UKKA KQuIP

UK Kidney Association

MKN Midlands Kidney Network

NHS

DAYLife revisited

Sharing best practice and planning future improvements to increase uptake and quality of home dialysis therapies

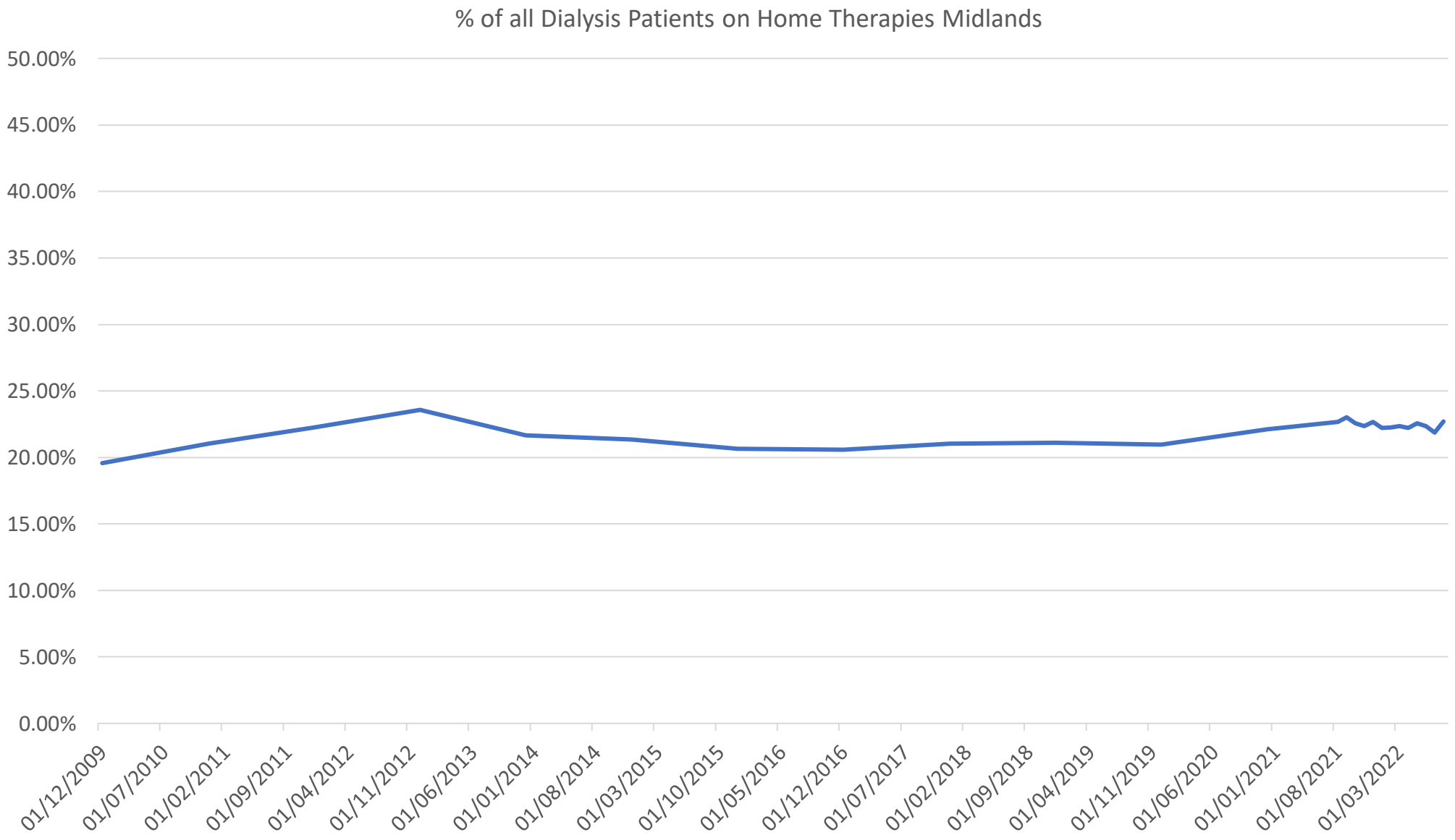
Kidney Care UK

Time	Item	Lead
9.30 – 9.40	**Welcome**	Mark Lambie
9.40 – 10.00	**The Renal Service Transformation Programme and Home Dialysis**	Albert Power
10.00 – 10.20	**Teamwork: Setting our challenge**	ALL – teamwork
10.20 – 10.40	**Intercept study update: What are the factors driving centre variation in uptake of home dialysis?**	Kerry Allen
10.40 – 11.30	**Teamwork: Reflections on the pandemic**	ALL – teamwork
COFFEE 11.30-11.45		
11.45 – 12.05	**Health equalities and DAYLife:** Does everyone have equal access to home dialysis therapies? If not, how can we make sure they do?	Jyoti Baharani and Neerja Jain
12.05 – 12.35	**Assisted PD – identifying and removing barriers, future use**	ALL - teamwork
12.35 – 13.00	**DAYLife revisited – unit discussions**	ALL - teamwork
LUNCH 13.00 – 14.00		
14.00 – 14.20	**Midlands Kidney Network**	Alastair Tallis
14.20 – 15.10	**DAYLife revisited – action planning**	ALL - teamwork
15.10 – 15.30	**Sharing session and What is next for DAYLife in Midlands?**	ALL - teamwork
COFFEE AND CLOSE 15.30 – 15.50		

KQuIP

Welcome

- Photographs will be taken today and shared on website and social media next week – let us know if you would **not** like to be in them – please avoid social media today
- Breaks and refreshments / timings
- Fire exits
- This workshop brings together healthcare professionals and people with lived experience of home dialysis – be aware of everyone in the room - help ensure all voices are heard
- Interactive day – please be open and share to make the most of our time together
- The role of Advanced Kidney Care in improving home dialysis uptake
- Special Interest Group meeting – 1pm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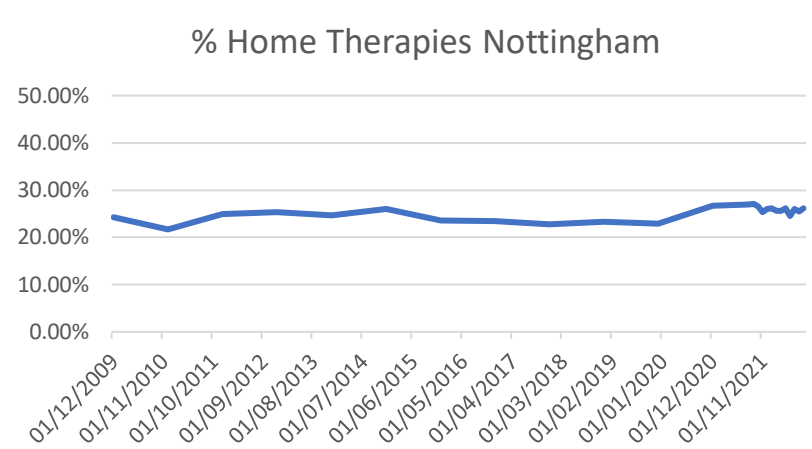
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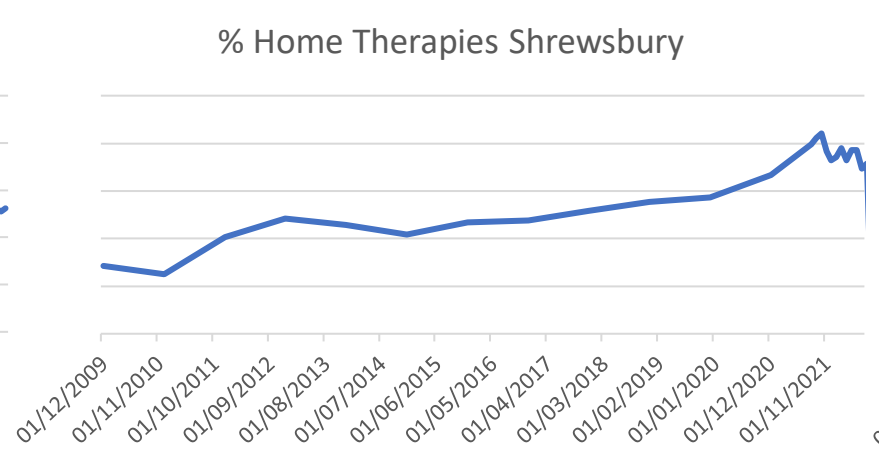
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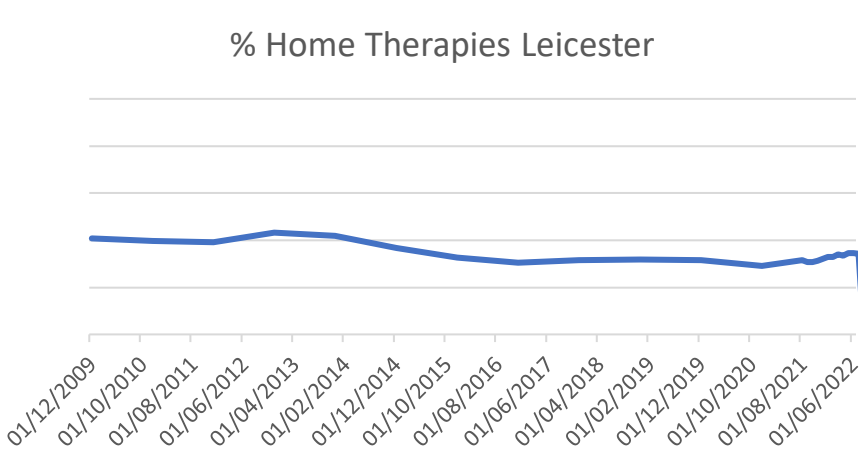
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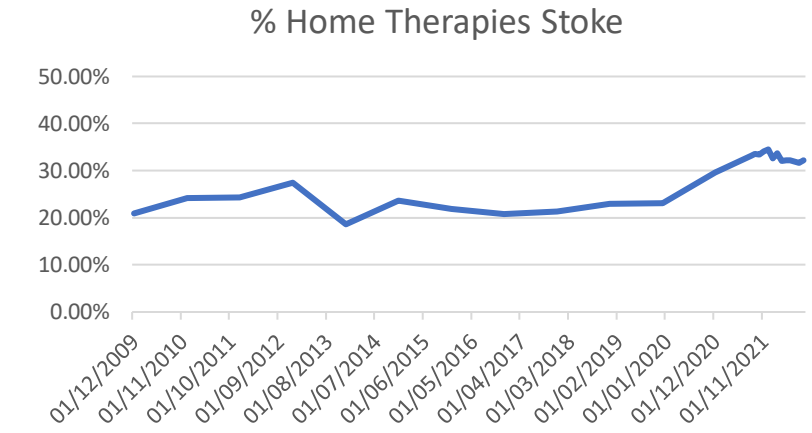
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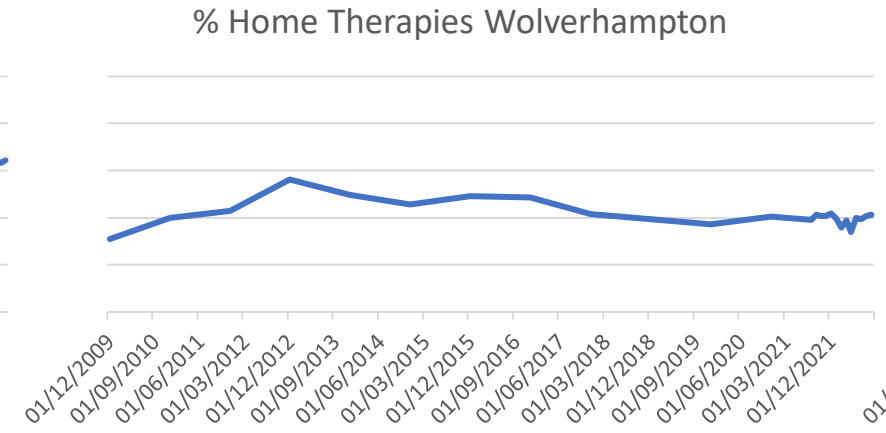
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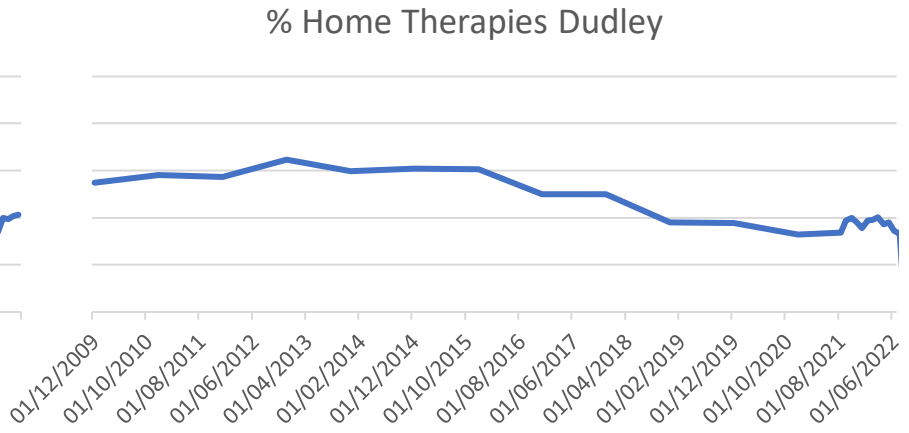
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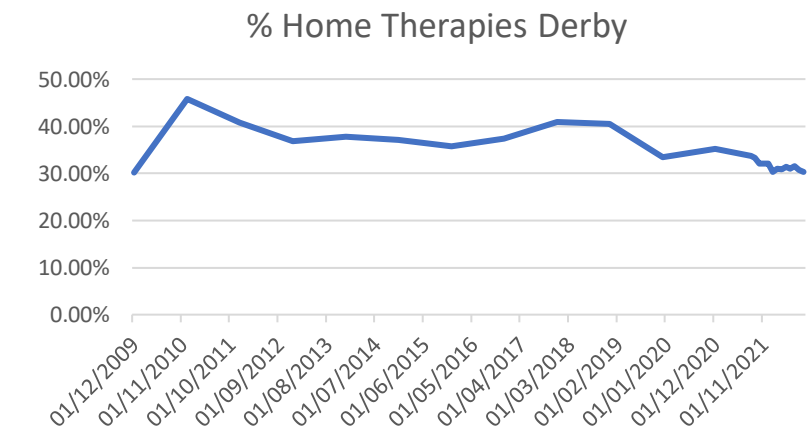
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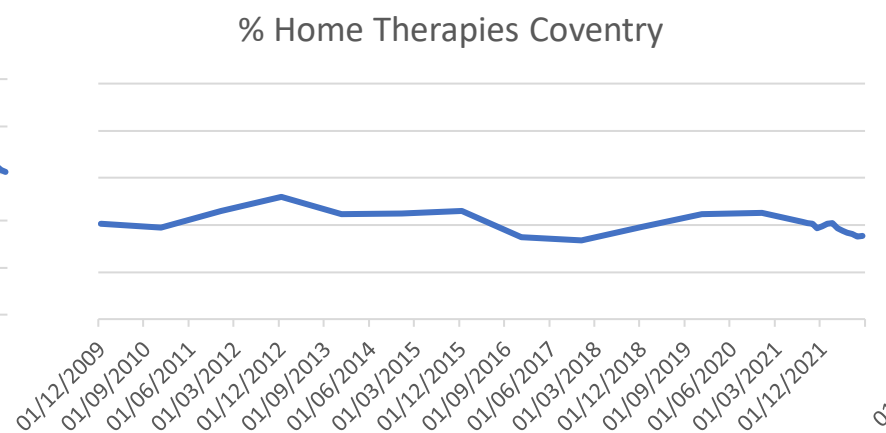
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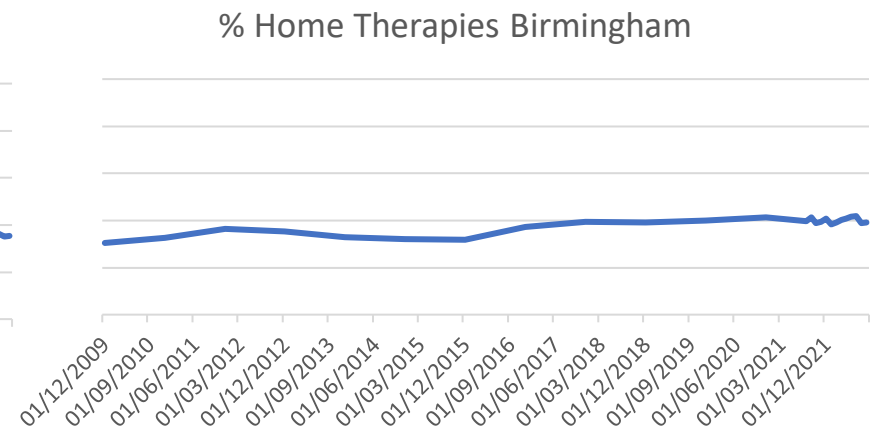
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The Renal Service Transformation Programme and Home Dialysis

