inequalities:

Whilst all factors on the generic list obviously apply particular concerns are:

Mental health

No local provision (no unit psychologist or even divisional psychologist)

Long waiting list for psychology input from NUH

Disability physical or mental

Learning difficulties nurse vacancy at trust level has been replaced after few months of no-one, however focus from their training is dementia rather than learning disability

Social deprivation

High contributor to attendance problems which have accelerated over the pandemic, related to health literacy and access to community healthcare

Ethnicity/language barriers

Although not a lot of ethnic diversity in our population it is possible that this actually increases barriers to accessing health care as no specific provision

Geography ?reduced with early repatriation





Next steps for our unit:

- Now established LD team meeting and update (every 2 months)
- Interview for new Tx coordinator role next week
- Review and revision of MIBI pathway (discussing with NM) to improve timeliness when required
- Looking towards Derby specific listing MDT with the Nottingham team on Teams



Living Donor Updates

The Royal Wolverhampton Hospital

Monday 12th September 2022



2022 data on transplant status for RRT starters for Wolverhampton

From 1.4.22 to 1.7.22

16 patients started RRT during this time frame

3 patient's had no plan/no discussion

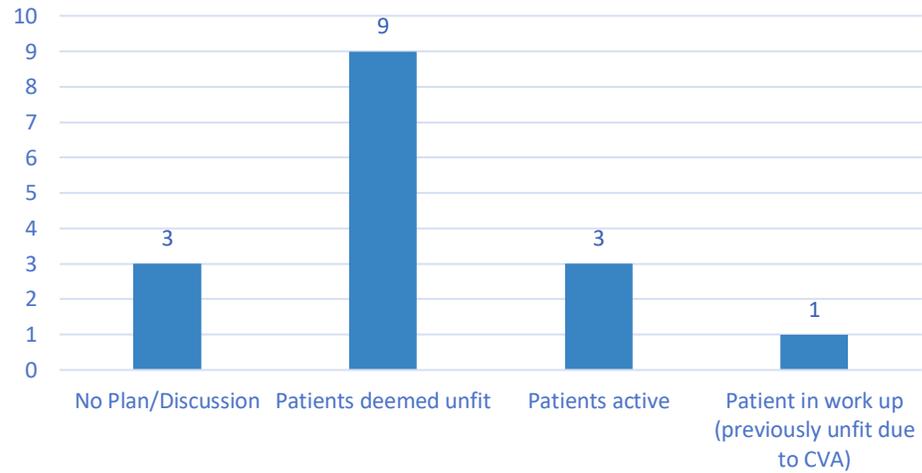
9 patient's deemed unfit

3 patient's active

1 patient working up- previously been unfit due to CVA



RRT starters 1st April – 1st July 2022





Reasons identified for 'Missed' patients at The Royal Wolverhampton Hospitals

3 Patients identified as no plan/ no discussion

1 patient was unsuitable but not documented

1 patient was unfit due to Ca

1 patient had rapid decline and then DNA'd appointment

NB: Outcomes would not have changed but not documented correctly



KQuIP



If collected: What % of patients have a living donor who has reached at least phase 1



1 active patient mentioned a live donor from overseas but no correspondence has been recieved





Next steps for our unit:

Funding received from Network for live donor/Listing nurse

- Improve/enhance service

- Timely listing

- Follow-up those that may have previously been unfit that could become eligible for listing

