

# BMJ Open Understanding the low take-up of home-based dialysis through a shared decision-making lens: a qualitative study

Jane Noyes <sup>1</sup>, Gareth Roberts <sup>2</sup>, Gail Williams,<sup>3</sup> James Chess <sup>4</sup>, Leah Mc Laughlin <sup>1</sup>

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<sup>1</sup>School of Medical and Health Sciences, Bangor University, Bangor, UK

<sup>2</sup>Department of Nephrology, Cardiff and Vale University Health Board, Cardiff, UK

<sup>3</sup>Welsh Clinical Renal Network, NHS Wales, Cardiff, UK

<sup>4</sup>Renal Unit, Swansea Bay University Health Board, Port Talbot, UK

## Correspondence to

Dr Jane Noyes;  
[jane.noyes@bangor.ac.uk](mailto:jane.noyes@bangor.ac.uk)

## ABSTRACT

**Objectives** To explore how people with chronic kidney disease who are pre-dialysis, family members and healthcare professionals together navigate common shared decision-making processes and to assess how this impacts future treatment choice.

**Design** Coproductive qualitative study, underpinned by the Making Good Decisions in Collaboration shared decision-model. Semistructured interviews with a purposive sample from February 2019 - January 2020. Interview data were analysed using framework analysis. Coproduction of logic models/roadmaps and recommendations.

**Setting** Five Welsh kidney services.

**Participants** 95 participants (37 patients, 19 family members and 39 professionals); 44 people supported coproduction (18 patients, 8 family members and 18 professionals).

**Findings** Shared decision-making was too generic and clinically focused and had little impact on people getting onto home dialysis. Preferences of where, when and how to implement shared decision-making varied widely. Apathy experienced by patients, caused by lack of symptoms, denial, social circumstances and health systems issues made future treatment discussions difficult. Families had unmet and unrecognised needs, which significantly influenced patient decisions. Protocols containing treatment hierarchies and standards were understood by professionals but not translated for patients and families. Variation in dialysis treatment was discussed to match individual lifestyles. Patients and professionals were, however, defaulting to the perceived simplest option. It was easy for patients to opt for hospital-based treatments by listing important but easily modifiable factors.

**Conclusions** Shared decision-making processes need to be individually tailored with more attention on patients who could choose a home therapy but select a different option. There are critical points in the decision-making process where changes could benefit patients. Patients need to be better educated and their preconceived ideas and misconceptions gently challenged. Healthcare professionals need to update their knowledge in order to provide the best advice and guidance. There needs to be more awareness of the costs and benefits of the various treatment options when making decisions.

## Strengths and limitations of this study

- Large-scale qualitative study with depth data from patients, family members and professionals.
- New understandings of actions and behaviours following pre-dialysis shared decision-making in a UK healthcare setting.
- Products include coproduced logic models and a road map and recommendations to support implementation of shared decision-making in a complex healthcare system.
- Black and Minority Ethnic (BAME) perspectives, and some underrepresented groups are a noted gap.
- Some findings and the products may not be applicable to substantially different healthcare settings and systems.

## INTRODUCTION

The increasing global prevalence of kidney disease and the burden of dialysis on healthcare systems have driven the need to increase home-based dialysis.<sup>1</sup> Dialysis in a hospital or satellite unit is collectively called Unit Haemodialysis (UHD) and is undertaken 3 times a week for 4 hour sessions at a time. Home-based therapies have a number of advantages compared with UHD. More frequent and longer dialysis is possible at home and can be associated with extended survival rates.<sup>2-6</sup> People with chronic kidney disease (CKD) receiving home dialysis experience better quality of life through greater independence and autonomy.<sup>7,8</sup> The flexibility of self-management and reduced need to travel to a dialysis unit provides greater opportunities for people to take on occupational and social roles.<sup>9</sup> Home dialysis is more cost-effective in many circumstances.<sup>10-12</sup> Those opting for UHD have spoken about their lack of confidence to undertake home-based care.<sup>13,14</sup>

