



Improving the quality and uptake of home dialysis across the UK

**Co-designing a national quality improvement initiative to promote Home dialysis therapy – Report from a patient insight event - 30<sup>th</sup> March 2023**

## Foreword

Home dialysis offers benefits of flexibility and better quality of life for most people and cost-effectiveness for the NHS compared to in-centre haemodialysis. However, the proportion of patients on home dialysis has remained unchanged at 17% for the last 10 years with wide and often unwarranted variation between centres (3-35 %). There are system barriers in the provision and access to home dialysis therapy which disproportionately affect ethnic minorities and the more socially deprived groups. Quality improvement initiatives have been undertaken by renal centres in the last decade to promote home therapy with variable success, but these have often lacked dissemination, spread, and adoption. The Renal, Getting It Right First Time (GIRFT) report described examples of excellent practice in some centres. It highlighted the potential for collaborative working in all renal networks and recommended a minimum prevalent home dialysis target of 20 % for all renal centres. Care teams strive to provide high-quality person-centred care, keeping patients' wishes and choices at the heart of all decisions. Kidney patients, carers, and kidney charities have always worked closely with their care teams. Providing a strong driver for change, they play an important role in policy development and commissioning of renal services. There is untapped potential that care teams could draw upon through co-designing interventions to bring about the real change that has long been desired. As 'experts by experience', patients have much to offer. They provide a unique perspective in understanding the problems in the system and identifying novel 'change ideas'. If we wish to truly enable suitable patients to receive home therapy, it is imperative that we understand what matters to them most when they are at key decision points in their kidney journey.



The Kidney Quality Improvement Partnership (KQuIP) has always demonstrated a strong commitment to involving patients in a meaningful way. The DAYLife project, a national initiative to promote home dialysis in the UK, was launched by KQuIP in 2019. The pilot in the Midlands region demonstrated how a collaborative approach to quality improvement could provide tangible outcomes at a regional level, benefitting several centres. Following a pause during the pandemic, DAYLife was relaunched in 2022 with uptake so far in the Northwest, Southeast, and Southwest. As part of this initiative, we invited around 30 patients and carers to a virtual event to co-design interventions to improve the acceptance and enablement of home therapies. Based on previous research evidence, we identified four key areas to explore: Shared care for in-centre haemodialysis, patient education and shared decision making, psychosocial care, and peer support. We are grateful to all the patients, carers, the professionals who facilitated the sessions, and Dr Kerry Allen from University of Birmingham for writing this report.

I hope this report provides useful insight to care teams on what matters to patients in choosing and remaining on home therapy, and the impetus to work more closely with patients and carers locally to implement these recommendations. The next step is a leadership event in June 2023 for home dialysis multidisciplinary professionals, those commissioning renal services, and patient charities, to develop a strategy to support the implementation of these recommendations nationally.

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## Plain English Summary

This report summarises the findings of a patient insight event that took place in March 2023, as part of the Kidney Quality Improvement Partnership (KQuIP) Dialysis at Yours – Life Fulfilled (DAYLife) home therapies programme. Its aim is to capture the perspectives of people with Chronic Kidney Disease (CKD) and their carers about what a good home therapy programme looks like, the challenges they face and their thoughts about what changes they would like to see.

### What we heard – Key Themes:

#### Shared care

The approach of sharing haemodialysis with health professionals and gradually building the skills needed, known as ‘shared care’, gave people a valued opportunity to make decisions in their own time. Patients saw peer support as essential for others considering shared care and home haemodialysis. We heard about best practices such as peer ‘meet and greet’ in shared care and establishing peer relationships that would go on to support people if they eventually decided to move to home haemodialysis.

*Key recommendation: ‘Shared-care’ haemodialysis should be offered by all care teams, alongside dedicated peer support and training for all staff. Shared care concepts should be introduced as part of pre-dialysis education.*

#### Patient education and dialysis choice

People found choices about dialysis difficult to engage with. This was felt most strongly by those who experienced emergency situations with no prior treatment education. Many people who had followed a more planned route to treatment also struggled with shock and fear, which had an impact on their ability to make treatment decisions. These fears could be easily exacerbated by negative staff comments and graphic descriptions of home treatments. What had helped people cope with fears were early conversations that started at a human level with their priorities and lifestyles, working back to assess what type of dialysis might suit them best. Talking to patients and carers with lived experience (peer support) helped people to decide on and prepare for dialysis.