- Increase live donor numbers

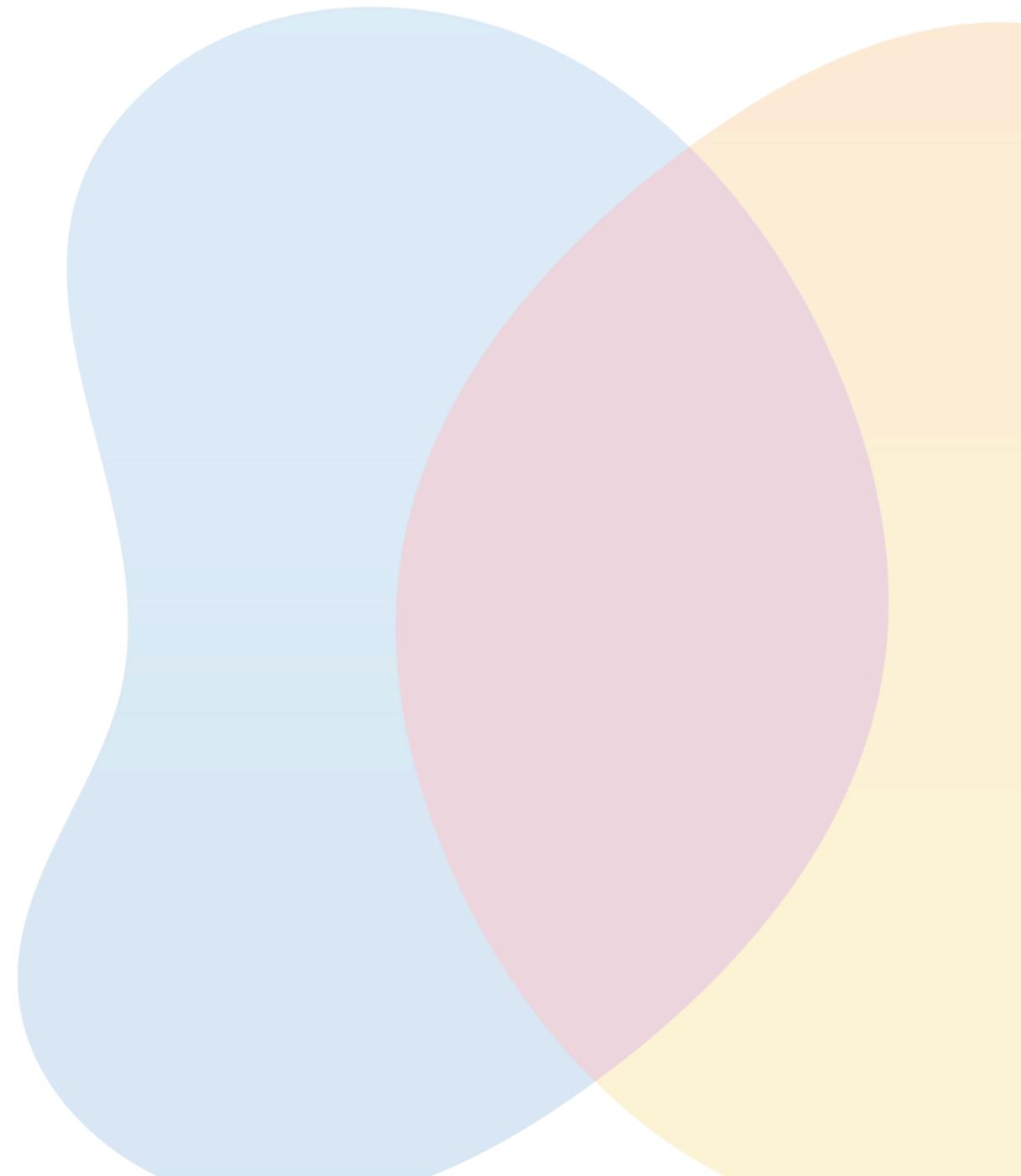
- Timely audit data

- Increase profile of transplantation/listing



Living Donor Updates Nottingham

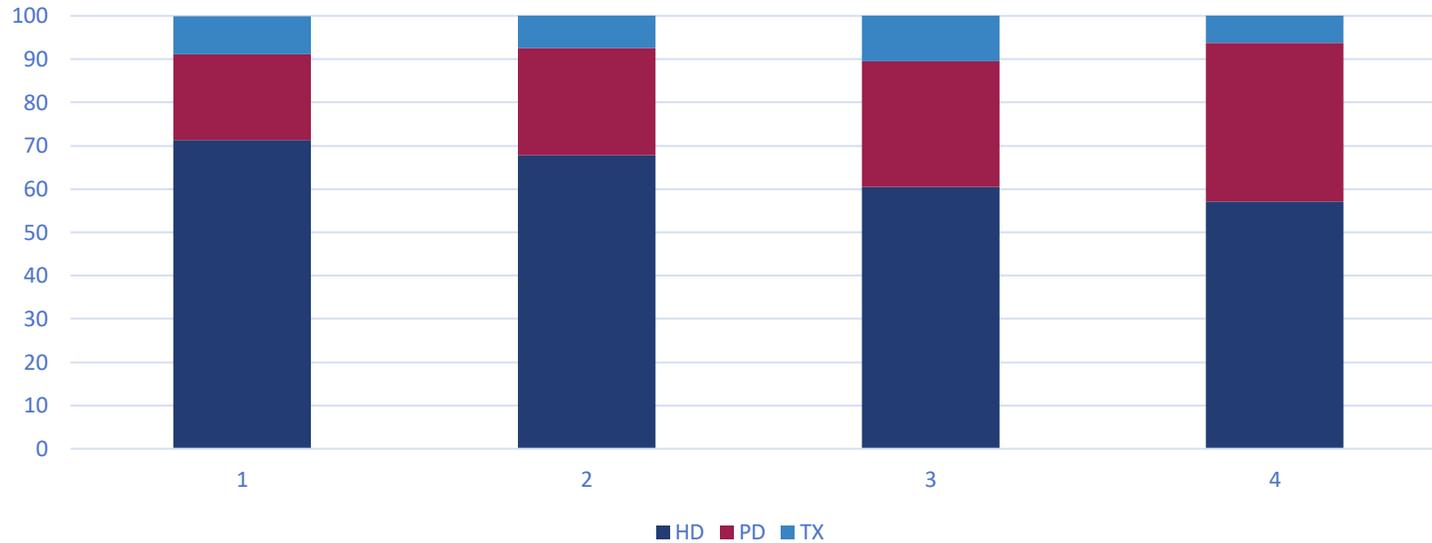
Monday 12th September 2022



2017-2020 data on transplant status for RRT starters for Nottingham



Modality at start of RRT



- NHSBT data April 2021-March 2022
- 50% of live donor transplants were pre-emptive
- 14% of deceased transplants were pre-emptive
- 57% of our patients are placed on national waiting list pre-emptively



Reasons identified for ‘Missed’ patients at UNIT

[Reasons why patients were still in category “working up or under discussion” or “not documented” at time of starting dialysis]



Reason	No (%)
waiting for other specialty	8 (12%)
cardiac imaging	9 (13%)
iliac doppler	6 (9%)
other imaging	3 (4%)
high BMI	6 (9%)
covid issues	5 (7%)
others	31 (46%)



If collected: What % of patients have a living donor who has reached at least phase 1



49 donors in work up : at least 1st visit booked
+ 5 pairs have a date for surgery this yr
+ 1 pair awaiting a date for surgery



Patient experience results (*paper questionnaire*)



- All questionnaires completed and sent back: results awaited



Locally identified health inequalities:

- Delays in imaging – worsened post Covid
- Mental health
- Psychology service waits
- BMI and access to weight loss support/bariatric services





Next steps for our unit:

- Start completing the transplant first data base
- Business case for extra psychological services – 1 year funding agreed
- Charitable funding for weight loss services to aid transplant listing – pilot of 40 patients only
- Re-audit the transplant referrals pathway due in April 2023