Albert Power, National Clinical Lead for Dialysis

RSTP & Home Dialysis

Dr Albert Power
National Clinical Advisor – Dialysis workstream

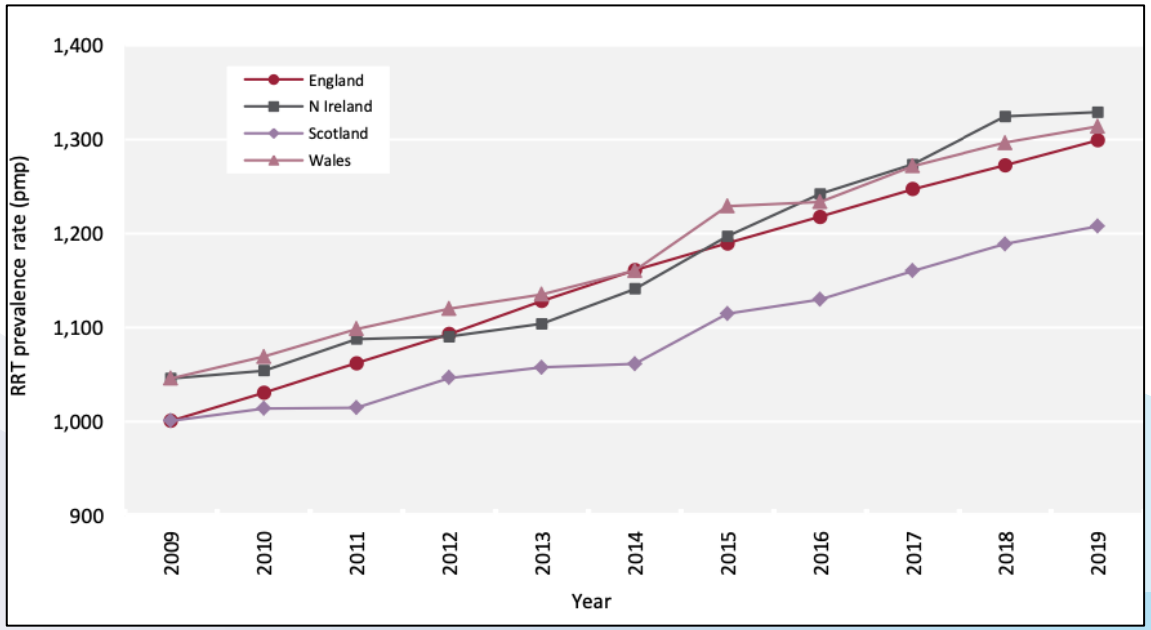
16th Sept 2022

Understanding the national perspective and trends

Increasing numbers of people treated for kidney failure

- On renal replacement therapies (RRT)
- Driven predominantly by transplantation

Progressively *older* people
Especially those on dialysis



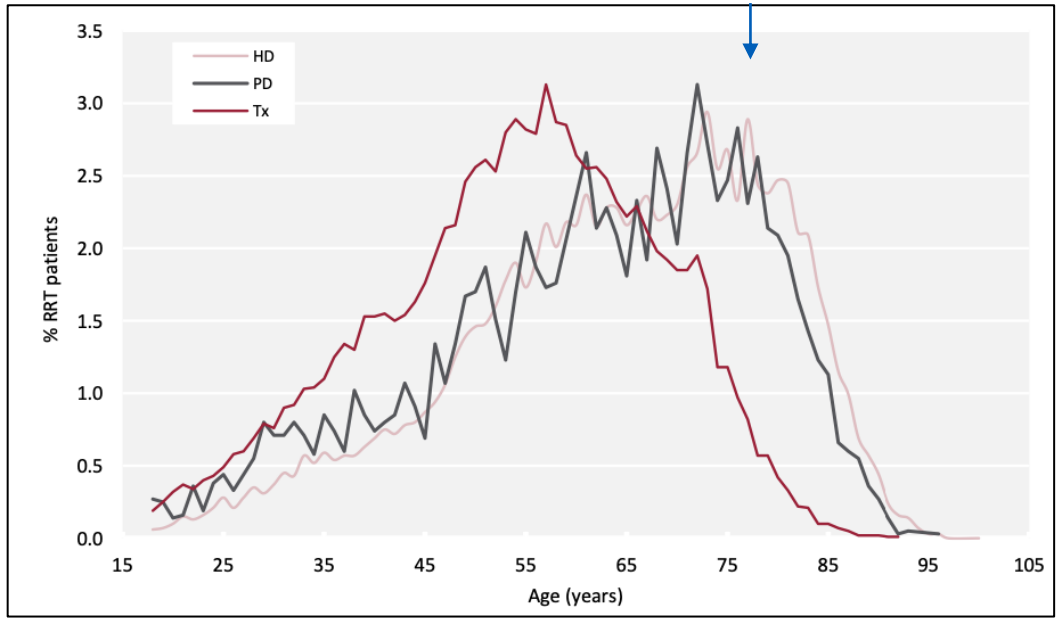


Table 3.4 Change in adult RRT prevalence rates by modality between 2015 and 2019

	Prevalence (pmp)					% growth in prevalence				
Year	HD	PD	Dialysis	Tx	RRT	HD	PD	Dialysis	Tx	RRT
2015	483	70	553	633	1,186					
2016	486	70	556	656	1,212	0.6	-0.1	0.5	3.7	2.2
2017	490	68	558	684	1,242	0.8	-2.9	0.4	4.3	2.5
2018	491	68	559	709	1,268	0.1	1.3	0.2	3.6	2.1
2019	489	69	558	735	1,293	-0.3	1.1	-0.2	3.7	2.0
Average annual growth 2015-2019						**0.3**	**-0.1**	**0.2**	**3.8**	**2.2**

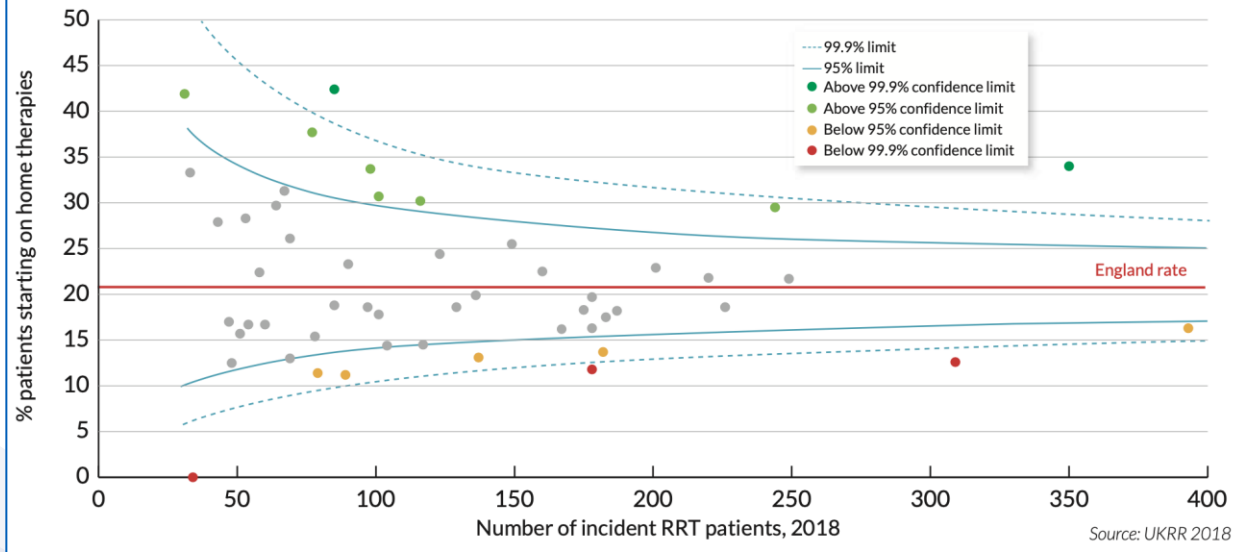
pmp – per million population

Type of Dialysis	
Tx	56.6%
Satellite HD	21.7%
Hospital HD	14.2%
APD	3.4%
HHD	2.1%
CAPD	2.0%

National Perspective – Variability in all elements of dialysis

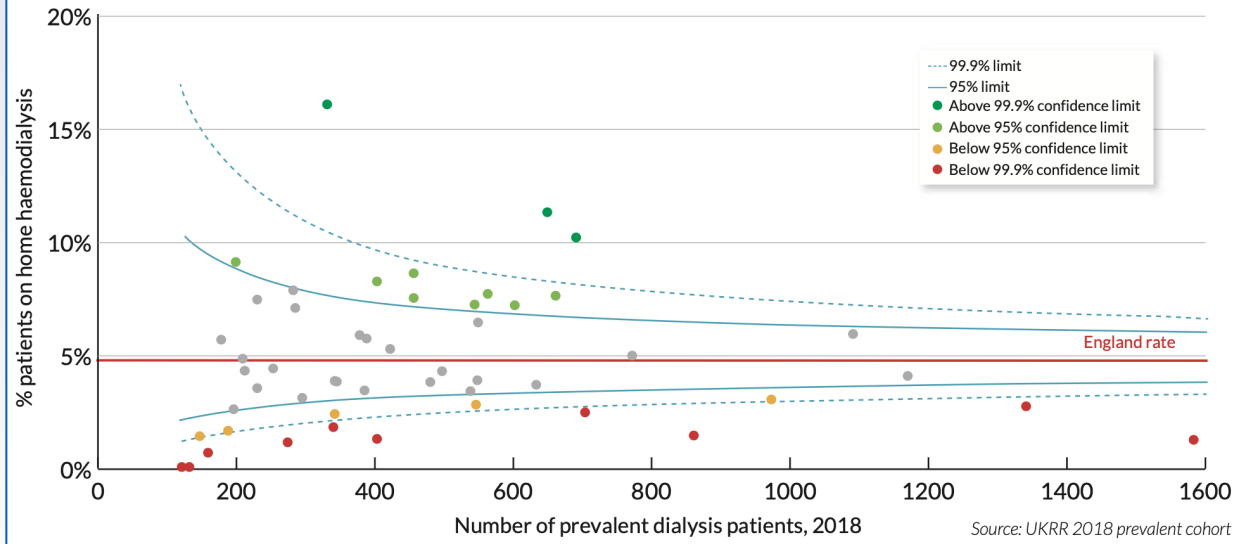
Source: UK Renal Registry 23rd Annual Report and Renal

Figure 19a: Proportion of patients starting renal replacement therapy on a home dialysis therapy*



Source: UKRR 2018

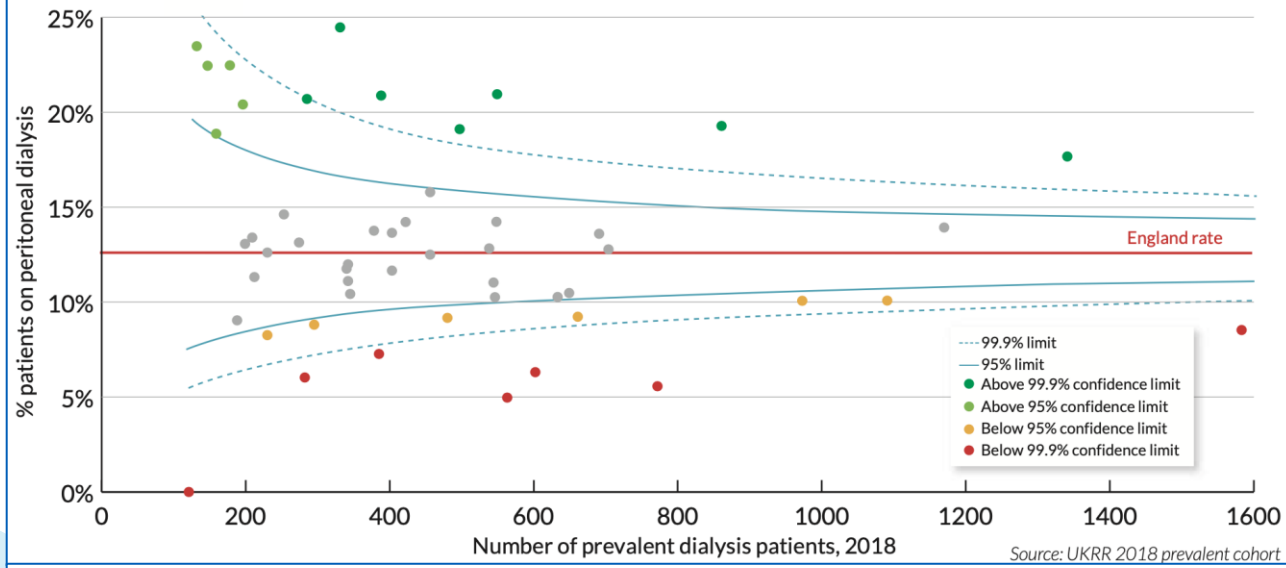
Figure 23: Variation in proportion of prevalent dialysis patients on home haemodialysis*



Source: UKRR 2018 prevalent cohort

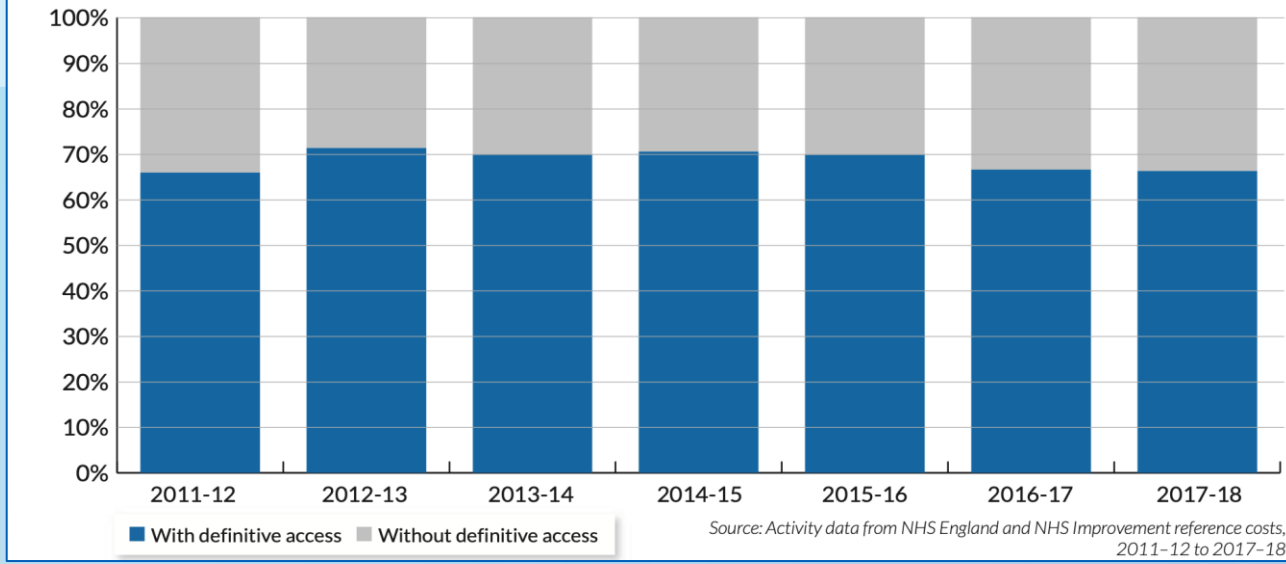
*The centre with a zero value does refer patients to a neighbouring centre for home therapy and since this data was gathered the two trusts have merged.