Sometimes staff attitudes prevented people from pursuing home therapies and bringing in their own voices and contribution. Consistency of knowledge and attitudes to home therapies are important to people receiving care, as is the ability to get involved and make improvements for others.

*Key recommendation: An earlier and more personalised approach to patient education which draws out the lifestyle priorities and encourages patient and carer voice.*

#### Psychosocial support

There was agreement that distress was an understandable reaction for people facing kidney failure and treatment decisions. Patients challenged us not to ask people whether they needed help, but instead to help them understand all the ways that they can build their ability to cope. Many people at the event displayed a lack of knowledge about existing high-quality support materials often co-designed by patients. Accessing resources that are relevant to an individual’s situation and that demonstrate positive messages about life with dialysis can make a difference in treatment decisions, self-image and well-being. The usefulness of patient-developed ‘frequently asked questions’ with co-produced answers featured multiple times in people’s accounts.

*Key recommendation: All care teams to provide early acknowledgement of the emotional and social aspects of living with CKD and signpost relevant resources and services.*

#### Benefits of peer support

Support provided by other patients and carers helps people to know about, choose and maintain dialysis at home. Although it had not always been easy to access, people told us that speaking to others that were using home therapy had given them the knowledge and confidence they needed to make their treatment decisions. Those that had benefitted from peer support suggested it was an essential component of all patient education programmes and could play a key role in minimising distress and isolation as a form of ongoing support. People drew attention to the hard work that went into setting up local peer support systems and volunteering in the roles. They questioned how bureaucracy could be reduced.

*Key recommendation: All patients should be offered peer support by their care teams. This should start early as patients are learning about treatment options and continue while on dialysis.*

## About the patient insight event

A patient insight event took place on 30<sup>th</sup> March 2023. It was the first event of the national KQuIP DAYLife programme to improve home therapy provision in the UK and influence clinical leadership and stakeholder education events later in the year. The event was attended by over 30 people living with CKD and carers. The group had experience with peritoneal and haemodialysis at home and in-centre settings. Some participants were also actively involved in co-producing and delivering practical advice/support care as peer supporters, advocates and campaigners. The session was facilitated by senior nurses, clinicians and representatives of kidney charities - Kidney Care UK and the National Kidney Federation.

The purpose of this event was to gain insight from those who use kidney care services that can inform how we promote and deliver home dialysis. The event aimed to take stock of issues that matter most to people as they make decisions about their dialysis setting and type.

Specific objectives were:

- To understand individual experience of choosing and being on a home therapy
- To discuss, explore and identify good practice within centres and how this might be supported at regional and national levels
- To explore barriers to accessing home therapies
- To identify potential practical solutions that might help overcome the challenges identified.

Based on previous research (Combes et al, 2015, 2017; McLaughlin et al, 2020; Noyes et al 2021) four applied themes were identified to guide discussion at the event:

- Promoting **shared care** amongst patients using or approaching in-centre haemodialysis
- Improving **patient education and shared decision-making** around treatment options
- Understanding the key **psychosocial issues** faced by prospective or current home dialysis patients and carers.
- Providing **peer support** to promote home dialysis therapies

## **Findings**

Participants had wide ranging experiences and views about home therapies. Not everyone chose to dialyse at home and we heard how interaction with health professionals and other people living with CKD had an influence on treatment decisions. Each person's experience was unique. This has resulted in diverse suggestions that address: patient and carer experience; service design; resource use; addressing inequalities; partnership working with local health and care systems; and national governance and coordination. We especially benefitted from the diversity of our participants as they identified the challenges of particular groups, for instance, how services should improve to better support young people, carers, people with disabilities and other conditions, and accommodate social and cultural differences. Despite these apparent differences, the range of experience revealed strong cross-cutting messages for the four applied topics, with implications for local, regional and national approaches. This report presents each topic and linked recommendations in turn.

## Shared care

People with experience of shared care talked about what they personally valued and gained. The initiative had fostered independence and control at a pace that was right for them. These accounts alluded to how important this sense of control often was, as from an early stage they had wanted to be able to do as much of their own care as possible. In some cases, they had uncomfortable experiences of ‘clumsy needling’ which had proven to be motivators toward greater self-care.