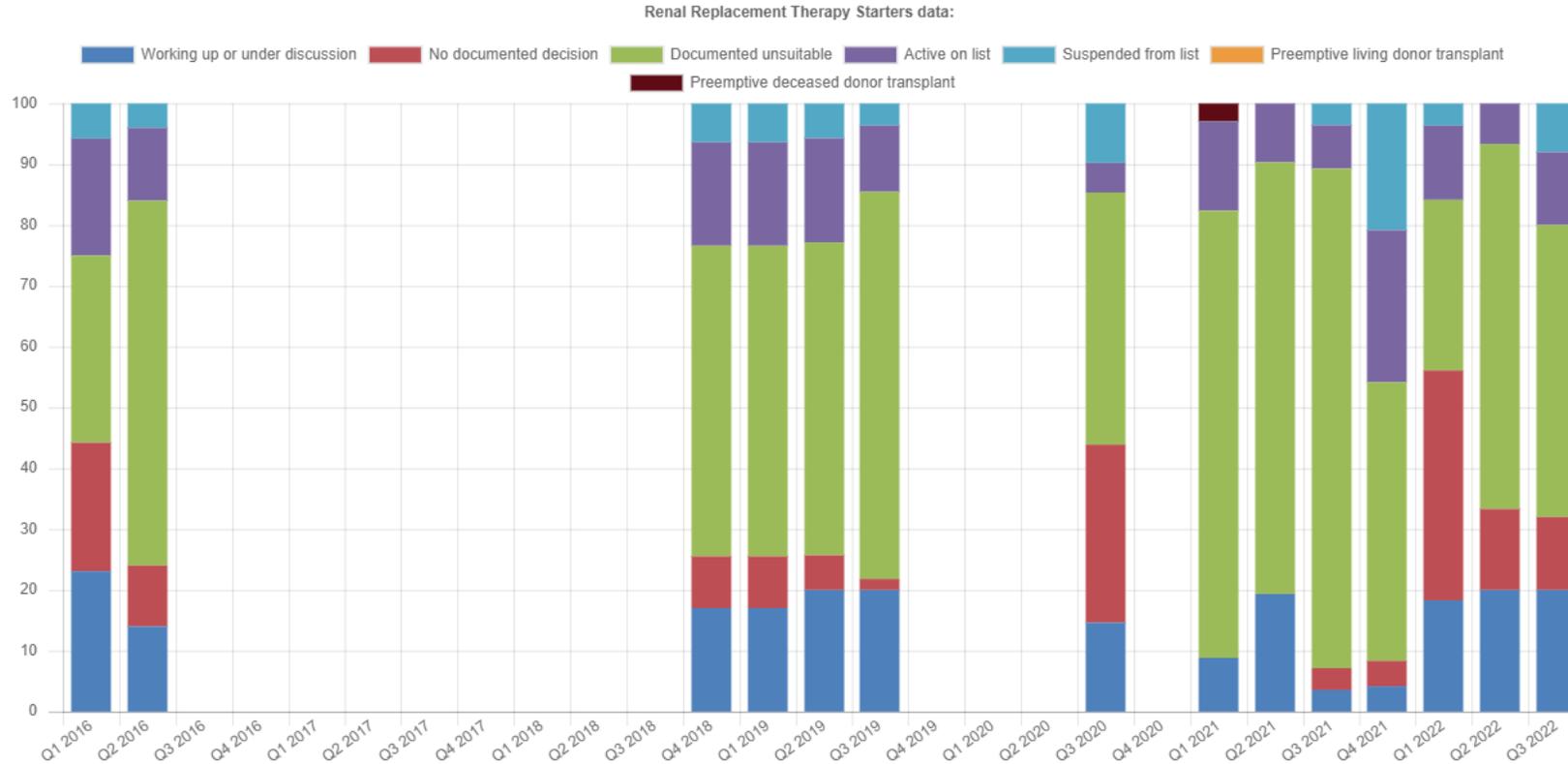
Living Donor Updates: Queen Elizabeth Hospital Birmingham.

Monday 12th September 2022

Laura Bedford, Amanda Smith, Anna Brotherton.



2021-2022 Data on Transplant Status for RRT Starters for QEHB: *Jan 2022 to end of August 2022*



Reasons Identified for ‘Missed’ Patients at QEHB: [Reasons why patients were still in category “working up or under discussion” or “not documented” at time of starting dialysis]



- Delays in the System Not Covid Related; (Referrals to Other Specialities) (E.g. Myoview/Urology)
- Interestingly, since the Covid 19 Pandemic – there is a noticeably higher percentage of ‘Medically Complex’ patients.
- Referred for Assessment with GFR < 15 (Knock on effect of Covid?).
- Unsuitable for Transplant **BUT** not Documented.
- Limited Complex Clinic Availability.
- There are a number of patients listed under “Active Monitoring” – This is inclusive of; GFR >15 (Or “Stable”); Weight Loss (BMI >35); Compliance; Generally Unwell – Requiring Investigation.



What % of patients have a living donor who has reached at least phase 1?



- On estimated for January – August 2022, there are 110 Donors who have reached Phase 1 Testing; this number represents those active in the programme.
- On estimated, there are 40 'Unsuitable Donors' – this number represents donors who were screened and as a result of their history did not progress to Phase 1 Testing.



Patient Experience Results (*Paper Questionnaire*):



- We submitted our Paper Questionnaires (x 5) – Please can we have our centre feedback on this, thank you kindly.





Locally Identified Health Inequalities:

- Geography: Birmingham, and the wider West Midlands territory, is the second most ethnically diverse region in the UK. The health of those living in Birmingham is generally worse than the England average.
- Social Deprivation: Those living in a socially deprived area are more likely to be diagnosed at a later stage of the disease, which may delay the start of adequate treatment and lead to poorer outcomes. When people from these groups experience kidney failure, they have poorer survival rates on dialysis and fewer of them are treated with peritoneal dialysis. This suggests appropriate tailoring of information is required for ethnic minority communities living in deprived areas, in order to achieve equity
- Ethnicity/Language Barriers: Language barriers can contribute to negative and or poor waiting times and continuity of care. There is also the misconceptions as a result of cultural beliefs which creates a barrier.
- Health Literacy/Education: Similarly, to Social Deprivation; one's limited health literacy can delay prognosis, treatment and outcomes.
- Gender: "Life expectancy for both men and women (in Birmingham) is lower than the England average" (NICE, 2018). Women are more likely to be diagnosed with CKD, which may link to their higher attendance and engagement with health services. Counterintuitively, men are more likely to start dialysis and our list is more male dominant.
- Age: Although, globally the average life expectancy more than doubled, health inequality still remains a major issue. As one of the largest Transplant Centres, our list is inclusive more so of an elder generation.
- Mental Health: Evidence is emerging that people with severe mental illnesses in the UK are more likely to have CKD and to be on renal therapy. In addition to this, those receiving dialysis are more likely to develop cognitive impairment with age, contributing to a faster decline.
- From a **Living Donor Perspective**: There has been a noticeable increase in **Genetic Testing**; while this increases our understanding of how variants of genes increase the chance of developing CKD, there is hope that in turn we can facilitate more LD Transplantations.