Clinical practice guidance in many high-income countries (eg, the USA, Canada,



Australia, UK and Europe) state that patients with CKD who may need kidney replacement therapy should be offered support to choose the dialysis modality—including home therapies—that best reflects their, and/or their family's circumstances, needs and values.<sup>15</sup> Recent updates to UK National Institute for Health and Care Excellence (NICE) guidance suggest that conversations with patients about future treatment options should start at least a year in advance of needing dialysis.<sup>16</sup> Different dialysis options continue to be made available, supposedly offering more tailored treatments and, therefore, a need for carefully tailored shared decision-making (SDM) in a clinical context.<sup>17</sup> UK trends show that UHD continues to increase and a huge variation of uptake of home dialysis between centres.<sup>18</sup>

Pre-dialysis education has previously been reported by patients across similar healthcare systems as being overwhelming and biased towards available rather than all options.<sup>19</sup> Ideally, choosing an option should happen through effective SDM<sup>15</sup> as poor decision-making experiences are associated with low treatment satisfaction.<sup>20</sup> Yet, while an estimated 50% of all patients are suitable for home peritoneal dialysis (PD) and at least 15% of patients with haemodialysis could dialyse at home,<sup>21</sup> international evidence shows that less than a fifth of dialysis takes place in the home.<sup>22</sup> Barriers to home dialysis have been found to be complex.<sup>23</sup> Patients have reported insufficient knowledge and education as a barrier to selecting home dialysis.<sup>24</sup> Practically, home dialysis requires people to have adequate housing including space for supplies and in the case of home haemodialysis (HHD), an affordable and satisfactory supply of water.<sup>25</sup> Studies also report a complex mix of more intractable social, psychological, economic and health system obstacles to home dialysis.<sup>8 14 20 26–28</sup>

Gaining a better understanding of the factors that impact on treatment choices, and, specifically, to better understand why so many patients default to UHD was the aim of the 'Dialysis Options and Choices Study'.<sup>29</sup> This 2-year mixed method coproductive study integrated analysis of electronic renal patient records with content analysis of pre-dialysis patient education programmes, interviews with pre-dialysis patients and their families, interviews with healthcare professionals and health economic analysis of dialysis modalities.

This paper presents findings from the qualitative component of the study examining the factors that impact on pre-dialysis choices made by patients. Using qualitative methods and framed within a model of SDM, we explored what patients and family members actually understand about the disease, the prognosis and the treatment options, how people's values and preferences impact on their choices and the extent to which these were elicited by clinical teams within the SDM process. We also explored the perspective of kidney healthcare professionals. In the context of diverse service provision within a healthcare system, the paper concludes by setting out options to improve healthcare and services towards

meeting the policy intent of increased uptake of home therapies.

## Methods

This was a qualitative coproductive study using the framework method<sup>30</sup> of data collection and analysis and reported using the Consolidated Criteria for Reporting Qualitative Studies checklist<sup>31</sup> (online supplemental appendix 1). A protocol was developed and published.<sup>29</sup>

## THEORETICAL FRAMEWORK

The study was informed by theory underpinning the Making Good Decisions in Collaboration (MAGIC) model and programme designed to test and identify the best ways to embed SDM into routine primary and secondary care.<sup>32</sup> SDM proposes that informed preferences—by which is meant what matters to people with health needs and families—should play a major role in decision-making instead of the assumption that decisions should be guided by scientific consensus about treatment effectiveness.<sup>33</sup> The MAGIC programme provides a multi-stage consultation process for decisions—such as dialysis modality—involving a 'three-talk model' for SDM.<sup>34</sup> The model was adapted for this study to reflect pre-dialysis decision-making (figure 1).

## Setting

The study took place in Wales, a semiautonomous country within the UK with a publicly funded healthcare system. There are five kidney services across the country that are commissioned, monitored and audited by the Welsh Renal Clinical Network. Incidence and prevalence of dialysis is higher in Wales than in other parts of the UK and despite half of patients being suitable for home therapies, only 12.9% are on PD and only 6.1% are on HHD with significant variation in patient modality choice across the country.<sup>35</sup> Wales also has an older and sicker population than the rest of the UK, with a mix of rural and urban settings, pockets of high deprivation with health literacy a recognised issue across all healthcare.<sup>36 37</sup>