### **Overcoming fears**

As with all patients starting any type of dialysis, fears and uncertainties were barriers for people engaging with ‘shared care’. These fears include self-needling, use of technology and mistrust in the corporations promoting home haemodialysis. Powerful descriptions of the extent of fear came from those reaching dialysis in emergency situations with no prior education about treatment. The individual in the quotation below explains how their initial overwhelming experience of helplessness, combined with little visibility of home-dialysis options, has led to their continued preference for in-centre care.

*“For me, the experience was from no dialysis to suddenly being on dialysis and being frightened witless. The only thing I could do was to hold my needles and even that frightened the life out of me. So I relied upon the healthcare professionals who've been trained to operate these machines.”*

Those beginning to engage in shared care often experienced a very specific fear of self-needling. Something that we heard could be worked through with the right support and a gradual approach. People also raised different technologies which had helped, such as different types of needles and buttonholing techniques.

*“I did seven months in shared care overcoming my fear of needles which was pretty extreme. Once I'd got over that I was developing soft skills at a slow pace, learning to line up the machine etc. Because the big issue for me was the needles.”*

Education and support for both carers and patients to address their fears about haemodialysis technology use were seen as vital. One carer and peer supporter for other families described the distinctive pressure often experienced by carers.

*“The carers are worried. It's their life in your hands is what they are thinking. Decisions like how much [fluid] to take off and how long to dialyse for are down to you as well. You do feel the responsibility. If you make a mistake it's not you that suffers”*

The option of peer support was seen as essential for others considering shared care and home haemodialysis. This was a strong cross-cutting theme that featured in discussions across the different topic groups, however, there was evidence that shared care settings, in particular, lend themselves to developing high-quality peer support. We heard about best practices such as peer ‘meet and greet’ in shared care and establishing peer relationships that would go on to support people if they eventually decided to move to home haemodialysis.

Another uncertainty that can be on people's minds is the competing motivations that centres might have for promoting home therapies. Unless the value of home therapies for the patient has been clearly communicated as the primary concern, people can look towards the financial motives for the NHS or companies that sell home dialysis machines. These systemic uncertainties can erode people's trust in their service provider, the same trust that underpins an individual's home dialysis choices.

*“I've seen papers looking at the cost of home dialysis and it's saving about 30 grand a year and I'm cynically looking at one of the companies involved. [name of company] are the ones who are providing the machines for people to do home haemo. I'll rest my case. (Patient, In-centre dialysis)”*

### **An enabling culture and relationship with staff**

The culture of haemodialysis settings and interactions with staff were often viewed as a significant challenge. People reported that an 'enabling' approach was not always consistent and stressed how demotivating negative comments about home treatment could be.

*"One big issue was that when I was doing shared care one of the nurses told me that I couldn't do solo home haemo because it was dangerous and I would bleed to death. I got horror stories that focussed on the difficulties rather than the positives and the ways to overcome them."*

Not all examples reported such dramatic language. In many cases, people felt that the haemodialysis staff just did not buy into the 'idea' or 'ethos' of self-management. Even this more subtle lack of support had important consequences for behaviours that were frustrating and discouraging for patients.

*"My experience has been I found that nurses found it very hard to let go of the control of the wheel. Down to things like I had to actually request to have the machine turned around so that I could actually reach the buttons."*

People saw dedicated spaces for shared self-management and staff training as immediate solutions to these issues. A patient with experience of kidney care in central Europe suggested that at a national level, a much greater culture policy and shift was possible, moving away from in-centre haemodialysis as the default in the minds of all staff.