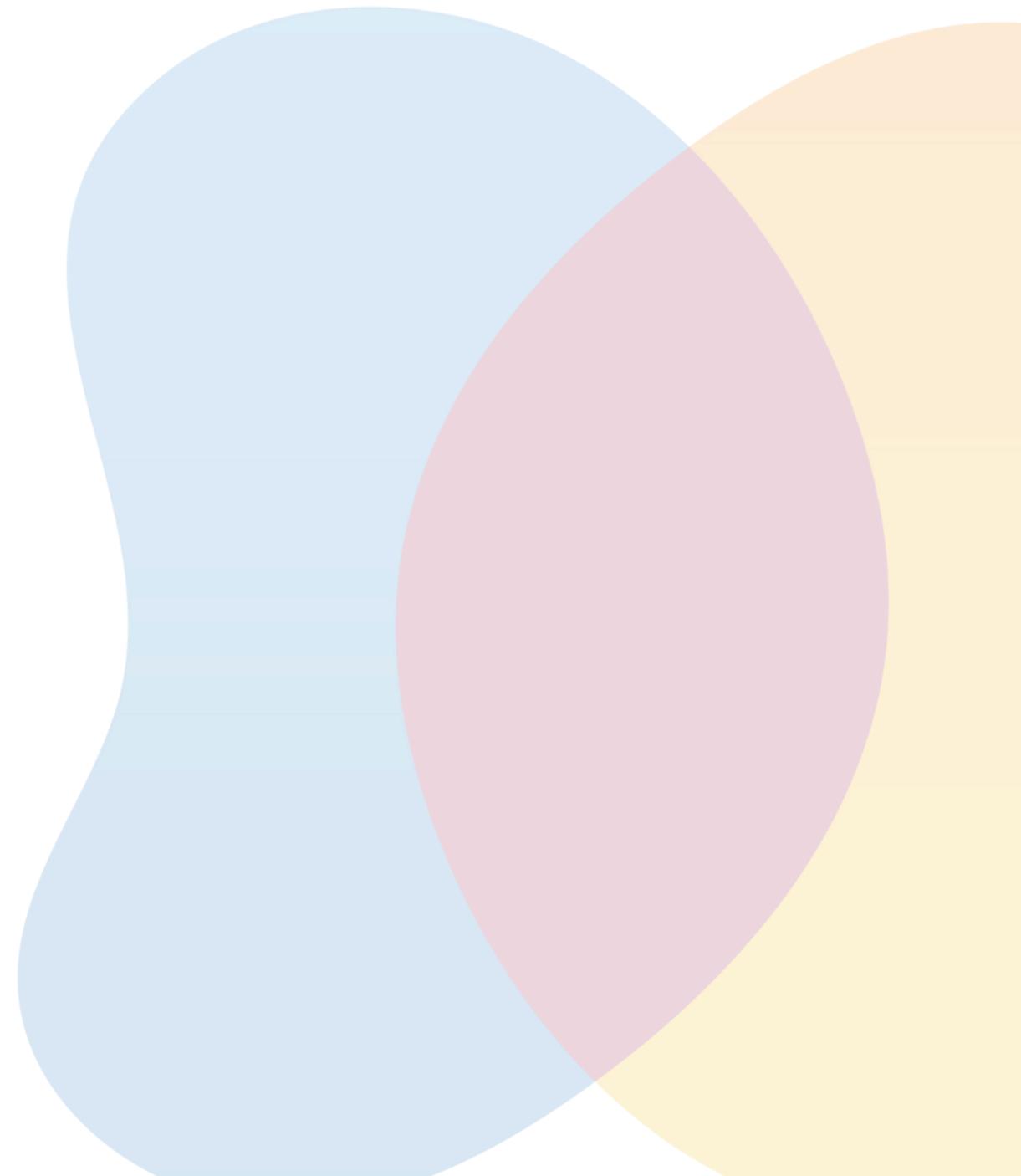
Next Steps for our Unit, QEHB:

- Low Clearance Clinic (LCC) & Chronic Kidney Disease (CKD) Clinic; Positively Reinforce a 'Transplant First' Culture.
- Thorough evaluations of those who are listed as 'Medically Complex'; revisiting those patients ensuring there is a clear plan of care (POC).
- Clear and concise documentation regarding Transplant Status; ALL clinic letters to include 'Transplant Status.'
- Referral Pathways to Specialities i.e. Cardiology/Urology/Gynaecology.
- Transplant Listing Clinics – Could we improve our educational resources?
- Reintroducing Recipient Coordinators visiting Dialysis Units/Centres – Collaboration.
- Structuring a Referral System for the Region – What is required for a complete referral? (Reduces Incomplete or Inappropriate Referrals).
- From a Living Donation perspective, the QEHB are currently working and developing a video, to be shown in Outpatient's (in multiple languages) to increase awareness to BAME Communities.



Living Donor Updates [UHCW, Coventry]