Figure 22: Variation in proportion of prevalent dialysis patients on peritoneal dialysis*



Source: UKRR 2018 prevalent cohort

Figure 15: Prevalent haemodialysis definitive access rate over time (since introduction of best practice tariff)



Source: Activity data from NHS England and NHS Improvement reference costs, 2011–12 to 2017–18

How you start RRT

Table 2.3 Demographics and start modality of adult patients incident to KRT in 2020 by centre

Centre	N on KRT	% on ICHD	% on PD	% on HHD	% on Tx	% pre-emptive listing/tx	Median age (yrs)	% male	Ethnicity				
									% White	% Asian	% Black	% Other	% missing
ENGLAND													
Bham	329	68.7	28.3	0.0	3.0	13.4	63.0	63.5	56.2	31.9	9.8	2.2	3.6
Bradfd	82	79.3	13.4	0.0	7.3	13.4	62.7	64.6	51.9	38.3	1.2	8.6	1.2
Brightn	142	73.9	22.5	0.7	2.8	10.6	68.1	71.1	89.9	5.4	1.6	3.1	9.2
Bristol	131	74.8	17.6	0.0	7.6	16.0	65.0	68.7	90.7	2.5	5.9	0.8	9.9
Camb	108	51.9	18.5	0.0	29.6	41.7	59.3	64.8	91.5	1.1	4.3	3.2	13.0
Carlis	34	70.6	26.5	2.9	0.0	11.8	62.0	67.6	100.0	0.0	0.0	0.0	0.0
Carsh	298	81.9	16.1	0.0	2.0	9.4	67.7	63.8	64.1	16.9	11.4	7.7	8.4
Colchr	39	100.0	0.0	0.0	0.0	5.1	72.6	56.4	97.0	0.0	0.0	3.0	15.4
Covnt	141	67.4	24.8	0.0	7.8	20.6	67.1	64.5	78.4	16.5	5.0	0.0	1.4
Derby	73	54.8	39.7	4.1	1.4	15.1	66.3	78.1	88.1	6.0	1.5	4.5	8.2
Donc	47	80.9	14.9	2.1	2.1	17.0	68.7	70.2	95.7	0.0	2.1	2.1	0.0
Dorset	88	72.7	19.3	0.0	8.0	27.3	66.1	64.8	98.9	1.1	0.0	0.0	1.1
Dudley	60	76.7	18.3	0.0	5.0	11.7	70.7	58.3	76.7	16.7	6.7	0.0	0.0
EssexMS	129	78.3	19.4	0.0	2.3	9.3	65.9	63.6	85.1	5.3	3.5	6.1	11.6
Exeter	105	82.9	15.2	1.0	1.0	14.3	66.9	67.6	94.3	3.8	1.0	1.0	0.0
Glouc	83	73.5	19.3	1.2	6.0	10.8	71.7	67.5	95.1	2.4	1.2	1.2	1.2
Hull	105	72.4	27.6	0.0	0.0	11.4	63.7	68.6	95.2	1.9	2.9	0.0	1.0
Ipswi	43	72.1	20.9	0.0	7.0	18.6	70.1	58.1	89.5	0.0	0.0	10.5	11.6
Kent	141	77.3	19.2	0.0	3.6	12.8	67.9	68.8	95.0	2.9	2.2	0.0	1.4
L Barts	200	34.0	60.0	0.0	6.0	24.5	58.6	57.5	26.5	40.9	27.1	5.5	9.5
L Guys	161	79.5	16.8	0.0	3.7	13.7	60.8	57.8	47.7	10.6	36.4	5.3	18.0
L Kings	158	70.3	27.9	0.0	1.9	12.0	57.8	61.4	43.8	12.5	38.9	4.9	8.9
L Rfree	231	61.9	31.2	0.0	6.9	15.2	64.3	62.3	44.6	24.9	15.5	15.0	16.5
L St.G	81	72.8	18.5	0.0	8.6	28.4	60.1	69.1	37.5	25.0	27.8	9.7	11.1
L West	361	67.3	28.5	0.0	4.2	16.1	63.9	65.7	39.6	38.5	18.3	3.6	0.0
Leeds	152	70.4	17.8	0.0	11.8	28.3	61.1	65.1	76.4	15.5	5.4	2.7	2.6
Leic	324	78.1	11.7	0.0	10.2	18.8	64.5	62.0	75.4	19.0	4.2	1.4	10.8
Liv Ain	43	72.1	25.6	2.3	0.0	2.3	52.8	62.8	97.5	0.0	2.5	0.0	7.0

How you continue on RRT

Table 2.8 Start and subsequent KRT modalities for adult patients incident to KRT in 2015 by time after start

Start modality	N	Later modality[1]	Time after start (%)			
			90 days	1 yr	3 yrs	5 yrs
HD →	5,671	HD	90.0	72.0	43.7	24.4
		PD	2.1	3.1	1.1	0.5
		Tx	1.3	5.6	14.6	18.3
		Other[2]	0.9	2.3	2.6	2.7
		Died	5.7	17.1	37.9	54.1
PD →	1,492	HD	7.0	18.7	21.8	14.6
		PD	87.3	56.9	18.6	6.1
		Tx	3.2	14.7	33.3	39.1
		Other[2]	0.5	1.1	1.9	2.5
		Died	1.9	8.6	24.4	37.7
Tx	615	HD	0.8	1.3	1.6	2.6
		PD	0.0	0.0	0.5	0.8
		Tx	97.7	94.6	91.1	87.3
		Other[2]	1.3	2.4	3.6	3.7
		Died	0.2	1.6	3.3	5.5

Shading indicates proportion of individuals maintained on their initial modality.
[1]HD included ICHD and HHD.
[2]Other is discontinued, recovered, moved away or currently transferring between centres.

Case for Change in Dialysis Services

[A] **National healthcare policy** – NHS Long Term Plan, Integrating Care White Paper

- Dialysis treatment accounts for a *disproportionately* high % of national health expenditure
- Restructured commissioning of dialysis and other specialised renal services

[B] **Drive for ongoing improvements in quality** of care / outcomes for all

- Reduce unwanted variation
- Improve quality for all stakeholders in dialysis services

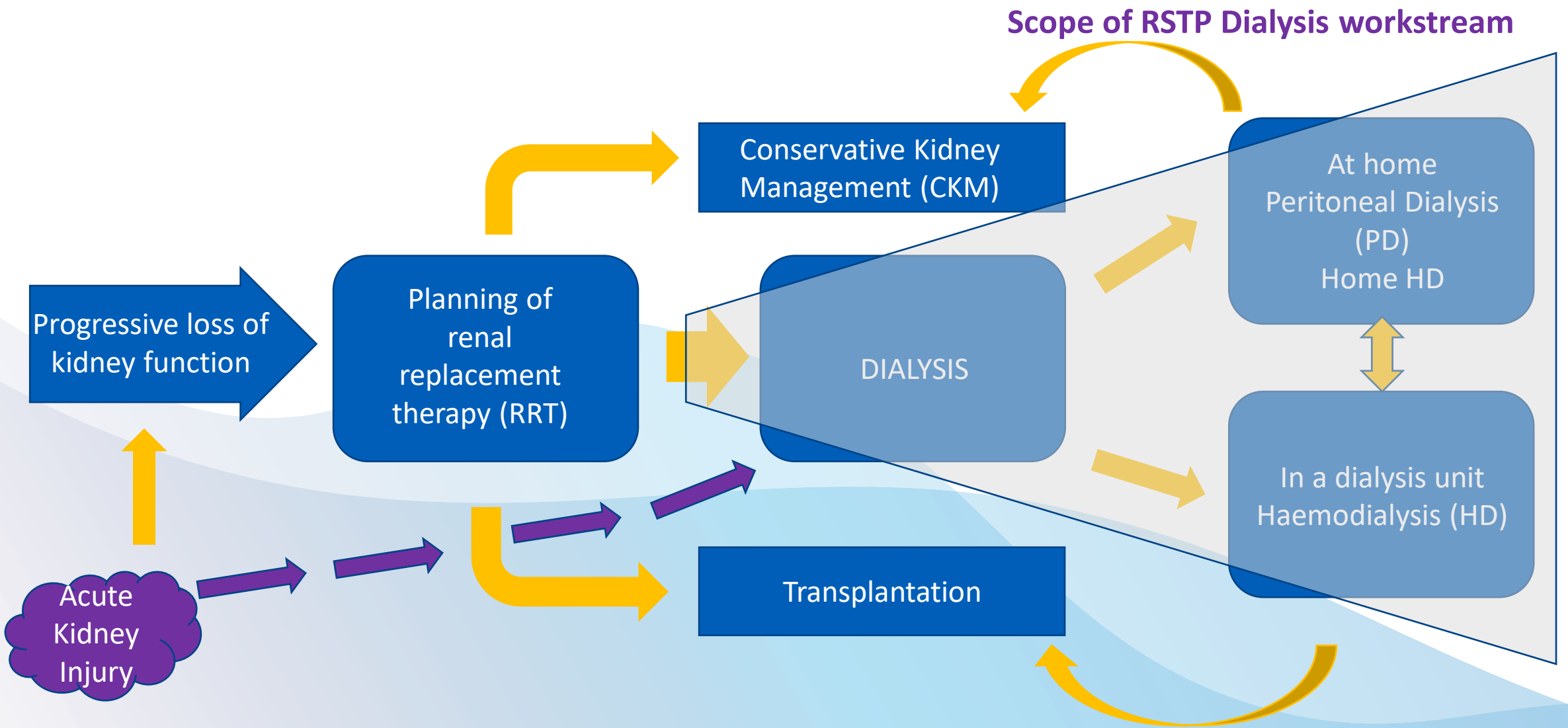
[C] **Improving equity** of access

- Empowering patient choice
- Minimising inequalities in dialysis (receiving treatment / type of treatment)

[D] **Improving value** to the healthcare system as a whole

- Supporting the concept of whole patient whole pathway approach
- Investing in preventive care by reviewing processes and resources leading to efficiencies

A patient's pathway to receiving dialysis



RSTP's 10 High Impact changes and opportunities identified in Renal Medicine GIRFT report

High Impact Changes	System Working	Dialysis	Transplantation	CKD	AKI
1. Address health inequalities	✓				
2. Improve access to transplantation			✓		
3. Improve access to effective and timely vascular access		✓			
4. Reduce patient infection rates		✓			
5. Establish a new national standard for AKI				✓	✓
6. Establish revised national standards	✓	✓	✓	✓	✓
7. Establish the optimum pathway		✓	✓	✓	✓
8. Improve psycho-social health		✓	✓	✓	
9. Establish new commissioning models	✓		✓		
10. Implementation of procurement and sustainability initiatives	✓	✓	✓		

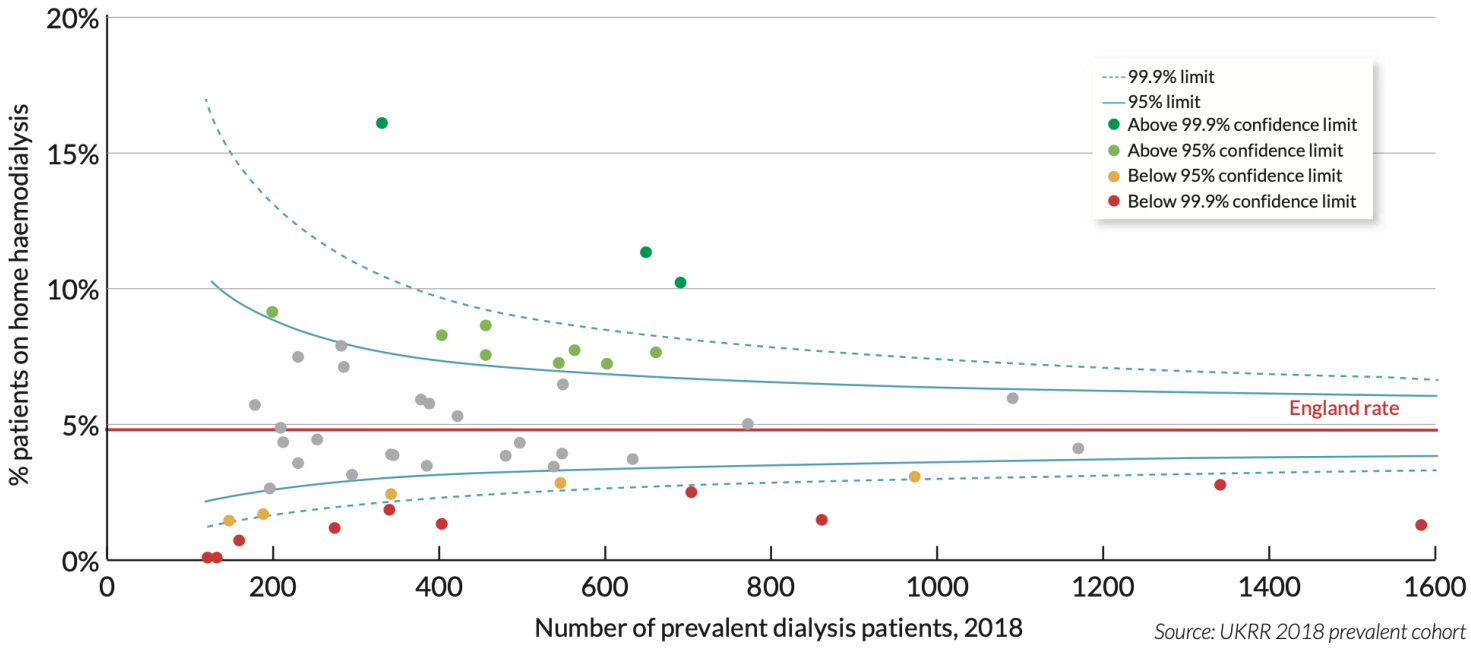
GIRFT recommendations – relevant to the workstream

- Ensure home therapy is promoted and offered for all suitable dialysis patients and that a minimum prevalent rate of 20% is achieved in every renal centre.
- Ensure that all renal centres adopt a systematic QI approach to (infection prevention and control IPC), with HD bacteraemia and PD peritonitis given equal priority.
- Ensure that procurement of HD facilities and home therapies delivered in partnership with the independent sector offers consistent quality and cost-effectiveness across the NHS in England.
- Reduce variation in incident and prevalent definitive HD vascular access rates and deliver RA clinical practice guideline minimum thresholds.
- ICHD non-emergency patient transport to be incorporated in the HD tariff or equivalent and responsibility for the management of these contracts to be transferred to renal providers.
- Ensure the patient experience and SDM are central to the planning and delivery of renal services.
- Ensure that data on hospitalisation of RRT patients are available and adopted as a routine element of the quality assurance process in renal care.

Case for Change in Dialysis Services: Home Therapies

- Multiple benefits for patients
  - Flexible treatment delivered around patient's lifestyle
  - Increased autonomy & ability to travel ; improved patient experience
  - Enable patients to continue in employment
- Benefits to healthcare system
  - Reduced cost to NHS – building maintenance, staffing costs, NEPT costs
  - Reduced medication costs – BP medicines, EPO doses, phosphate binders
  - Potential for reduced unemployment & associated costs to Treasury

Figure 23: Variation in proportion of prevalent dialysis patients on home haemodialysis*



Source: UKRR 2018 prevalent cohort

*The centre with a zero value does refer patients to a neighbouring centre for home therapy and since this data was gathered the two trusts have merged.