*"The expectation was a more flat level that people would do it for themselves. Those that couldn't that was a separate area and they were looked after too. Whereas here [UK] the expectation is that the nurses will just do it all for you."*

### **The solutions**

Discussions of the challenges of shared care surfaced a number of practical recommendations:

- Shared-care haemodialysis should be offered by all care teams alongside dedicated peer support and training for all staff.
- Access to one-to-one peer support conversations as well as peer discussion groups that include carers to make the range of experiences and views visible. These might be facilitated sessions such as the patient insight event.
- Patient generated 'frequently asked questions' that can be shared with all patients. The answers should be co-produced, combining the knowledge of people using dialysis with clinical input.
- Mandatory education and awareness about shared care and home dialysis for all staff groups, including reflection on their own practice and the impact of staff/patient interaction.
- Developing a positive culture toward shared care and home dialysis that is motivated by a belief in the benefits for patients.
- Exploring policies and processes around techniques and technologies that can help people overcome the fear of needling.
- Greater national consideration of self-care units in the community with technicians to support machines, rather than nurse-led ones. These can offer dedicated spaces for independent haemodialysis, a sense of community and opportunities for people to move around the country without needing to visit hospitals.

## **Patient education and shared decision making**

### ***A comprehensive and inclusive training style***

Positive experiences of preparation for treatment choice were associated with allowing people to have enough time to take in complex information and realise the implications of different options for their own lives. Conversations that start with the individual's priorities, hopes and concerns with opportunities to bring in the other care partners had been beneficial. 'Encouraging', 'coaching' and 'empowering' were frequently raised as ideal educational styles.

*"The nephrologist at the time, with the home therapies team, really sat down with me and my parents...spent hours one-on-one. What do I want out of my life and therefore what dialysis is going to suit me best and I think that philosophy really should be heavily reflected in pre-dialysis conversations."*

Learning about kidney treatments has proved difficult when too much information is covered too quickly. People related this to information sessions they had attended where all treatment options are covered. While this was helpful as an introduction, the opportunity for follow-up had not been made clear. Those that were dealing with a high level of psychological distress, or difficulty concentrating as a symptom of kidney failure, found that large amounts of information about treatments alone did not help them to reach a decision with confidence. People facing dialysis choices in an emergency unplanned route described understanding very little of the education and having low involvement in treatment decisions.

*"[I would suggest] Perhaps coming in low level not bamboozling you with all these things [treatment information], because literally what happened to me I went into hospital didn't even know what this was all about and then it was 'bang, bang' procedure after procedure which I didn't really know what was going on."*

The importance of an individualised approach with regular ongoing support was a strong theme. Knowing that there would be accessible support for people using home dialysis was a significant reassurance for those choosing home therapies, for instance, peritoneal dialysis units. Many people had felt scared when they were told about the graphic technicalities of treatments or when the risks had been covered in detail early on in their education programme. This fear has an important impact on people's confidence and ability to make choices. We also heard that many would have welcomed a much greater depth of knowledge later on in the process. Some wanted to know more scientific detail about dialysis once they had taken initial steps to accept and engage with the process. A more informed and central role in diet information and analysis of the impact diet might be having was also desirable.

Inconsistency of care approach and of health professionals was a challenge for many people, who did not want to have to 'start at the beginning' every time they had contact with their care team. There was a preference that people's care could be shared within a small group of known health professionals, allowing relationships and knowledge to build over time.

*"What I'm finding really difficult is that it's very hard to get to talk to the same person twice in clinic. Now every time I go in there seems to be different nurses or there seems to be a different consultant and I'd love to have some consistency of care."*

Certain attitudes in clinic or in dialysis units were felt to be relevant to patient education and decision-making. People thought that staff should not have preconceived ideas about people's eligibility or preference for home therapy. Unfortunately, this is something experienced by participants in relation to older people and those living in smaller houses or flats. The group also voiced that all staff should be trained and aware of home therapy and its benefits. One home therapies participant currently using in-centre haemodialysis temporarily commented on the absence of any home therapies knowledge or promotion within that setting.

*"We need more education and units having home hemo and PD leaflets and information. Because the unit that I'm in do not know anything about home therapies."*



### **Access to wider resources and training**

People spoke about positive experiences of learning by talking to or observing peers and attending dedicated training centres. Participants reflected that they would have benefited from these experiences early on in their education programme to put some of the information they were receiving into a real-world context. People described being grateful for the immediate insights that seeing different types of dialysis first-hand had for treatment choices.