Monday 12th September 2022

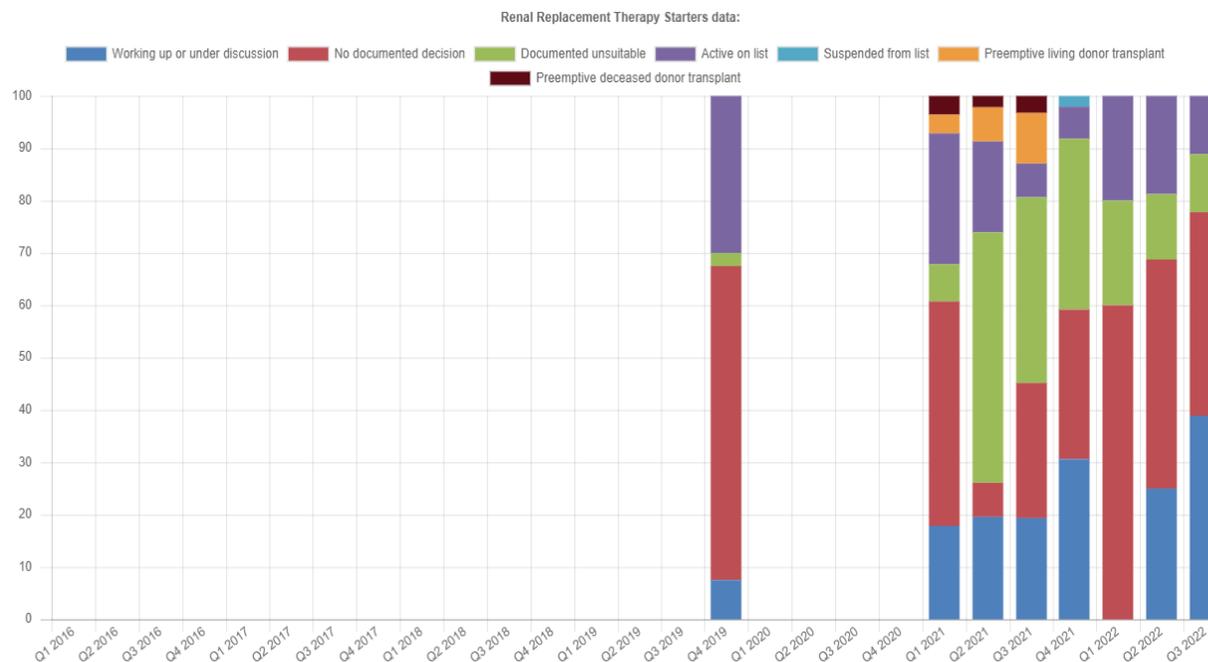


2021-2022 data on transplant status for RRT starters for UNIT NAME

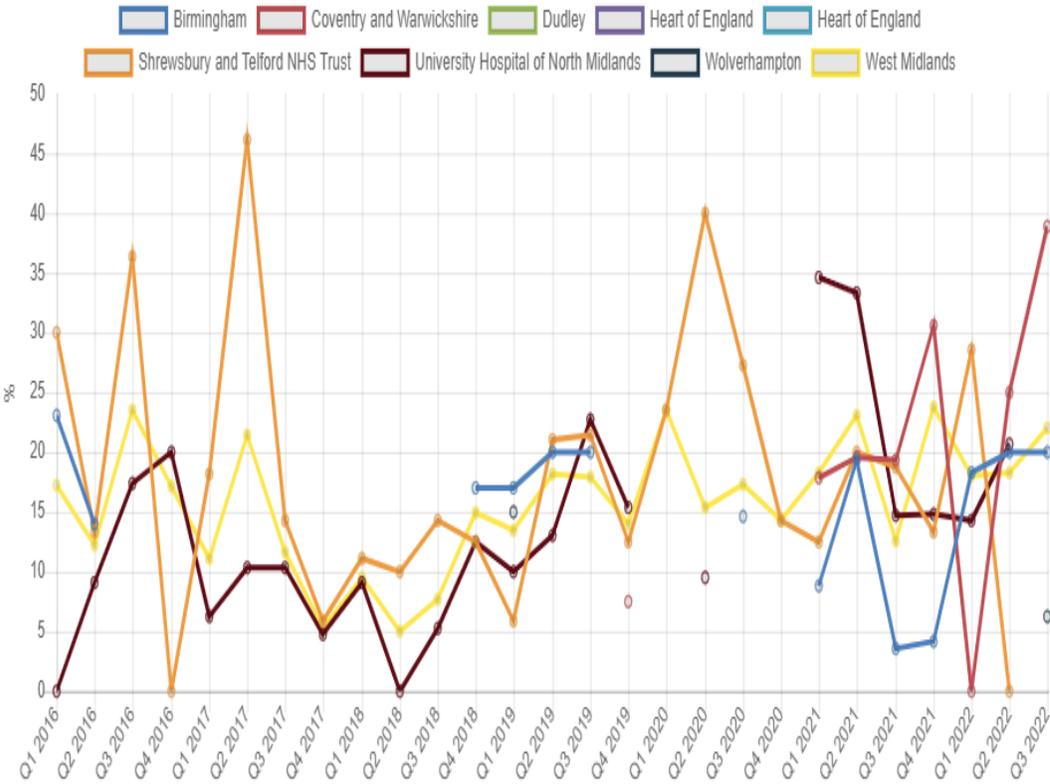
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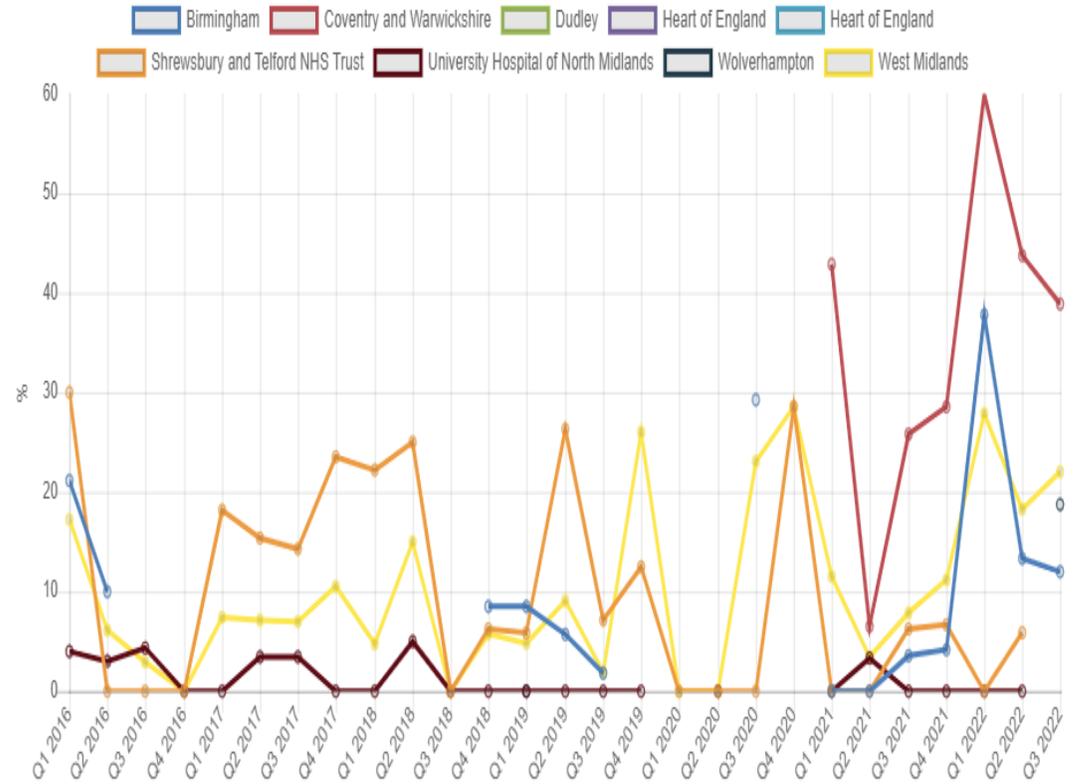
Coventry and Warwickshire Renal replacement therapy starters charts



Patients who are still being "Working up or under discussion"