Improvement (opportunities are per annum)	National average or better			Top Quartile or better		
	Target	Activity opportunity	Gross notional financial opportunity	Target	Activity opportunity	Gross notional financial opportunity
Increase proportion of dialysis on home treatments** Source: UKRR 2018	Home treatment rate – 20%	937 patients	£5.0m	Home treatment rate – 20%	937 patients	£5.0m

NKF Increasing Home Dialysis Report (2022)
Renal GIRFT report (2021)

Dialysis – Workstream plan

Objectives	Outcomes/Action
Minimising access infection	**Reducing rates of infection for patients of HD -** Define and draft best practice pathway guidance that will lead to
	Reducing rates of infection for patients of PD - Define and draft best practice pathway that will lead to
Timely dialysis access formation and preservation of function	Collection & reporting of access data from all renal centres
	Timely access formation & maintenance of function of HD access - Define and draft best practice pathway guidance
	Responsive access formation & maintenance of function of PD access - Define and draft best practice pathway guidance
Align renal services and commissioning to enable greater access to home dialysis	Home Dialysis implementation pack based on GIRFT recommendations including best practice pathway guidance

Driving change forward through RSTP's dialysis workstream

Potential Benefits

For patients:

- Improved Quality of Life
- Improved access for appropriate patients
- Personalised choices
- Improved experience of care
- Reduction in financial demands associated with travel to hospital

For providers

- Better capacity in-house
- Upskilling of resource and utilisation within service
- Better patient flow
- Improvement in quality of service

For ICS

- Reduction in system blockage
- Improved personalised care
- Reduction in demand of hospital based services
- Reduction in health inequalities
- Reduction in cost of patient transport

End State

A key focus of our programme of work remains on identifying best practice that will enable systems:

- To ensure that home therapy options are effectively communicated to those patients for whom a pre-emptive transplant (Transplant First) or a conservative approach is not appropriate,
- To measure to address inequity of access
- To ensure home therapy is promoted and offered for all suitable dialysis patients and that a minimum prevalent rate of 20% is achieved in every renal centre.
- Effective use of data to monitor quality and performance of dialysis services and use data insights to drive improvements at local and regional levels

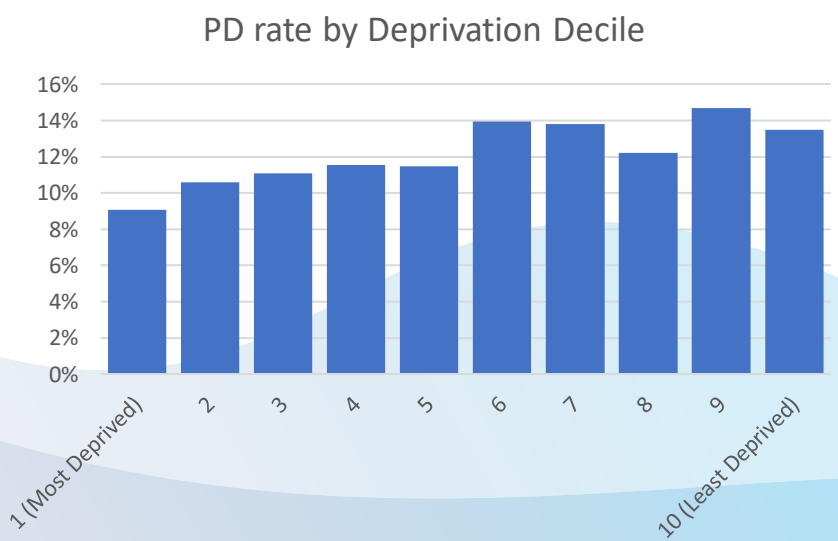
Appendices

In focus: Supporting uptake of Home Dialysis variation in home therapies age and gender

- The purpose of the pack is to support ICSs and providers to achieve equality of access to home therapies (HT) and more widely identify best practices that could increase the prevalence to 20% of all dialysis patients
- The graphs below provide snapshot of variation in home therapies based on age and gender. More details can be found in appendix.

Gender	PD
Male	11.5%
Female	12.4%
Grand Total	11.8%

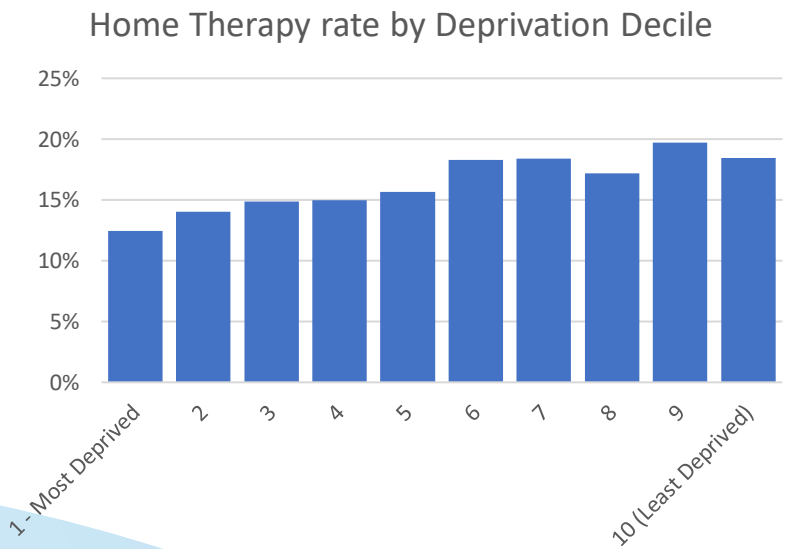
Age Group	PD
<75	12.4%
75+	10.7%
Grand Total	11.8%



Numerator = PD patients
Denominator = all dialysis patients

Gender	HOME
Male	15.5%
Female	16.5%
Grand Total	15.9%

Age Group	HOME
<75	18.0%
75+	11.9%
Grand Total	15.9%



Numerator = patients on PD or Home HD
Denominator = all dialysis patients

PD/HD – Indication of lower rates in most deprived groups
Age – Lower rates of home HD in >75 years

Workstream membership

Albert Power (NCA)	Ahmad Saleem Ullah (RSTP Head of Programme)
Sarah Afuwape	Rachel Gair
Katie Bluer (Workstream lead)	Nitin Kolhe
Mike Bassett	Mark Lambie
Rachna Bedi	George Palmer
Elaine Bowes	Nicholas Palmer
Sharon Byrne	Carol Rhodes
Jeremy Crane	Catherine Stannard
Kelly-Anne Dyson-Baggaley	Jacquie O'Shea
Enric Vilar	Brett Thompson

Teamwork:
Setting our challenge
10 minutes to discuss, 10 minutes to share

- Do you agree with the 20% home dialysis target?
- Do you want to set a (different) local goal?
- Do you have enough information about your current data to set a local goal?
- Is your goal SMART?

Specific

Measureable

Achievable

Relevant

Time Bound

Output:

- An understanding of where teams are and where they want to be
- SMART goals for each unit team, or;
- An understanding of what further info teams need to gather get to set a local goal

KQuIP

What are the factors driving centre variation in uptake of home dialysis?

Kerry Allen, Inter-CEPt Study

UNDERSTANDING CENTRE VARIATION IN UPTAKE OF HOME DIALYSIS WORK PACKAGE 1: ETHNOGRAPHY

Inter-CEPt

Sept 2022

Dr Kerry Allen, University of Birmingham

k.allen@bham.ac.uk

FUNDED BY

NIHR | National Institute for Health Research

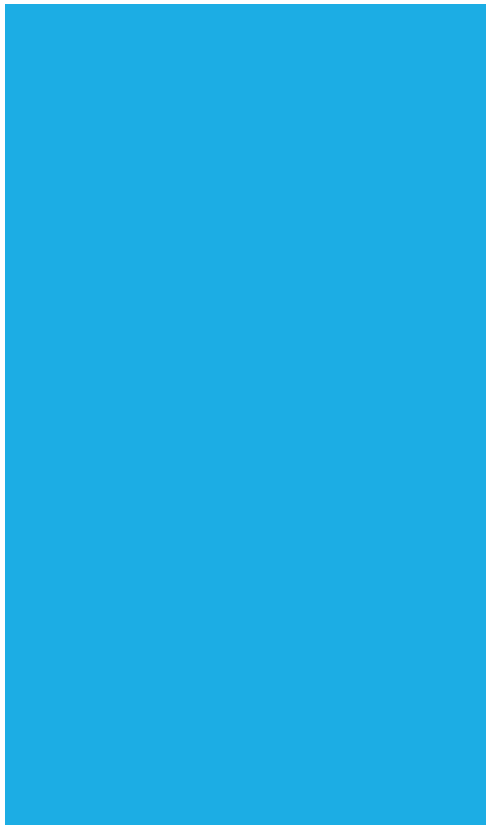
INTERCEPT AIMS AND THE ETHNOGRAPHY

Our overall question: What are the factors driving centre variation in uptake of home dialysis, and how do these inform the design of an intervention bundle to overcome this?

WP1 Ethnographic study - in 4 high performing sites to examine relationships between patients, carers/families, staff, organisations & their cultures. BME/ deprived populations represented.
In-depth interviews
Observation
Documents

WHAT WE FOUND

- Sites have different ways of organising their services, there is no ideal model.
- What all sites shared were aspects of their culture, attitudes and behaviour that led to good uptake of home therapies.
- Sites acknowledge that there were inequalities and welcome greater investment in people's social, psychological and cultural needs



SITES HELP PATIENTS TO ENGAGE WITH HD BY:

Sites help patients to engage with HD by:

- Exploring eligibility
- Providing high levels of preparation, assessment, training and follow-up
- A shared belief in value of home dialysis for patients
- Recognising and addressing the holistic impact of home dialysis on each person's life
- Creating and maintaining an organisational culture that is supportive of home dialysis
- Being outward looking, influencing the decisions made about home dialysis both locally and nationally
- Teams recognise and attempt to address barriers faced by under-represented groups

Despite making strong attempts to provide an equitable service – avoidable, unfair and systematic differences remain

Sites help patients to engage with HD by:

Presuming eligibility *"We would just say yes to anybody until we prove that we can't do it."*

"That's the big box, they want to do home HD".

- Overall focus on "the right dialysis for the right people"
- Transparency about all options
- Manage uncertainty - plan early
- Expect & identify barriers
- Find solutions, build them into future working

I don't think there is a type.

we've done it with people on narrow boats and in caravans

Sites help patients to engage with HD by:

Providing high levels of preparation, assessment, training and follow-up

- High levels of preparation, assessment, training and follow-up
- Work hard to solve problems:
  - Bespoke or additional training
  - Write to landlords
  - Tailor delivery of supplies

to make sure we improve our shared and self-care, we've transformed one of our dialysis units…we're trying to transform it into a home therapies – a home haemo unit

Sites help patients to engage with HD by:

Having a genuine belief in the value of home dialysis for their patients

- HD Champions
- Developed pathways that include HD (shared care, review)
- Communication is tailored to audience (e.g. patients, staff, commissioners)
- Work with the public, colleagues and charities to raise awareness

one thing we do stress is how could this fit in with your lifestyle, not how can you fit in with the dialysis.

Sites help patients to engage with HD by:

Recognising and addressing the holistic impact

- Decision-making pathways -
  - Build up to dialysis gradually
  - Make it real
  - Talk about all aspects
- Provide holistic support
  - Refer to specialists
  - Peer support, highlight lived experience
  - Kidney charities

peer support is very important…I say 'I've never had a PD catheter, I've never been on peritoneal dialysis, but I'm lucky enough to know a lot of people who have and you may want to speak to one of those people because they have had the surgery, they have managed their dialysis

although I've seen friends who've been on this type of dialysis with the fistula, until I actually see what's involved, how complicated it actually is, if it's – then I'll take a view of taking the training and having it at home

all I'm doing is taking one bit at a time

Sites help patients to engage with HD by:

Fostering a culture that supports home dialysis

- Despite different team structures and different ways of doing things - sites have common features
  - Strong leadership & champions
  - Inclusive teams & mutual respect across staff roles
  - Build strong networks with others
  - Improvement & learning built into routine working
  - Staff retention
  - Foster confidence of the wider Trust

Sites help patients to engage with HD by:

Influencing the decisions *"I am working with the kidney charities in the UK to change that…."*

Solutions:

- Good at building business cases
- Work with others to shape the agenda, local networks and charities
- Raising awareness (education & visibility)

energy bills is soaring, and if someone is going to do home haemodialysis, maybe they will think, I can't afford doing this

Training that takes place at the Baxter Education Centre…is unfortunately only two days long, And it used to be five days long. And of course it is really about supply and demand..

I think the new network structure that we now have is going to help with that because we have the ear of the commissioners in a much more regular way

Despite making strong attempts to provide an equitable service – avoidable, unfair and systematic differences remain

Multiple interacting issues – no quick fixes

Sadly for people that, perhaps, have quite challenging lives, living in social deprivation, their sense of self-efficacy and their self-belief is really low,….

The difficulty we find is that you can't build self-efficacy when all the challenges of social deprivation and difficulty still exist. So, if somebody's not got a house to live in, then that is their priority need, and until you can address those things, it's going to be very hard for them to build their confidence and their belief in themselves, because there will constantly be all those other factors that undermine it.

Culture matters

I say this to our trainees when they come on placement, is it's okay to not know about somebody's cultural background, but it's not okay to not ask. And so, ask, as part of that process. If you're meeting somebody for the first time and you're going to be working together on choosing a dialysis, explicitly ask them about cultural beliefs, about their community, about their religion, about spirituality.

Representation matters

The staff members in the kidney team is diverse so having that it also helps us really more with patients because we're share the same culture, we share the same beliefs. ….. It does make a massive difference in terms of their decision and the trust that they give to us.

Culturally aware but not truly competent

The younger generation of people coming through are really struggling with that mismatch between their background culture and their parents or their grandparents' expectations and beliefs, and then what they themselves think and feel. It's certainly a hard area, and I think it's something that perhaps in the NHS as a whole, not just in renal, we're not that great at understanding.

Teamwork:
Reflections on the pandemic
40 minutes to discuss, 10 minutes to share

- Did your processes change because of COVID?
- What do you want to keep?
- What do you want to ditch / what went backwards that you want to recover?
- What new thing do you want to bring in?

Use your Home Dialysis process map produced pre-COVID if you have it to aid discussion

Use post-it notes to highlight changes to your processes – use different colours for positive, negative and new changes

Listen to people with lived experience – what was good, bad from their perspective?

Output:

- An overview of the impact of COVID on home therapy pathways
- Teams to have reflected on the past two years and use this learning to begin thinking about and planning for the future.

KQuIP

COFFEE AND ADVANCED KIDNEY CARE SURVEY

Health equalities and DAYLife: Does everyone have equal access to home dialysis therapies? If not, how can we make sure they do?

Jyoti Baharani, Neerja Jain and Maz Ali

Improving access to home dialysis- Addressing Inequalities in care

Neerja Jain Health Equalities Programme Manager Kidney Research UK

Jyoti Baharani Consultant Nephrologist UHB

‘Health inequalities result from social inequalities.

Action on health inequalities requires action across all the social determinants of health.’

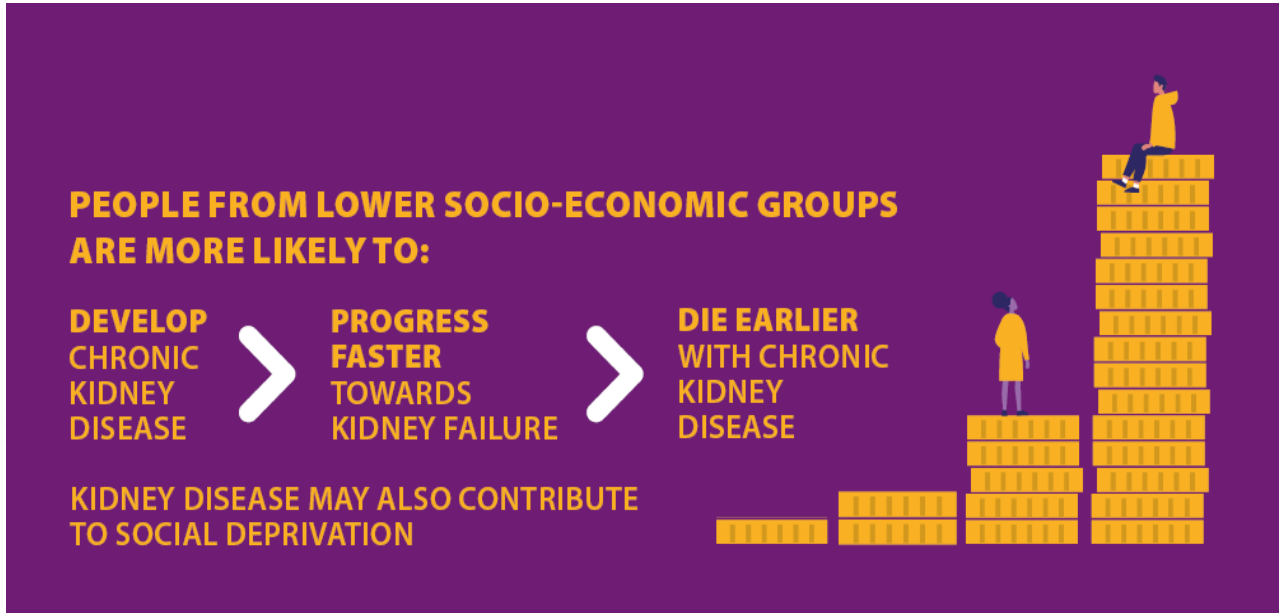
Marmot M. Fair Society, Healthy Lives: the Marmot Review. 2010.