*“So like a practical walk-through. If I could see the whole process you realise exactly what you're doing and if that's done for home [treatments] as well that would have been really, really good. That sort of lived practice of dialysis would really have helped me to decide on home dialysis.”*

Finding quality training resources such as leaflets, videos, cookbooks and FAQs could be difficult. The problems people were having did not seem to be about a lack of resources, but more about not knowing where to look. Greater signposting to help people locate the resources that would be most relevant to them was felt to be essential and could have particular benefits for those seeking language/culture-specific support. The group reflected that careful thought should be given to what resources exist and where our gaps are, ensuring all people that can use home therapies are represented. There was a desire for more positive and inspiring content, showing the successes of people living with CKD in their careers, education, families, hobbies and travel. We heard how important positive messages can be for younger people whose self-identities and aspirations can be significantly disrupted by CKD.

*“I've talked to a lot of young people. They give up a lot of their career aspirations, they make changes to their degree choice when they go into kidney failure. I don't personally think that's always necessary, but it's just the fact that they did not receive the right support or information to know that they can actually continue to pursue the career that they want.”*

### **The solutions**

The following recommendations were raised to address challenges experienced when learning and deciding on treatment:

- Earlier treatment education, including public awareness raising and targeting communities underrepresented in-home therapy use.
- Greater consideration of the education pathway for those with unplanned routes to dialysis, revisiting education and treatment choices periodically.
- Treatment education should be offered as ongoing rather than a one-off opportunity and consistency of care staff should be considered.
- All patients and carers should have access to one-to-one conversations with peers who have experienced different settings and types of dialysis. These should be offered online as well as face-to-face.
- All patients and carers should be able to observe treatment first-hand, either in person or in training videos.
- A central hub of resources should be available where people can easily locate high-quality materials which are disability accessible and relevant to their situation.
- All staff should receive home dialysis training, including how to approach eligibility openly and minimise unconscious bias.
- A personalised approach which draws out the person's own lifestyle priorities and questions. Risks and technical detail should be approached when people are ready. Coaching techniques and staff education about individualised 'learning styles' can help to develop the skills required for these interactions.



## **Psychosocial support**

Many of the themes from the education and decision-making group were highlighted again in discussions of how to support people's psychological and social well-being. The importance of gradual education approaches that develop confidence and the negative experiences of those that reach dialysis in emergency situations with no prior education featured strongly. The idea that treatment education should begin earlier was voiced even more directly in this discussion, suggesting that the current typical starting point for pre-dialysis education is too late for most.

*"If I could have changed something I feel that engagement earlier in terms of education should happen as early as possible. What happened to me and I think happens [to other people] is that they find out about the intricacies of dialysis and how it affects you, both positive and negative, too late. At low clearance clinic, I think that's too late then finding out about what the next part of your journey is going to be."*

### ***Acknowledging fear and redefining psychological support***

People shared the powerful sense of isolation and distress they had felt at the point when they were facing the need to dialyse, yet many had been unable to share this with their care teams. Even when psychological distress is an understandable reaction, being able to recognise this in yourself and find the right person to ask for help was not straightforward for most people. This patient and peer supporter describes how fear influences people's decision-making and engagement and how the current approach needs to be redesigned.

*"The first thing that kills us is the 'Fear Factor' and when we go to the hospital we are not even able to listen to the doctor properly. Some of us don't even want to go to consultation and when we manage to go to consultation we are not concentrating. I think all of this should be refactored."*

We heard that health professionals should acknowledge that people will be in a state of heightened anxiety and take steps to support each person through this. Suggestions in terms of language use, were that conversations should not start with 'if they were okay?' or 'whether they would like to speak with a psychologist?', but rather 'how are they coping and what might help?' accompanied by suggestions of useful services and resources both within and outside the kidney care service. This shift in approach acts to normalise understandable feelings of distress at the outset of a chronic illness and prevent further issues from developing.

*"From the perspective of someone who has never accessed any mental health or psychological support, I do know resilience is key. Sometimes I think people have been asked and they're like oh I don't need to see a psychologist I'm not you know I don't have mental health issues. They don't even realise perhaps what that support does mean and can look like."*

People suggested that regular 'check-ins' with their care teams, peer supporters, faith groups, counsellors and social workers could all help, although these were not all consistently available in all centres. We heard that carers as well as patients were likely to experience burnout and should be considered in approaches to psychosocial support.