Patients who have "No documented decision" status

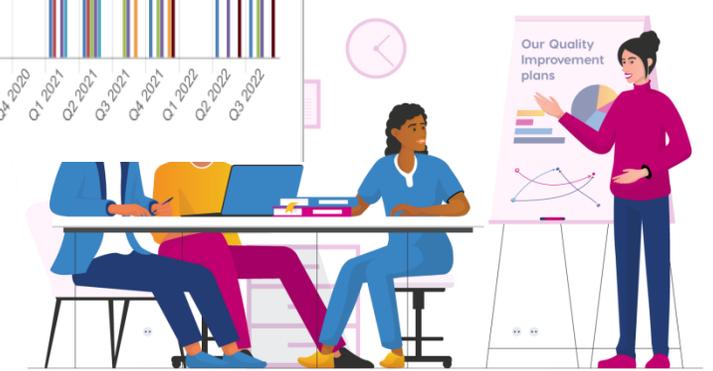
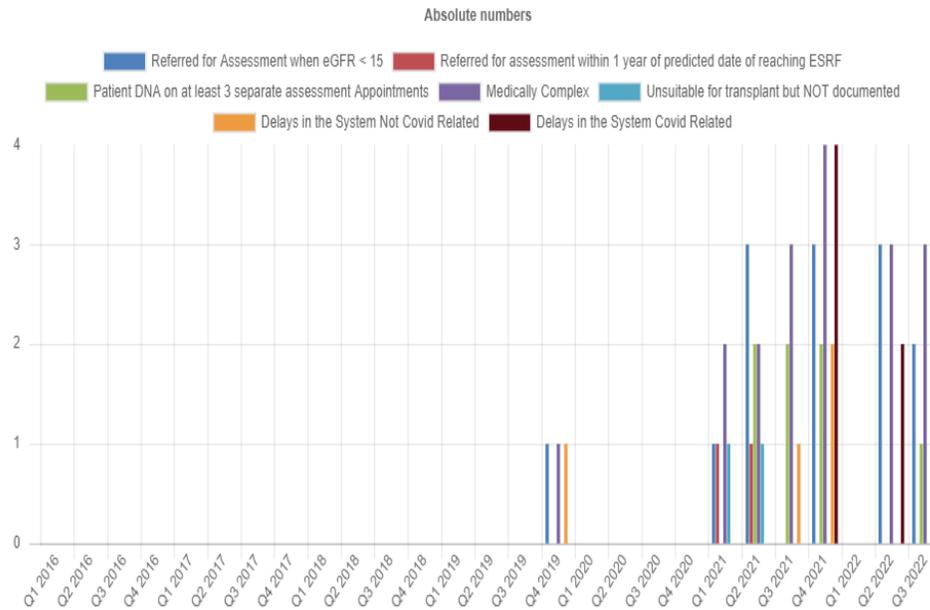
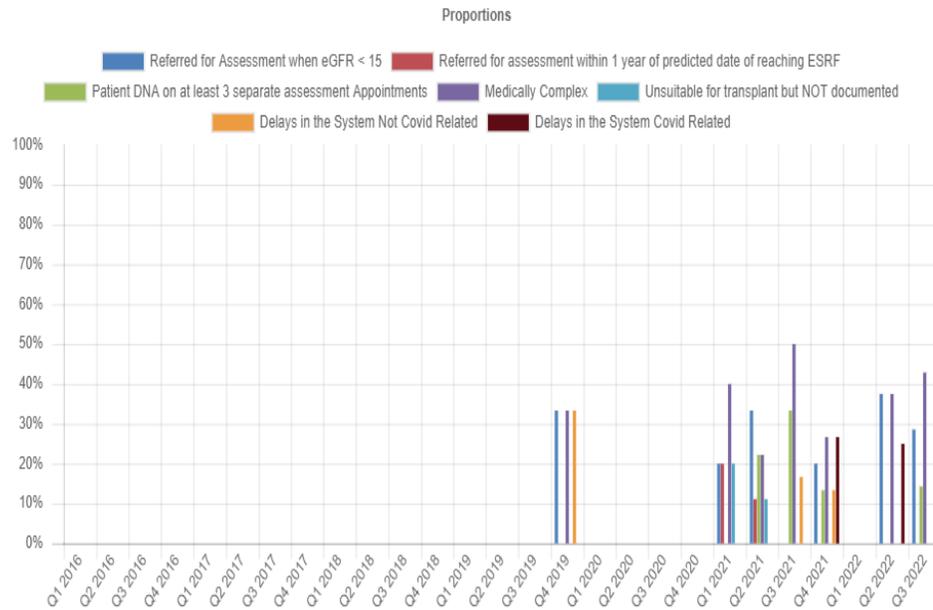


Reasons identified for 'Missed' patients at UNIT

[Reasons why patients were still in category "working up or under discussion" or "not documented" at time of starting dialysis]



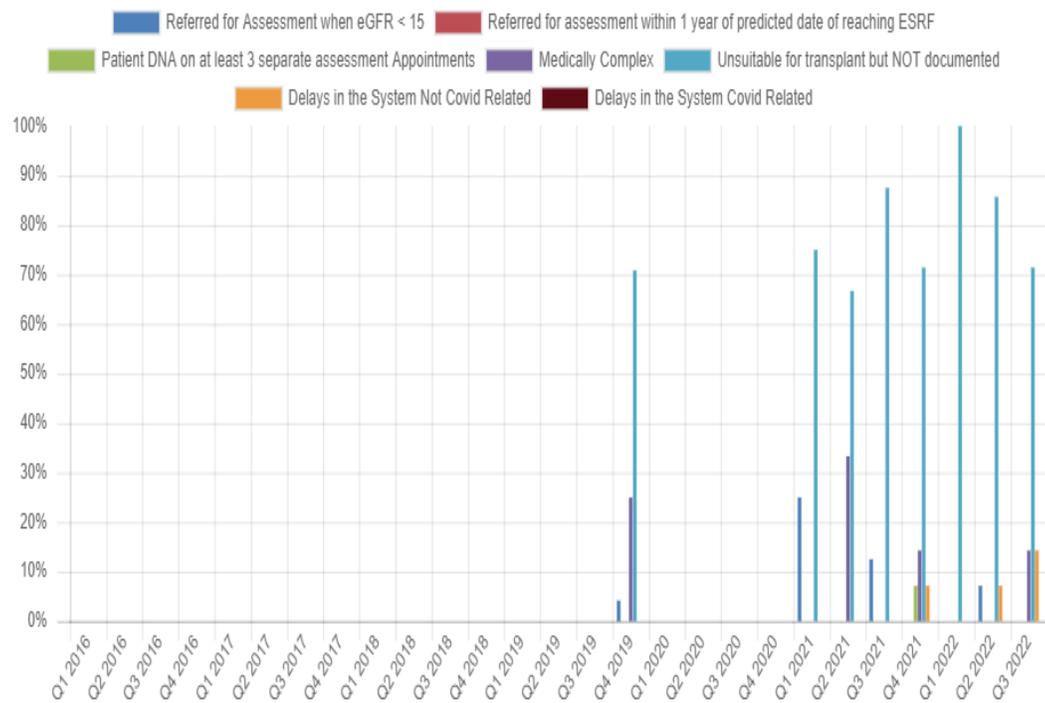
Reasons why patients were still in category "working up or under discussion" at time of starting dialysis