Social determinants of health equity

Economic Stability	Neighborhood and Physical Environment	Education	Food	Community and Social Context	Health Care System
Employment	Housing	Literacy	Hunger	Social integration	Health coverage
Income	Transportation	Language	Access to healthy options	Support systems	Provider availability
Expenses	Safety	Early childhood education		Community engagement	Provider linguistic and cultural competency
Debt	Parks	Vocational training		Discrimination	Quality of care
Medical bills	Playgrounds	Higher education		Stress	
Support	Walkability				
	Zip code / geography				

Health Inequity in Kidney patients

- Both a risk factor for and effect of, kidney disease
- Tend to be diagnosed later
- Poorer survival on dialysis
- Lower rates of transplant
- More likely to experience risk factors for CKD



Home dialysis in the west Midlands 2014

Unit	% on PD
A	**27**
B	**22**
C	**21**
D	**21**
E	**14**
F	**13**
Heartlands	**6**


£5
© Rex Features


NHS
Birmingham Heartlands Hospital
Main Entrance

2 x a day?
AM or PM?
Take with food?
May be drowsy?
Half or whole?


ACCIDENT & EMERGENCY
Emergency

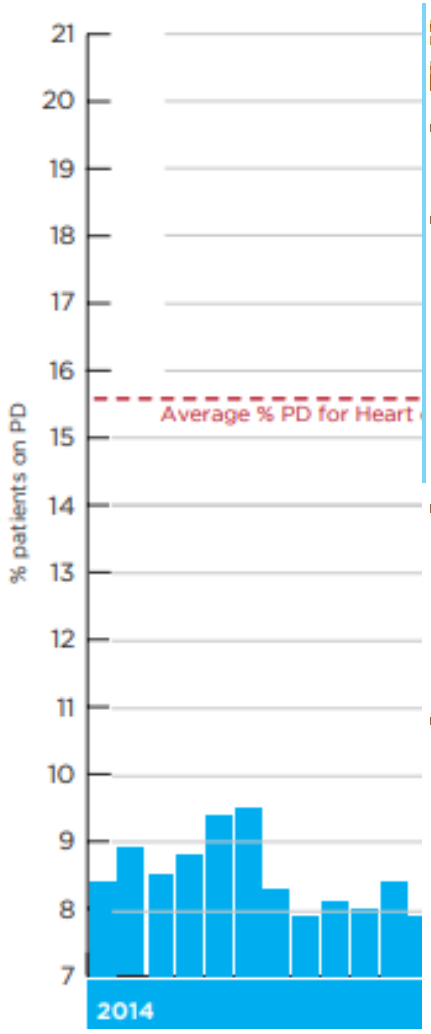
What caused the issue ?

All change!

- Changed the education process
- PD for first RRT option as the default unless there is a good reason not to offer it
- More operators to insert PD tubes
- Acute PD
- PD from prevalent population(education, roadshows, shared care)

Our journey in stages

2014

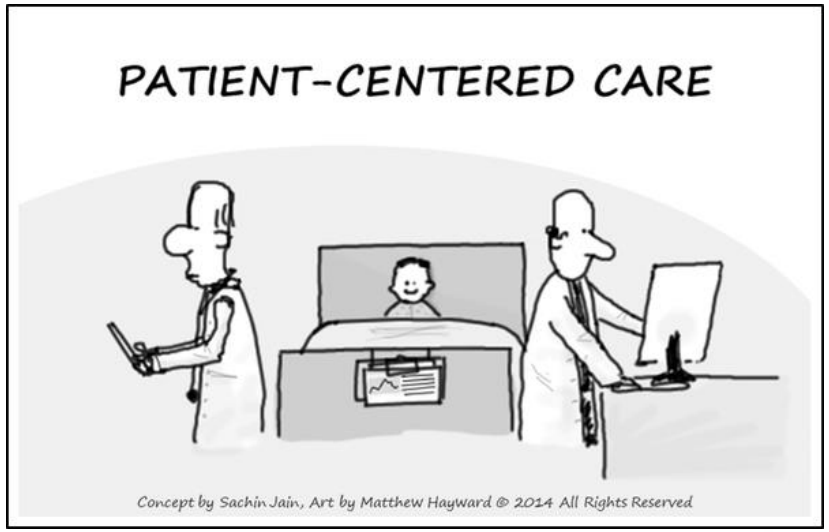


System Design – building the infrastructure

- Dr Baharani appointed Home Therapies lead
- Formation of Home Therapies Multi-Disciplinary team (MDT) which included staff from pre-dialysis, PD, HHD and vascular access, who met fortnightly from this point forward
- Home Therapies team away day including a review of patient education, pre-dialysis and the decision to adopt a PD first policy
- Additional consultant trained and starts medical insertion of PD catheters – increasing operators from 1 to 2 to ensure catheters could be inserted in a timely manner

- But we were still struggling to the message that ‘home is best’ to the hard-to-reach communities

- Being at home fits with Patient centred care

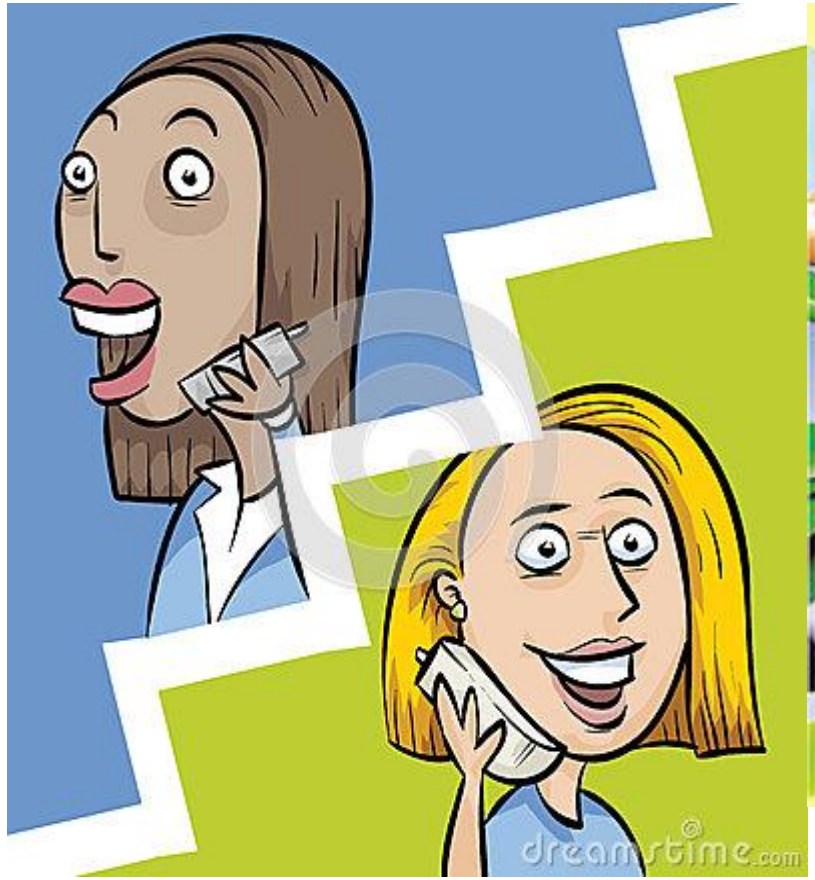


"The lack of patient engagement is the Achilles Heel of health care delivery."

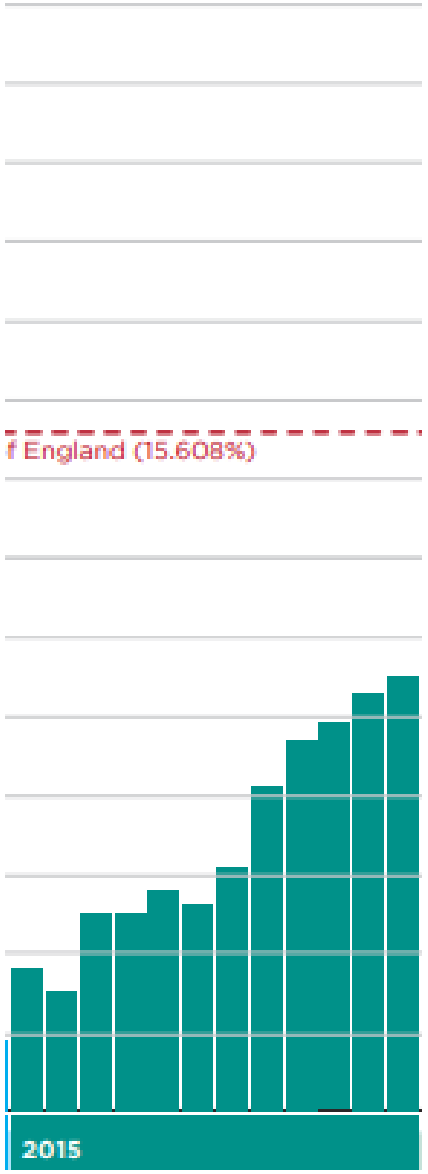
Adapted from quote by Terry McGeeney, MD

The problem is not so much that patients are unengaged

...but rather that providers are not always very engaging


dreamstime.com

2015



Education and upskilling of the wider team

- Review of Pre-Dialysis Education
- ACE (Acceptance, Choice and Empowerment) project begins – a 17 month pilot of a peer educator based community project involving trained and accredited volunteers who have a natural empathy with the patient group through language, culture, religion and healthcare experience. All volunteers had personal experience of RRT *https://doi.org/10.7861/futurehosp.6-1-s9 (Future Healthc J March 2019)*
- E3 (Educate, Enable, Empower) programme commences - providing information to enable the ICHD nurses to discuss alternative dialysis therapies with their incident HD patients

Kidney Research UK is the largest charity dedicated to funding research into the causes, prevention and treatment of kidney disease;

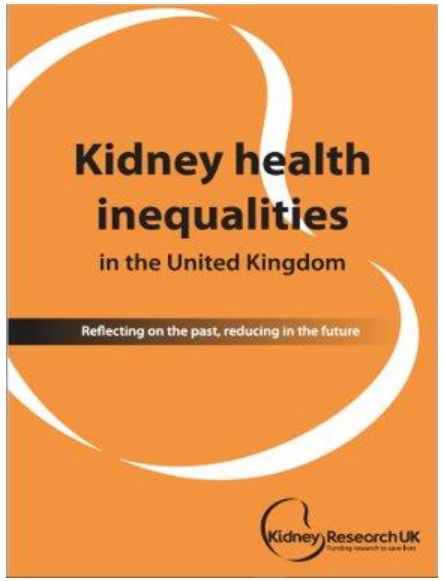
HUGE AWARENESS & EDUCATION ROLE

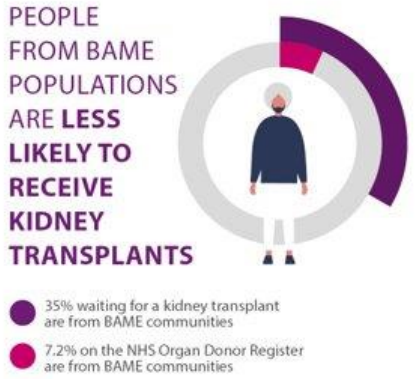
Our research strategy

www.kidneyresearchuk.org

NEED & BACKGROUND

- Health Equalities – cross cutting Strategic theme for Kidney Research UK
- Minority Ethnic groups represent 14% of the UK population
- South Asians represent 7.5% of the UK population- largest group
- South Asian, Black African and Black Caribbean make up 22.7% of people in the UK receiving RRT.
- More likely to need a transplant, less likely to donate and more likely to wait longer for a donation.
- Lack of awareness – e.g. diabetes and high BP as leading causes of kidney failure
- Misinformation – the law, operations, myths of mutilations, delayed burial etc.
- Cultural and religious misconceptions
- Language barriers;
- Lack of trust in NHS/outside their community
- EDI agenda





- Complex interaction between ethnicity and socioeconomic status
- Faster progression
- Much more likely to experience risk factors, but varies between groups
- Over-represented in dialysis
- Lower take-up of home therapies

Kidney Research UK

ACE – Acceptance, Choice and Empowerment for pre -dialysis patients: A Peer Educator based community project that aims to improve choice and quality of life for patients.

The “Right” messenger

Peer Educators – The Right Messengers

"Education is the most powerful weapon which you can use to change the world."

Nelson Mandela 1918-2013 RIP

Helping to reduce inequalities: Peer Educators – who are they?

- Empathetic – volunteers are truly representative of target Ethnic Minority Groups (EMG's) - "right messengers": cultural, faith, language, health care experience/literacy & health behaviour
- Wealth of (life) experiences - diversity
- Simple, v. flexible model (kidney disease spectrum)
- Passionate!....to give back to the NHS & to their communities
- Accredited training & supported to deliver the "right messages"
- Cost effective & sustainable
- Building capacity ("bottom up")
- Increase PE's confidence & opportunities

.

Peer Educators – overview

- >170 Peer Educators trained since 2005 around UK - cross section of ages, education, ethnicities, religion & socio-economic status
- Engagement with > 40,000 people ‘at risk’ in: Leicester, Luton, Bradford, Glasgow, Edinburgh, Birmingham, across London…..many projects
- Events held at places of worship, community, cultural and social events etc.; media opps ++
- Thousand’s of people signed up to the NHS ODR; 136 at one event alone.
- Multi award winning & evidence based

Experience Across the Disease Pathway.

Adapted for a range of Ethnic Minority Groups as well as segmented for age and gender (plus clinicians)

Evaluation pre –ACE

- Education in some groups of patients sub-optimal – difficult to get rapport
- Misinformation
- Haemodialysis became the default as patient not empowered
- Not enough kudos for home therapy as the majority dialysed in centre
- Co-production of home visits and clinics for new patients choosing renal replacement therapy = more informed and empowered patients; increase in home therapies

A proven & evidence based model

A peer outreach initiative to increase the registration of minorities as organ donors: Jez Buffin; Robert Little; Neerja Jain; Anthony N. Warrens Clinical Kidney Journal 2015; doi: 10.1093/ckj/sfv066.

True Partnership:

- Patients, carers and families
- Peer Educators
- A Charity: Kidney Research UK
- Renal Unit Staff @University Hospitals of Birmingham
- Funders, Baxters Healthcare

Kidney Failure Education Session

Agenda

09:30	Registration- Tea & Coffee	- All
09.50	Welcome and Introduction-	Annette
10:00	Functions of the Kidney -	Annette
10:15	Peritoneal Dialysis	- John
11:00	Living with a family member on dialysis	- Debbie
11:10	Refreshment Break	- All
11:35	Haemodialysis & Home Haemodialysis	- Pete
12:30	Renal Diet Advice & Renal OT	- Annette
12:45	Transplantation	- Shahnaz
13:15	Close	- Annette

ACE in practice

Peer Education: 4 Pronged Approach

- Home Visits
- Patient Education Days
- Clinics
- Telephone follow up

➢ Dialysis Decision Aid
➢ Standard Operating Procedures developed
➢ Reflective practice diaries
➢ Emotional support for PE's – Charity counselling service and de-briefing sessions with the team and nursing staff

Patient Information Days

- 5 patient information days held, invite via a personalised letter followed up by a phone call
- 3 tailored to our target audience with agenda's: day, venue.
- 50 patients and 44 family members attended (Normal average 1 South Asian patient/event)
- All patients said it had helped them make a decision *and* that it was a positive experience