### ***Addressing isolation and facilitating peer contact***

Not all patients using home dialysis described themselves as feeling isolated. However, people who had moved from shared care to home haemodialysis suggested that this transition could feel a little lonely, especially in instances where peer support had been strong in their shared care setting. People using peritoneal dialysis described the isolation of not knowing that they were doing okay on an emotional and human level compared to others in a similar situation, as they lacked access to a network of people in a similar position.

*"When I started dialysis it was very hard for me to understand whether or not I was doing well and that can be part of the isolating factor. It's hard to move forward from that point because you just feel like you're constantly trying to become the person that you used to be, but that's not always quite possible. And that's okay, but no one told me that's okay."*

People at the event suggested that over time they had found ways around this isolation, often through social media-based patient groups, and local peer support initiatives, becoming peer supporters themselves in many cases. Importantly they also spoke about people who had not found these solutions and given up on home therapies as a result of this loneliness. People gained a lot from care teams that organised simple social events to bring together home dialysis patients. These events offer connections which can spark lasting relationships for those that would benefit most.

### ***Psychosocial care outside of the kidney care team***

Some patients had successfully gained support such as counselling or alternative complementary medicine outside of their kidney care service, but were not confident that relevant services would be signposted to them by their care teams. The quotation below describes the insular and risk-averse culture that a participant associates with. Similar themes were raised about lack of encouragement for peer support, with people noting that some clinicians had been 'reluctant to refer'. These aspects of organisational culture can be challenging to change, but are having a very real impact on the scope for future involvement of patients and ultimately quality of care.

*"When nurses and doctors and consultants come to do their job in the hospital they are concentrated on their job. So they are scared of channelling people to any other source that is different from what they should be doing ordinarily."*

There is potential to improve psychosocial support through greater integrated working between acute, community and primary care sectors. One aspect of signposting other sources of support that people thought deserved attention was provided for those with sight impairments. As many support options become digitalised not all online support meets with accessibility requirements. Ensuring face-to-face options reduces the risk of disability-based exclusion. Local authorities were highlighted as key partners to ensure housing was suitable for home therapies. We heard that where accommodation adaptations or changes are required, these tend to be actioned too late and can limit home dialysis choices.

### ***The solutions***

Recommendations to improve psychosocial support for people living with CKD should cross-reference to the 'Patient education and decision-making' solutions. The group identified several additional suggestions:

- Earlier patient education about all treatment options was introduced gradually before low-clearance clinics.
- An early conversation with the care team to acknowledge the emotionally distressing nature of CKD diagnosis and signpost relevant resources and services, including local peer support. Carers should be included.
- Regular check-ins from care teams for people dialysing at home, including how people are feeling and coping.
- Access to high-quality specialist counselling support.
- Regional work with local care partners and patient associations to build awareness of services outside kidney care services that could help support the psychosocial needs of people living with CKD.
- National agreement with local authorities to address housing issues in a timely way.
- Kidney care services can address isolation by offering home dialysis patients positive reinforcements to keep in touch and bring people together e.g. letters, and social events.
- Inspiring and enabling material should be developed which can help people recognise what they can achieve while living with CKD or as carers. All patient groups should be represented.

## **Peer support**

We heard that to develop a successful patient pathway involving dialysis choice - *'you've got to humanise it'*. Peer support was viewed as a core element of achieving this. It has helped people to become more aware of dialysis options, make confident choices and be an ongoing source of support for those using dialysis. Peer support got people on to the right form of dialysis for them and helped them to stay on it. It had given people the initial belief that shared or home therapies were possible, reduced feelings of isolation and provided positive insights that life continues and can be rebuilt.

*"It took another individual to explain the pros and cons of the treatment that they went through, which enabled me to make a decision."*

### **Accessing peer support**

Many people shared how difficult it had been to find peer support. The picture of the current access was patchy. Some had been offered or were volunteers at peer support services with their kidney care service or with a national charity, while others had never come across peer support services before. Peer support in shared-care haemodialysis settings received very positive feedback, with peritoneal dialysis, transplant and conservative care more likely to be overlooked. Those with experience of peer support suggested that it should be accessible early on in the patient's journey, to help with decision-making and that clinicians should be actively encouraging and linking people with peer supporters. A typical experience was to seek out others using home dialysis by asking the care team or independently through social media groups and charities.