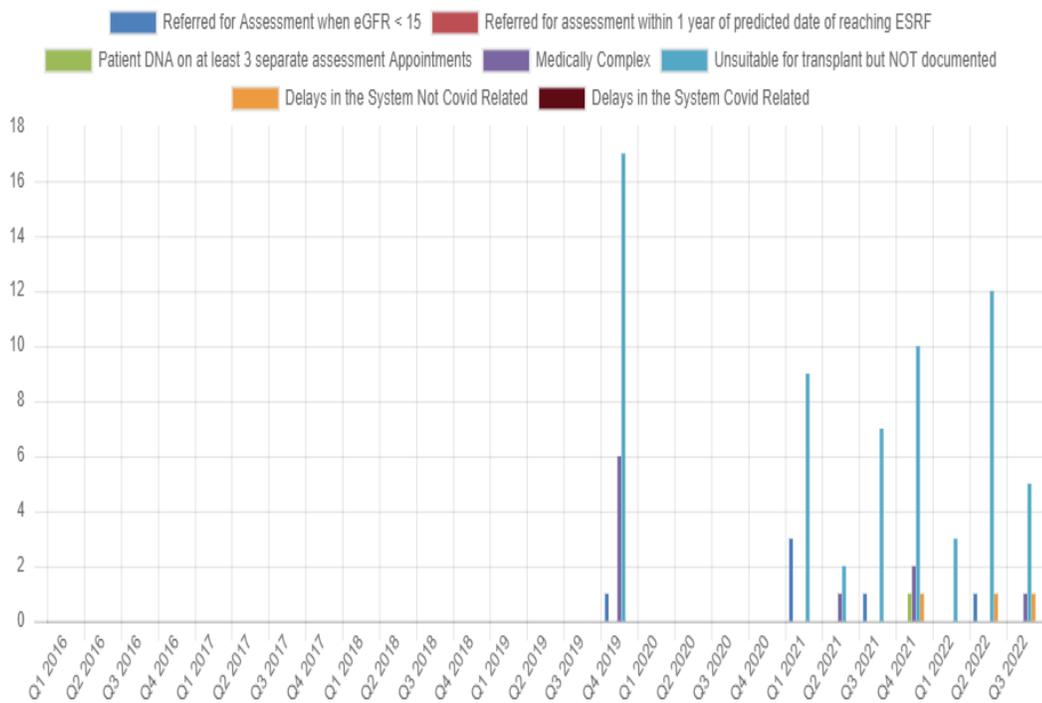


Reasons why patients were in the "not documented" category at time of starting dialysis