Evaluation

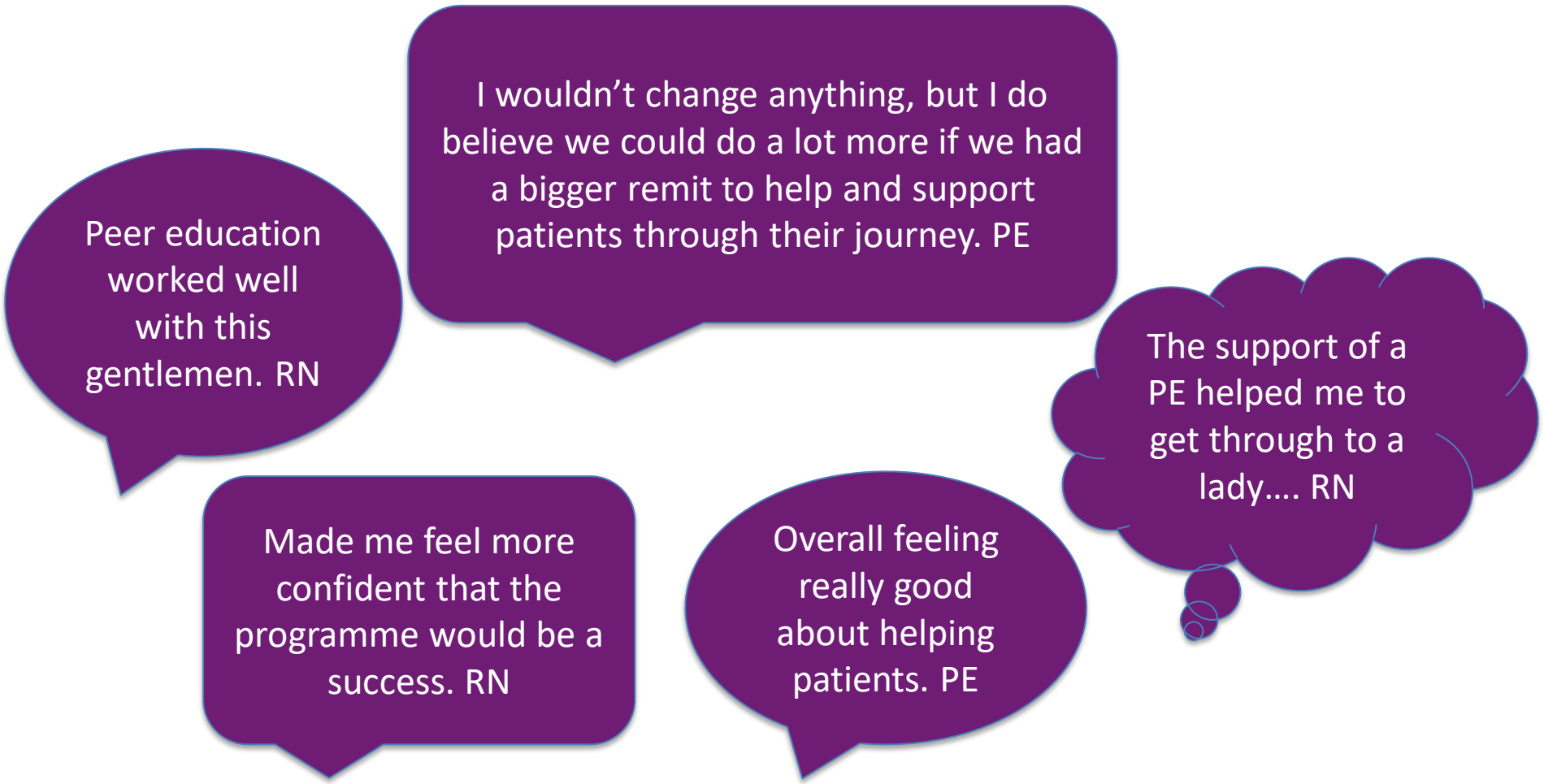
- Baseline – 13% of patients on home therapies
  2.5 years later – 28.8% of patients on home therapies
- Focus groups completed for PE's and staff to evaluate the new service model – overall very positive
- Excellent feedback from patients and carers – via questionnaires and verbally!
- Pt Info Days: 50 patients and 44 family members attended (Normal average 1 South Asian patient/event)
- All patients said it had helped them make a decision *and* that it was a positive experience

Measurable success!

Patient Experience Network National Awards(PENNA):

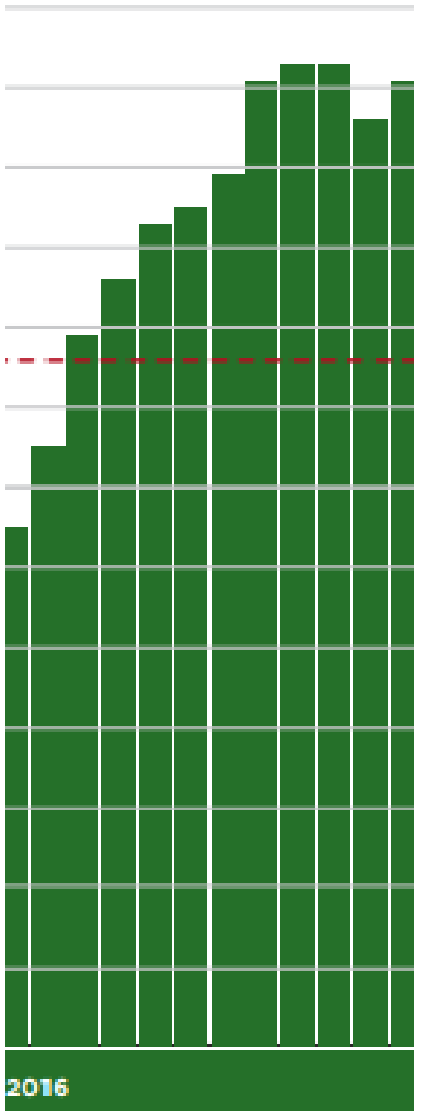
1)Communicating Effectively with Patients category – runners up;
2)Continuity of Care - Finalists

Winners! ☺… in the “Supporting self-care” category at The West Midlands Academic Health Science Network


I wouldn’t change anything, but I do believe we could do a lot more if we had a bigger remit to help and support patients through their journey. PE
Peer education worked well with this gentlemen. RN
The support of a PE helped me to get through to a lady…. RN
Made me feel more confident that the programme would be a success. RN
Overall feeling really good about helping patients. PE


It was a very good experience for the patients (carer)
Different individual experiences
Very informative and time to ask questions
It gave me a helpful insight into the reality of dialysis.
Excellent, very helpful educational
Very good.
Provided reassurance

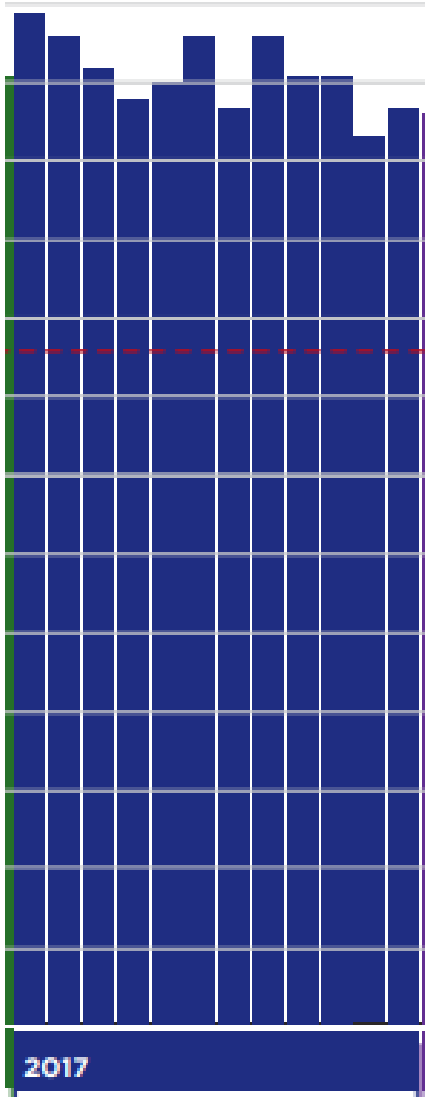
2016



Rapid Improvement Events – from referral to patient initiation on RRT

- An interactive workshop was organized with the renal team to create a process map that reviewed the "current state" showing every point at which a patient interacted with the Renal Unit on their journey to RRT.
- The process map provided a comprehensive visual representation of the patient journey in its entirety and expanded team understanding of each step on patient experience and patient flow
- Action plans enabled introduction of urgent start PD and a new consultant appointed already trained to medically insert PD catheters increasing operators from 2 to 3 and expanding the techniques used
- Increase in PD nursing staff

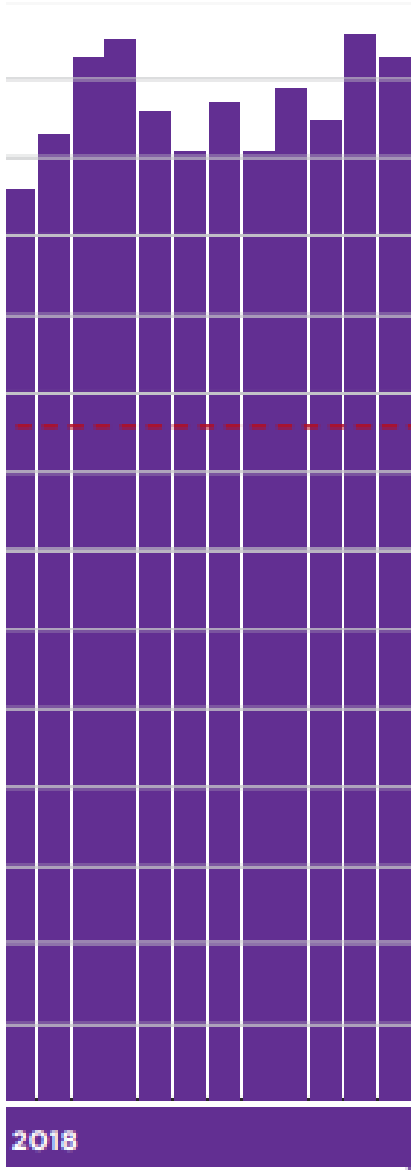
2017



Embedding Home Therapies

- Further Quality improvement workshops created the future state pathway and action plans to support home therapies goals. The future state process map did not see any reduction in the number of steps in the patient journey, but focused the team on how each step was implemented
- In depth pathway mapping with the Vascular Access team was undertaken to support the business case required for service redesign
- Maintaining the PD programme resulted in system change, decreasing the need for further late ICHD evening shifts that can be antisocial for both patients and staff and indeed resulted in the closure of one existing late evening shift
- Home therapies roadshow started to drive uptake of home therapies at pre-dialysis stage, now take place annually

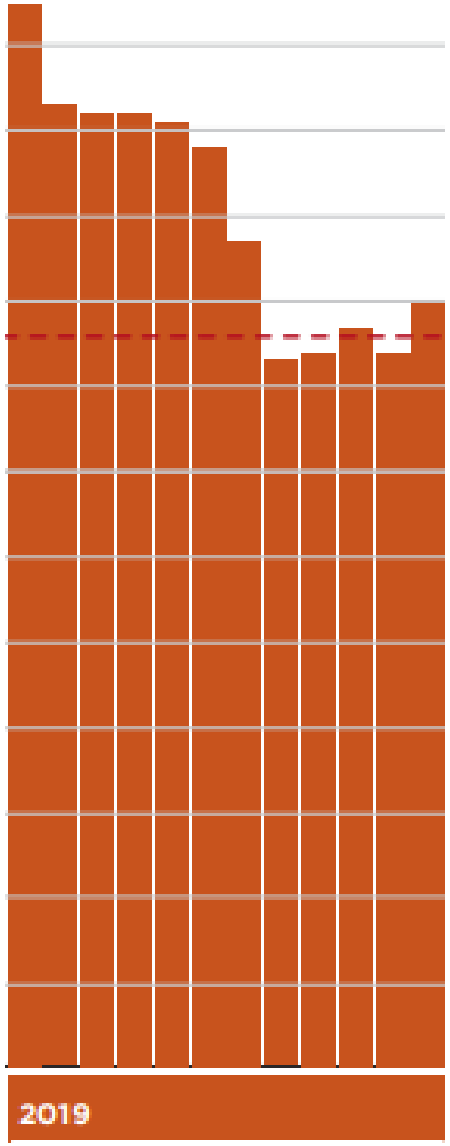
2018



Continuous Quality Improvement to sustain improvements

- A monthly audit was undertaken of all factors contributing to PD cessation to identify priorities for improvement. The data showed the percentage of patients lost to transplant varies over time; at the same time the percentage of patients dying whilst on PD increases. This may indicate that the additional patients accessing PD, in addition to those 'bridge to transplant' patients are to some degree elderly patients who would otherwise have ended up on ICHD but have been able to remain at home.
- The home therapies team completed a cause and effect diagram; visualisation tool to review potential causes of peritonitis and identify root causes. From 2014 to 2018 the PD programme grew from 36 to 94 patients whilst the peritonitis rate remained stable

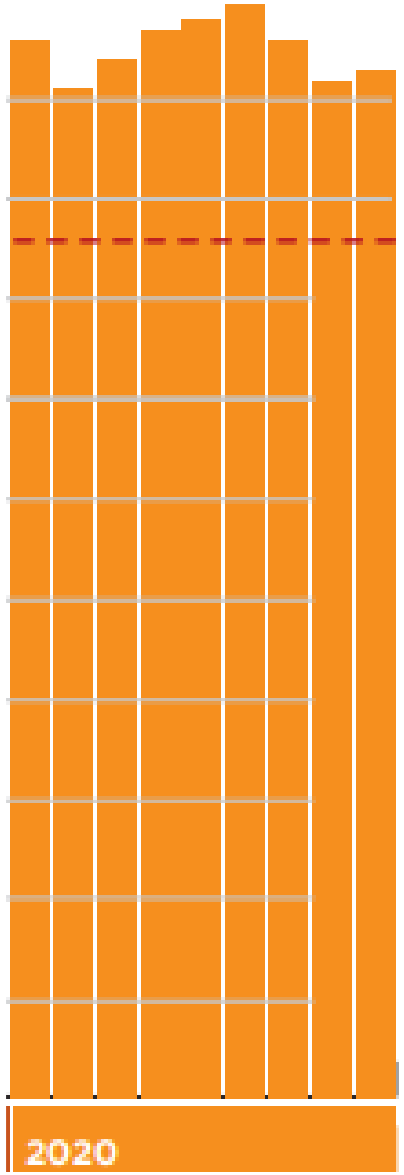
2019



Plan, Do, Study, Act (PDSA) cycles of improvement

- Renal Units across the Midlands began to work on Kidney Quality Improvement Partnership (KQUIP).
- A retrospective Root Cause Analysis (RCA) of all patients who chose home therapies but did not end up at home – Modality Selected, Modality Started. Why the Disconnect. Completion of the RCA resulted in an improved education pathway and a checklist of additional information for patients prior to transfer home
- To reduce drop-off from infection by reviewing patient technique for connect/ disconnect
- Merger with QEB presented opportunities for shared learning and standardisation of varied practice
- Merger with QEB also meant teams have been going through structural changes across the service causing instability