*"I asked [the clinic staff] to be put in touch with someone who was already doing home dialysis. They didn't come to me I had to go to it, which I think is wrong really. If I hadn't taken the initiative I don't know what necessarily would have happened and I'm glad I did."*

Another factor that people thought needed further consideration is how to match people with similar issues or characteristics. One example given was two people meeting who were managing diabetes, as well as their home dialysis, and were able to provide reassurance about the compatibility and effectiveness of treatments for both conditions. We also heard about the various formats peer support could take. Both online and face-to-face options were popular and people valued the ability to be able to share visuals of treatment equipment. Ensuring peer support is disability accessible was important, including the idea of matching people with the same sensory conditions. At a pre-dialysis stage, it was suggested that group approaches could help to reduce bias, allowing patients to see lived experiences across a range of treatments. This home therapy peer supporter reflects on her own positive bias and managing this within her peer interactions.

*"The challenge is keeping it as unbiased as possible. Obviously, you've got to be careful someone doesn't say 'this is going to solve all the problems'. I get very enthusiastic and positive about my dialysis, but I know my experience isn't the same as everybody."*

### **Governance and training**

Issues around the organisation, coordination and the nature of training generated much discussion. Participants told us that volunteer training and careful coordination were vital to ensure the quality of the service, in the interests of volunteers and participants alike. We heard that training should prepare people for different scenarios, and teach skills for active listening and positive communication while being honest about the realities of life with CKD.

People saw clear benefits to both national and locally housed peer support services. Discussions focussed on how to combine the best of both. There was consensus that much greater uptake was likely if peer support services were seen as part of the kidney care service and were offered as part of the core pathway, rather than being seen as an 'add-on'. However, there was also a sense that setting up and running the services had been more time-intensive for centres and volunteers than it should be. For volunteers processes around recruitment, such as Disclosure and Barring Service checks, Trust level obligatory volunteer training modules, or data protection protocol seemed to take up too much time and even put potential volunteers off altogether. The lack of a clear framework and national guidance created additional work that could add further delays.

*"It was difficult for us to set up our peer support group for the simple reason you were tied up and down with red tape and GDP and are you safe and DBS and God knows what else. It's just jumping through hoops and hoops and hoops."*

Frustration was voiced about a lack of leadership for peer support at the national level. Sometimes this was framed in terms of the 'politics' of kidney charities. People viewed the benefits of high-level leadership as standardising guidance around all aspects of recruitment, training and day-to-day operations, as well as an increased database of volunteers that might help make meaningful peer matches.

### ***The solutions***

The suggestions of this topic group discussion were:

- All patients should be proactively offered peer support by their care teams directly, including outlining the benefits to patients. This should happen frequently and start as soon as treatment education programmes begin and continue whilst on dialysis.
- Consider a range of formats for peer support including individual and group sessions, one-off questions, online and face-to-face.
- Greater national/regional leadership and coordination to ensure peer support is: provided by trained peers; reducing the burden on individual kidney care services; simplifying processes for volunteers; and addressing how peer supporters can be best matched with those requesting support.

## References and resources

Combes, G., Allen, K., Sein, K. Taking hospital treatments home: a mixed methods case study looking at the barriers and success factors for home dialysis treatment and the influence of a target on uptake rates. *Implement Sci* 2015; 10: 148

Combes, G., Sein, K. & Allen, K. How does pre-dialysis education need to change? Findings from a qualitative study with staff and patients. *BMC Nephrol* 2017; 18: 334

McLaughlin L, Williams G, Roberts G, et al. Assessing the efficacy of coproduction to better understand the barriers to achieving sustainability in NHS chronic kidney services and create alternate pathways. *Health Expect.* 2022 Apr;25(2):579-606.

Noyes J, Roberts G, Williams G, et al Understanding the low take-up of home-based dialysis through a shared decision-making lens: a qualitative study. *BMJ Open* 2021; 11: e053937.

Peer support toolkit <https://www.kidneycareuk.org/health-professionals/peer-support-toolkit/>

Kidney Kitchen <https://www.kidneycareuk.org/about-kidney-health/living-kidney-disease/kidney-kitchen/welcome-our-kidney-kitchen/>

Dialysis reimbursement tools <https://www.kidneycareuk.org/about-kidney-health/living-kidney-disease/home-dialysis-reimbursement-patients-guide/>

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