Proportions



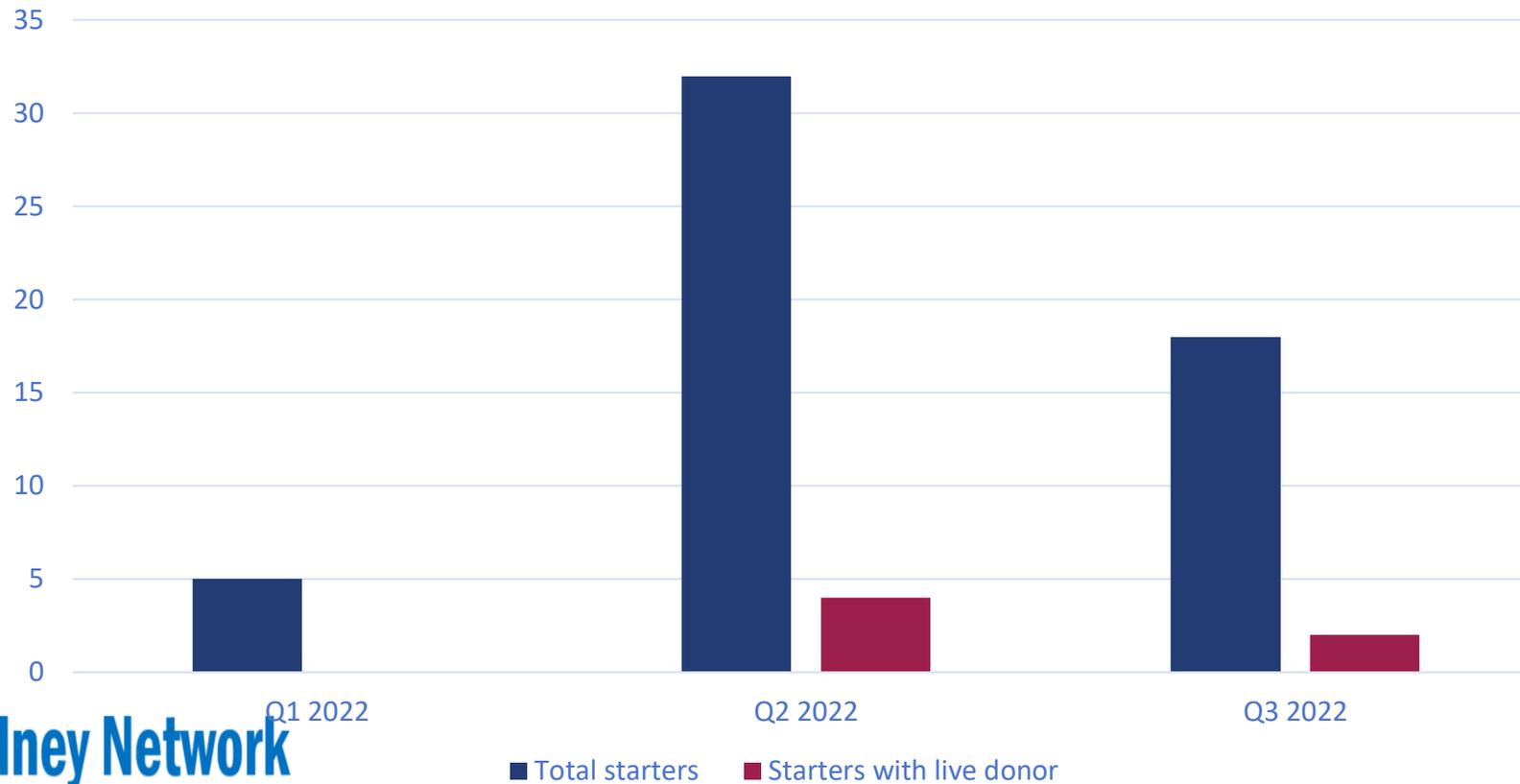
Absolute numbers



If collected: What % of patients have a living donor who has reached at least phase 1



Chart Title





Patient experience results (*paper questionnaire*)

- 4/5 Patients- Overall good review
- 1/5- Poor review for most questions asked including if their concerns were taken seriously
- Actions-
- One area of improvement identified- Support to patients so as to discuss live donation with family members
- Peer supporters were working on this in the community previously before Covid- to restart.





Next steps for our unit:

1. Better Documentation- started Pre-Transplant MDTs to identify patients being 'missed' and to document the transplant suitability
2. Education days for transplantation- restarted.
3. Cardiac Investigations- This problem which was responsible for delays has been addressed. Also started Cardiology Tx MDT once a month.
4. E-referral system starting October 2022 to avoid delays in the system

KQuIP 10 Steps to improvement



Midlands Kidney Network



KQuIP 10 steps to improvement

1. **Agree an area for improvement**
2. **Involve and assemble your team**
3. **Understand your problem/ system**
4. Define project aim and scope
5. Choose 'just enough' project measures
6. Develop change ideas
7. Test change ideas (PDSA)
8. Measure impact of changes
9. Do further testing of change ideas
10. Implement successful changes

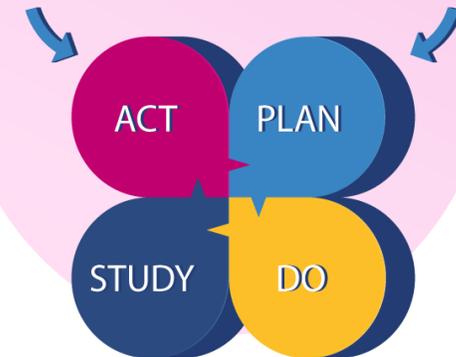
Share your progress

Model for improvement

What are we trying to accomplish?

How will we know that a change is an improvement?

What change can we make that will result in improvement?

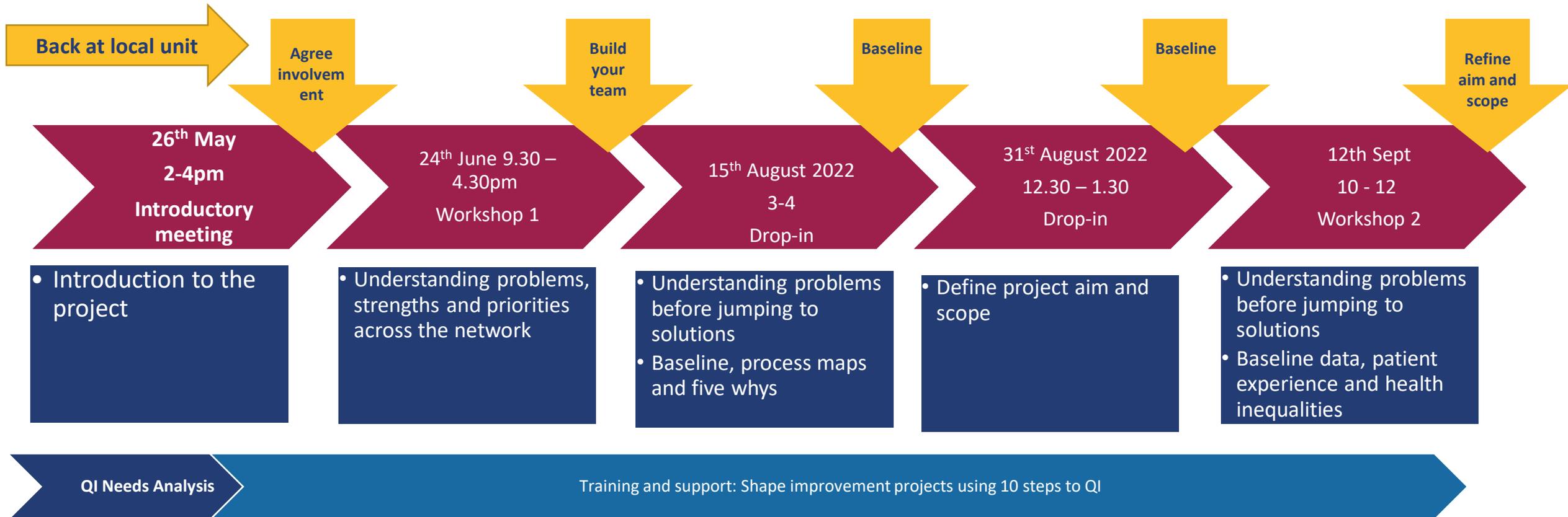


IHI Model for Improvement

Midlands Living Donor Project timeline



Midlands Kidney Network





Back at local unit

Refine QI measurement

Build driver diagram

Test changes

Publish learning

Drop-in
Wed 26th Oct
12 - 1

Drop-in
Thurs 17th Nov 10 -
11

Drop-in
Friday 9th Dec
12 - 1

Workshop
26th January 11 – 1
Communicate,
spread and sustain

- Choosing 'just enough' measures – measuring impact

- Developing change ideas

- Sharing improvements/challenges with a peer assist approach

- Communicate, spread, sustain

Training and support: Shape improvement projects using 10 steps to QI

Review

Communicate, spread,
share, sustain

Review

Got a question?



Your KQuIP programme manager is:

Catherine Stannard

catherine.stannard@renalregistry.nhs.uk

We are here to help!