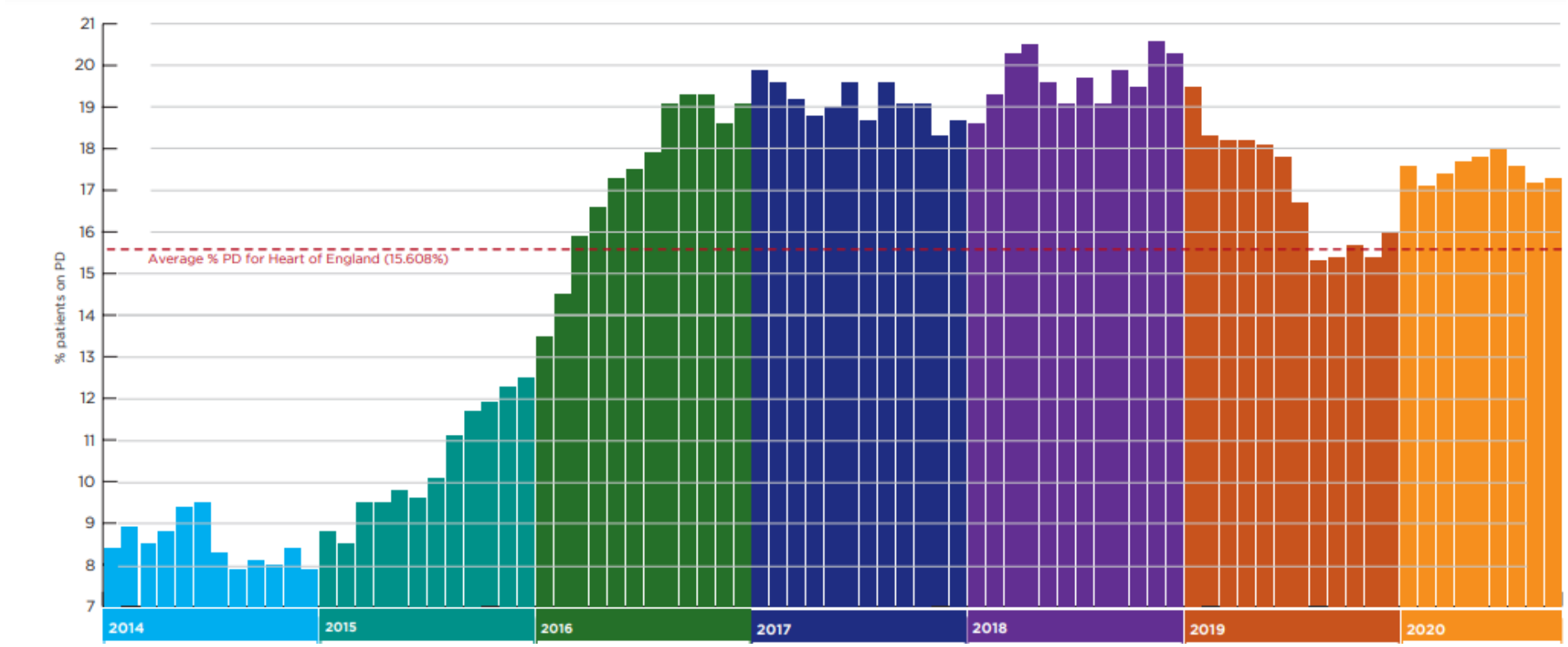
2020



Global Pandemic

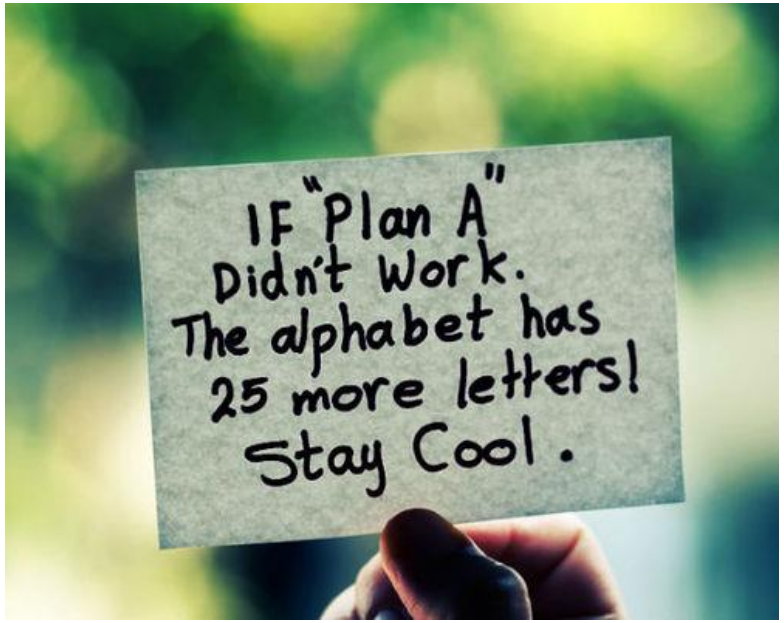
- Good habits persist despite the pandemic, demonstrating how quality improvement has been embedded in the unit
- Little room for further innovation at this time, so looking towards 2021 shared learning and standardisation of varied practice

The journey so far



ACE-2

Thank you- happy for any questions

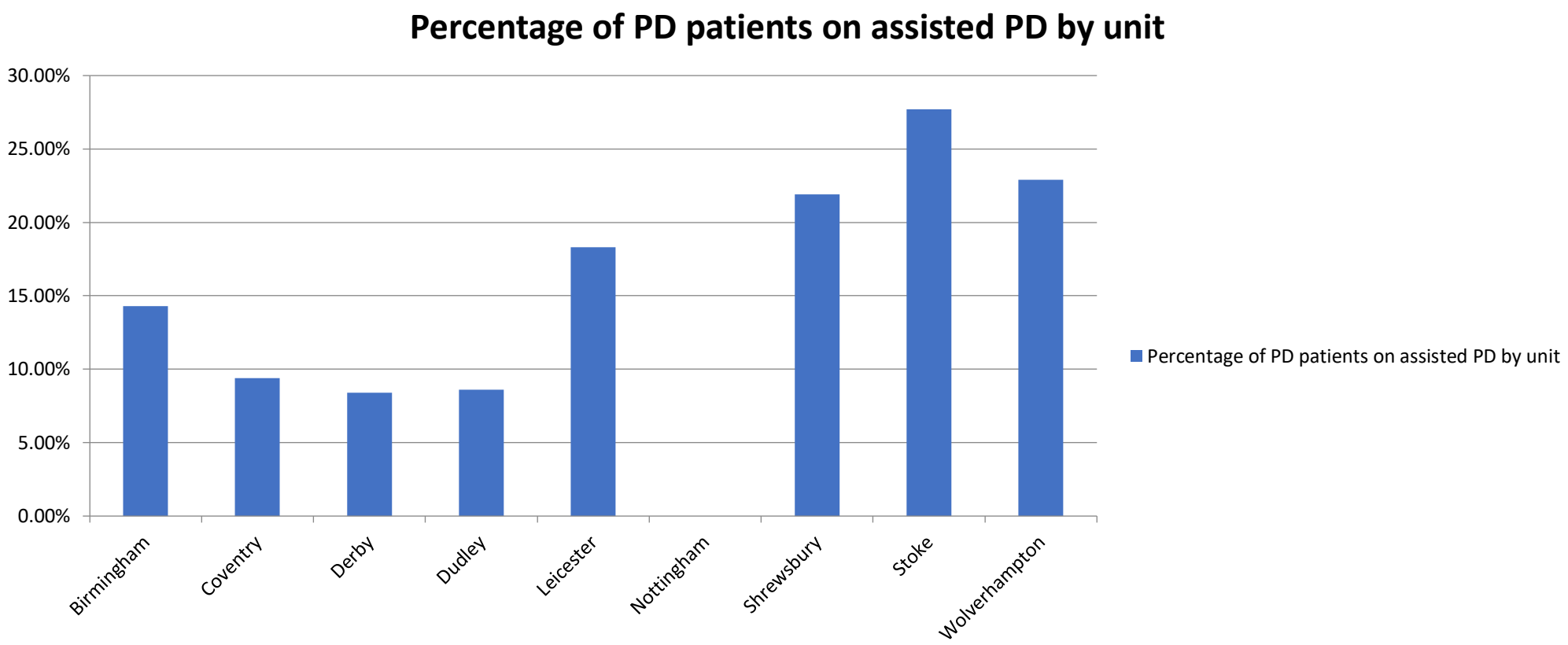


Jyoti.baharani@uhb.nhs.uk
neerjajain@kidneyresearchuk.org

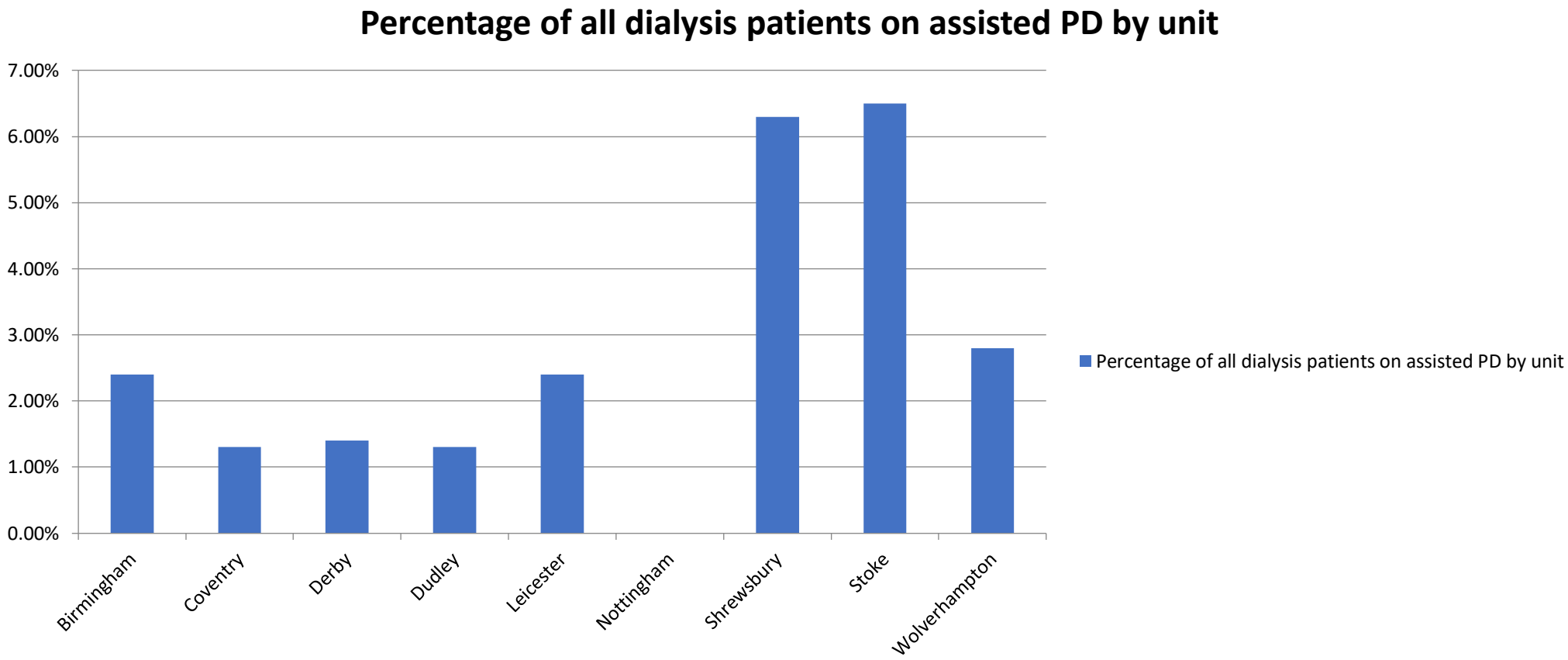
Assisted PD – identifying and removing barriers, future use

Mark Lambie

% of PD patients on assisted PD (June 2022)



% of all dialysis patients on assisted PD June 2022



Teamwork:
Assisted PD – identifying and removing barriers
15 minutes to discuss, 10 minutes to share

- How do you use the assisted PD service?
- What assistance do people need?
- What are the challenges in offering assisted PD?
- How would you like to use assisted PD if challenges were overcome?

Move through each question one by one – three minutes quick-fire on each

Use post-it notes to capture everyone's ideas – use half a flip-chart page per question

Output:
- An overview of the use of assisted PD across the Midlands region
- Capturing ideas for improving the way assisted PD is offered to people with kidney disease

KQuIP

Teamwork – with buddy units
DAYLife revisited
15 minutes to discuss, 10 minutes to share

- What are the components required to make the project work?
- How are we going to share?

- **Clear lines of communication (introduce peer support)**
- **Education of medical team – particularly junior team members**
- **Continuation of pre-COVID QI work around AKC – encouraging assisted PD, shared care and HT early on, medical catheter (Notts)**
- **Standardisation across network (Lincoln) – need someone from each team as part of project**
- **Patient socials – to see team members regularly**

KQuIP

LUNCH – PRESENT THE ADVANCED KIDNEY CARE SURVEY DATA

Midlands Kidney Network

Alastair Tallis

MKN

Midlands Kidney Network

NHS

Background

- The Midlands Network incorporates the whole Renal pathway from primary care to dialysis, transplant and end of life care. The Network has been developing priorities based on the outcomes from the Getting It Right First Time (GIRFT) review and the National Renal Services Transformation Programme which is being run by NHS England.
- The Network received funding in April 2021 to set up a formal commissioned network following on from the informal Essential Services Network developed in the Midlands on an informal voluntary basis and historic funded networks.
- The movement to Integrated Care Systems Commissioning a wider portfolio of services, including commissioning some Specialised commissioned services means that Networks are more important and the system working should reduce organisational barriers currently in place.

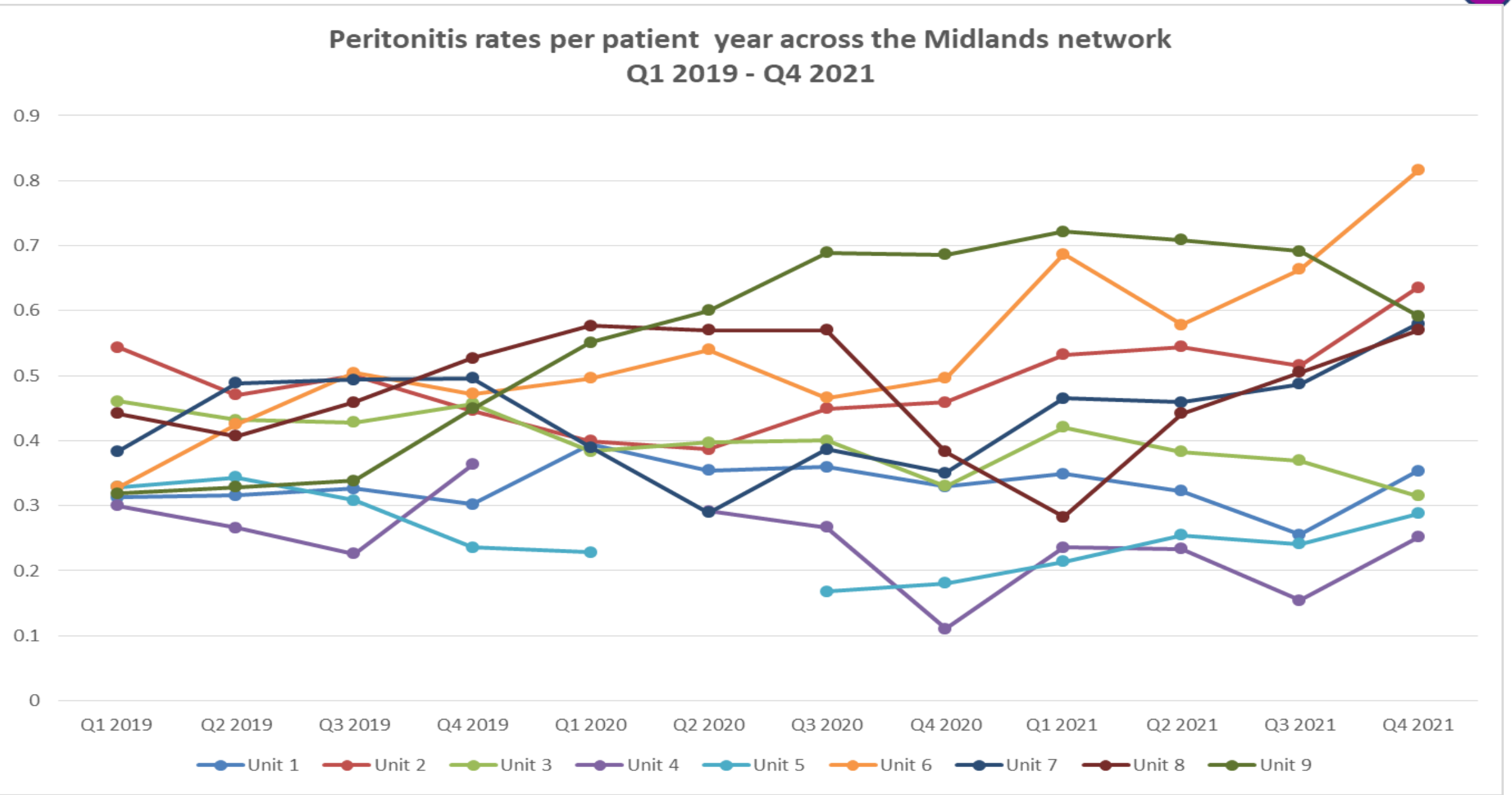
Value of the Network

- "Networks are a powerful way of sharing learning and ideas, building a sense of community and purpose, shaping new solutions to entrenched problems, tapping into hidden talent and knowledge, and providing space to innovate and embed change." Huerta, Casebeer & VanderPlaat, 2006
- Consider the big picture – not focused on individual trust priorities but focused on the network priorities.

Why Network?

- To improve outcomes
- To share good practice
- To ensure equitable services

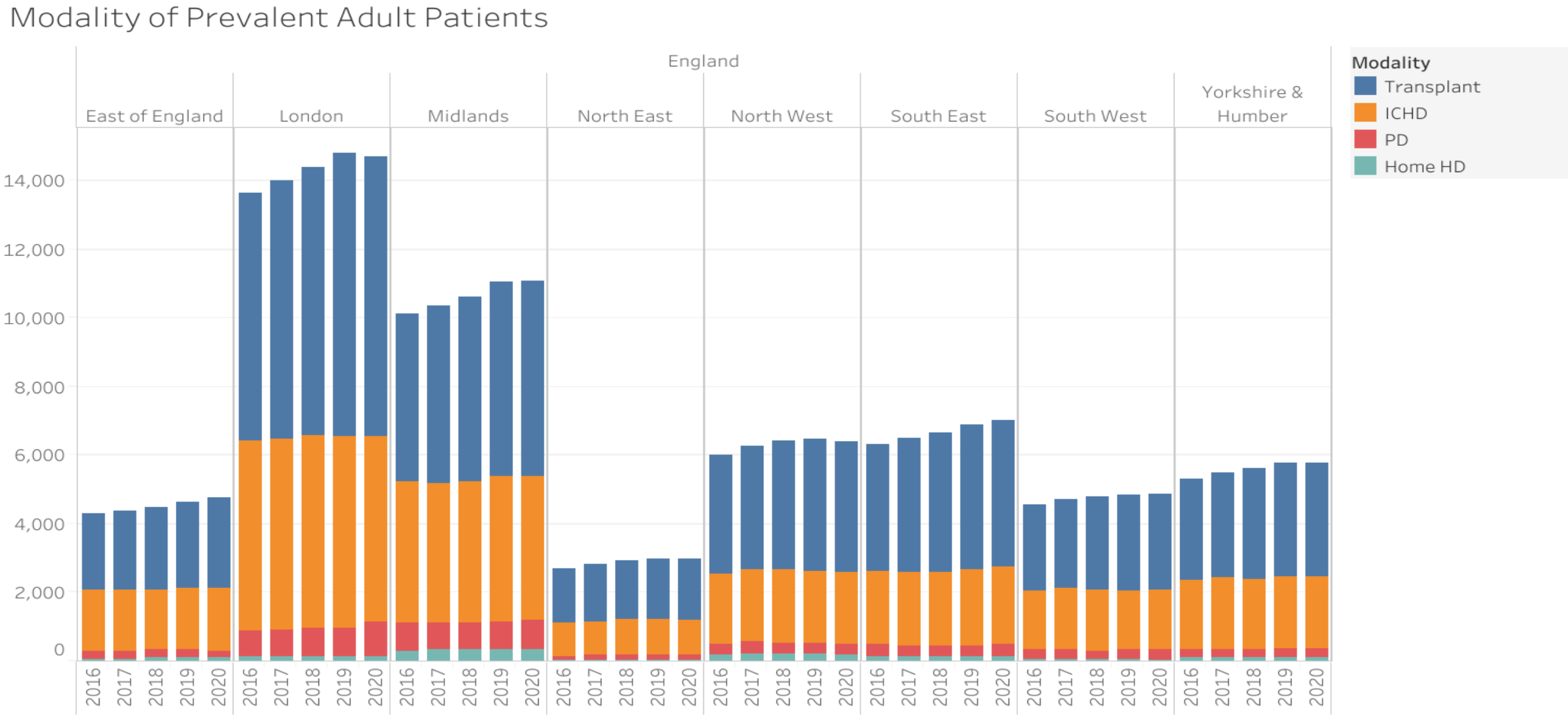
Unwarranted variation



Renal network context

- In England there are around 57,000 patients on renal replacement therapy (RRT).
- 1 in 10 people will suffer from kidney disease during their lifetime.
- 1 million people in the UK have kidney disease but don’t know.
- The spend on renal is in excess of £1.45 billion in England (2009/10 cost review) and the estimated cost is now £2b.
- The spend on renal dialysis was over £600m last year in England which shows a £10m per year increase

Regional Numbers



ICS's within the Midlands

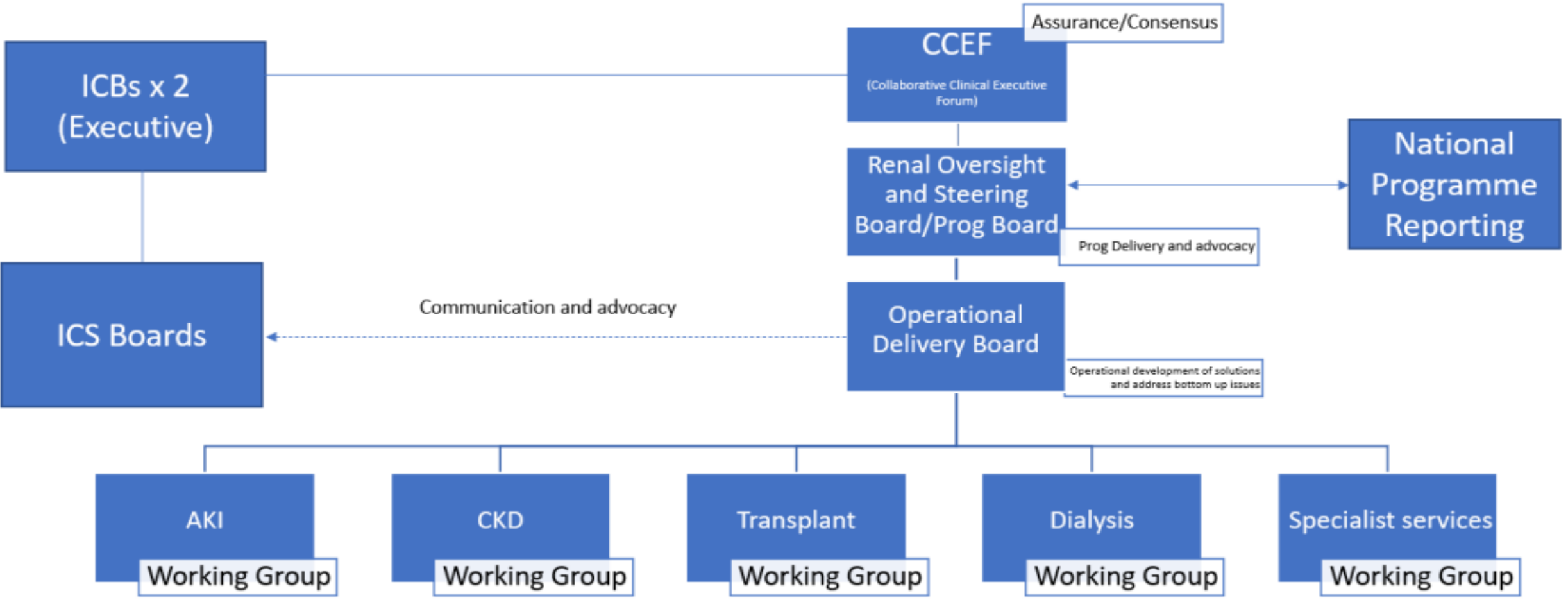
East Midlands	Hospitals they cover
Derbyshire	Royal Derby and Burton
Leicestershire	Leicester General and Royal Infirmary
Lincolnshire	United Lincolnshire
Northamptonshire	Northampton General and Kettering General
Nottinghamshire	Nottingham

West Midlands	Hospitals they cover
Black Country and West Birmingham ICS,	Dudley, Sandwell, West Birmingham, Walsall and Wolverhampton
Coventry and Warwickshire	Coventry, Warwick, George Eliot
Shrewsbury, Telford and Wrekin	Shrewsbury and Princess Royal (Telford)
Birmingham and Solihull	University Hospitals Birmingham, BWCH,
Herefordshire and Worcestershire	Wye Valley, Worcestershire Acute
Staffordshire and Stoke on Trent	Royal Stoke and County Hospital

Midlands renal network – governance and infrastructure

- The governance structure has been formally in operation since March 2022.
- A robust governance and reporting structure is being embedded to support the network to enable change and to support the delivery of the objectives.

Midlands renal network – governance and infrastructure

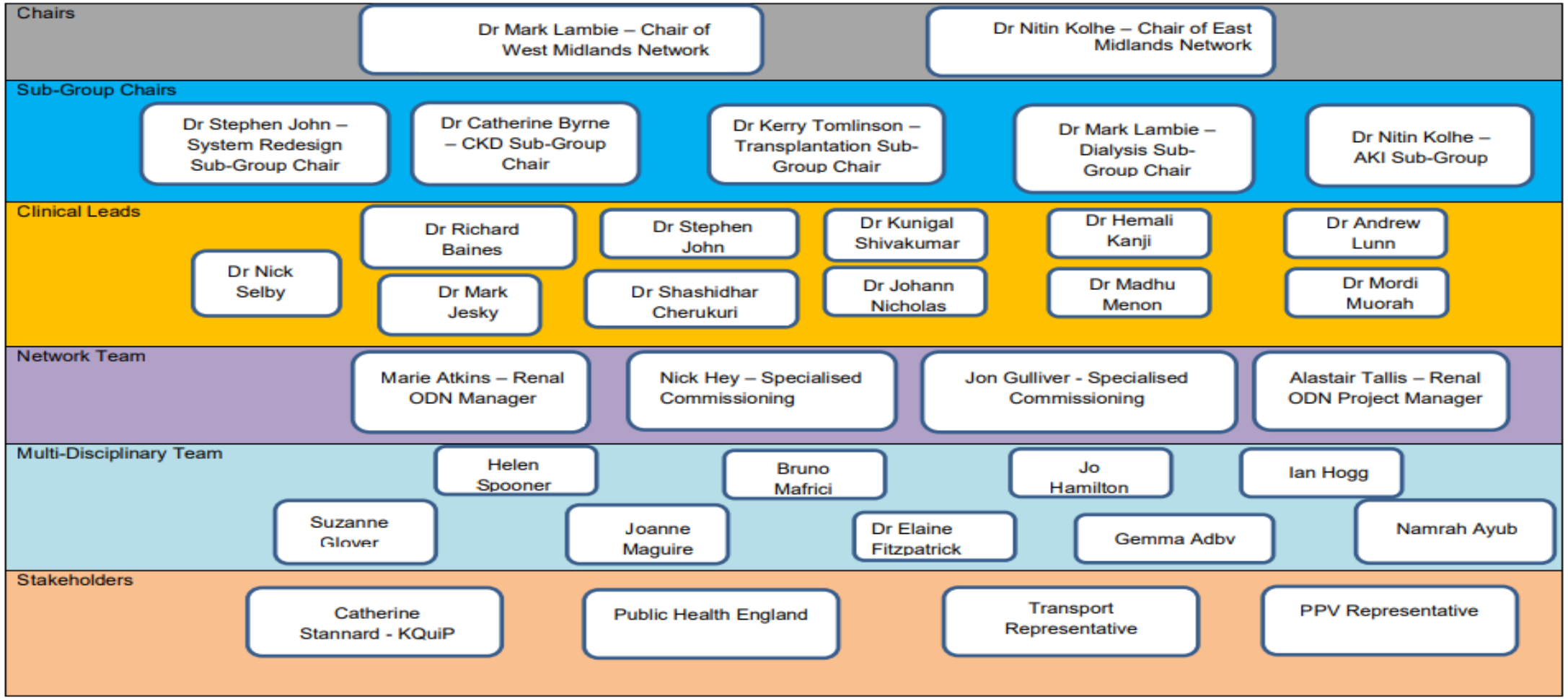


Renal Operational Board Membership

- Chairs of Network – Dr Mark Lambie and Dr Nitin Kolhe
- Clinical lead from each trust
- Service lead from each trust
- Chairs of the sub working groups
- Commissioning lead from the Midlands Regional Commissioning Team
- PPV representative
- Network Manager and Network Administrator
- Transport representatives
- Public Health
- Allied Health Representatives (Dietitians, Occupational Therapists, Nurses, Pharmacists and Psychologists)

Operational Delivery Board Organisational Chart

Midlands Kidney Network



Primary Care

- Close collaboration with primary care will be needed to deliver certain services, for example, virtual renal clinics and remote forms of consultation. This can be co-ordinated and supported at regional level with horizontal working between providers.
- We have a couple of primary care representatives on network but are looking to engage more colleagues.

Quality Improvement

- The GIRFT report recommends that QI is best co-ordinated regionally.
- We work with UK Kidney Association and KQuIP to support the network's QI priorities and upskill the MDT with quality improvement skills to achieve sustainable change.
- We have various work streams and QI projects already underway in the renal network.

Work streams

- We have mirrored our regional work streams on the Renal Services Transformation Progamme (RSTP):
- Acute Kidney Injury (AKI)
- Community Chronic Kidney Disease (CKD)
- Dialysis
- Transplantation
- Systems Optimisation

Kidney Beam

- Midlands Renal ODN is paying for this for the whole of the network so our patients can continue to access Kidney Beam and you can also sign up new patients.
- The network is currently sorting the logistics and marketing details, once we have these then the Kidney Beam team will be in touch with login details etc and how to promote it to your patients.
- The Kidney Beam team have marketing materials that they need to send to each renal unit and satellite unit that comes under your service.
- Evaluation in 12 months time to review benefit.

Kidney Beam

- Web- based self-management programme: designed to allow people with kidney disease to learn about their condition and provide support to them, both physically and emotionally.
- Co-developed to support people living with kidney disease during the COVID-19 pandemic and beyond.
- Digital delivery allows:
  - Provision of evidence-based physical and emotional wellbeing
  - Delivered across England
  - Free at the point of contact

Peer support KCUK

- Kidney Care UK leading and developing their peer supporter programme piloted in West Midlands and commenced in July 2020 during the Covid-19 lock down.
- In conjunction with the West Midland's hospitals and Kidney Care UK many of these kidney patients with lived experience have now become peer supporters and Giulietta Whitmore who is qualified in Volunteer Management 7 Peer Support Training, acts as a gateway to connect these people to support one another.
- The Peer Support service has been seen to be a valuable asset and allows patients to be connected with one another from the commencement of diagnosis right through to treatment options and beyond.

Peer support KCUK

- Peer Support is confidential, factual, and informal and available when you need it. All peer supporters are fully trained and regularly reviewed.
- Giulietta works with a team of volunteers and colleagues who are Kidney Patients and can support your patients with their Kidney journey.
- We try and meet at least once a year to get together and share experiences.
- The peer support programme can be accessed by contacting Giulietta Whitmore directly or via email at volunteer@kidneycareuk.org

Peer support NKF

- https://www.kidney.org.uk/peer-support
- The free service is aimed to support people who:
- Would like someone to talk to regarding the options of dialysis at home
- Or have just started home dialysis and would like further support
- Patients can be matched with a peer supporter who have experienced home dialysis themselves or are a carer of someone on home dialysis
- 24 fully trained Peer Support Volunteers
- The contact point for people who would like some Peer Support is the NKF Helpline 0800 169 0936 or email helpline@kidney.org.uk

Home reimbursement

- NHSE has sent a circular guidance on reimbursement for patients on home dialysis.
- Recommending all patients nationally are reimbursed for Home Haemodialysis, something that is not occurring nationally, however in our region every adult unit is reimbursing patients for Home Haemodialysis.
- Also that this reimbursement is also offered to all patients on home peritoneal dialysis (PD) and for all paediatric patients on home dialysis treatments.
- NHSE also produced guidance offering a universal commitment of transport support for all patients attending in-centre haemodialysis .
- NHS commissioning » Transport support for patients attending in-centre haemodialysis (england.nhs.uk)

Reimbursement calculator

- This has been proposed as a reimbursement calculator by the UKKA:-

Recommended Home reimbursement rates:

Utility	Reimbursement per day of home PD (HPD)	Estimated cost per month per HPD patient*	Reimbursement per session of home HD (HHD)	Estimated cost per month per HHD patient*
Electricity	£0.25	£7.00	£2.30 (daytime, standard session)/ £2.70 (night-time or long session)	£36.80/ £43.20
Water	N/A	N/A	£1.50 (for homes with metered water usage only and not on the WaterSure program)	£24

* Assuming 7 sessions per week HPD or 4 sessions per week HHD

Questions?

Further information

- Contact – Alastair.Tallis@uhcw.nhs.uk
- Mobile: Mobile: 07468708485
- Follow us on Twitter @MidlandsKidney
- Please contact Alastair to arrange to be on our mailing list.

Teamwork:
DAYLife revisited – action planning
40 minutes to discuss, 10 minutes to share with buddy units

- Update process maps with current pathway (or think about your current home therapy processes if you don't have your process map)
- Where are there blockages/improvement opportunities / successes?
- Prioritise areas for improvement
- What is the role of the Advanced Kidney Care team in your project?
- Who needs to be involved?
- Create a 30 – 60 – 90 day plan

Use post-it notes to highlight changes to your processes – use different colours for blockages, improvement opportunities and successes

Use a flip-chart page to create your 30-60-90 day plan

Output:

- Beginnings of a co-designed action plan and team
- Teams prepare to share their reflections on whole day in next session

KQuIP

SHARING SESSION
20 minutes

- Each table to share outcomes from day

➢Reflections and learning
➢Pathway changes
➢Priorities for improvement
➢Next steps

Output:
- What are the common themes from local teams?
- What is missing?
- Agree future steps, future meetings and support.

KQuIP

COFFEE AND CLOSE