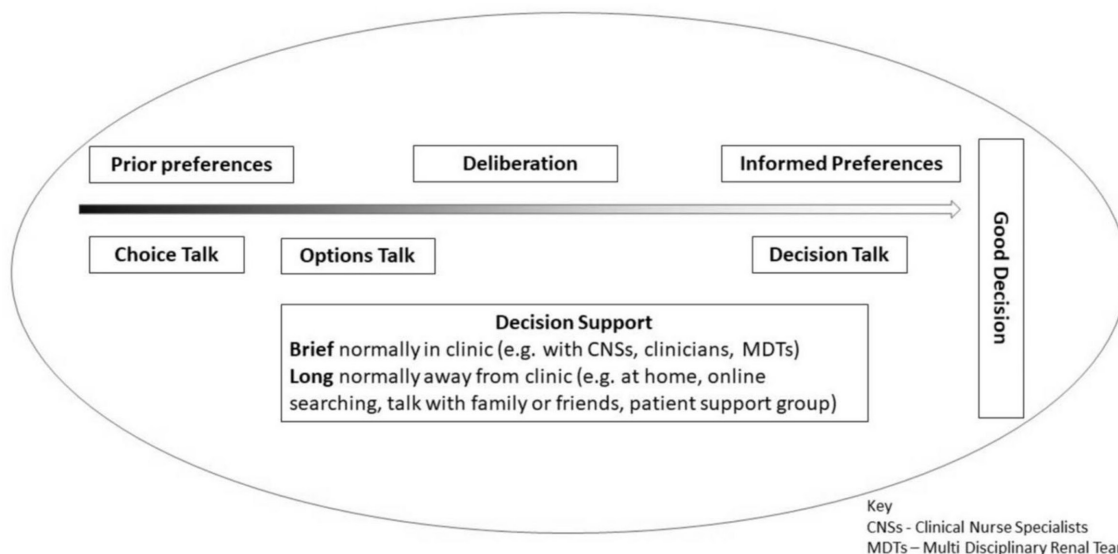
## ETHICS

Ethical approval for this study was granted by the Wales Research Ethics Committee (Reference 19/WA/0020).

## PATIENT, PUBLIC AND STAKEHOLDER INVOLVEMENT

The study was funded by Health and Care Research Wales under the Research for Patient and Public Benefit Scheme and a themed call: 'Can co-production lead to more sustainable services'. Elsewhere, we report the outcomes from the coproduction in relation to specific service improvement aspects of the study.<sup>23</sup>

In this paper, we include the patient and public involvement (PPI) and wider stakeholder activity related to the empirical research study. We map the PPI in the study against the UK standards for public involvement<sup>38</sup> in an



**Figure 1** Three-talk model of shared decision-making adapted for pre-dialysis decision making.

online file (online supplemental appendix 2). Three PPI/stakeholder meetings were specifically curated to present data and gain input from people not directly involved in the study but who had expert perspectives. We hosted these meetings to present and receive input on three key elements (1) pre-dialysis SDM processes, (2) interviews with patients, family members and professionals and (3) developing the logic model of stages, moderators and outcomes of getting onto a home therapy and a road map to service redesign, including practice recommendations (box 1).

## Data collection

### Patient and family members' interviews

Any person over 18 within 5 years of pre-dialysis education and their family members were eligible, including those family members who identified as a caregiver.<sup>39</sup> Participants were purposively sampled to represent a range of decision-making processes (including those who remained 'undecided' post initial education programme visit) in addition to demographics including deprivation, education level, age, gender and kidney service. (table 1) Nurses who deliver pre-dialysis education were tasked with

identifying potential participants and seeking consent for the research team to contact. Interviews continued until no new themes were coming through and the sample represented a maximum variation. Table 2 and online supplemental appendix 3 provides further details of interview processes with demographics presented in table 1.

### Professional interviews

Members of the research team who were also healthcare professionals and highly engaged in SDM with patients helped identify and send out initial invitations to key people involved in pre-dialysis decision-making, namely nephrologists and the pre-dialysis nurse specialists. Many nephrologists have specialist training in certain kidney replacement therapies (eg, transplant) and others have specific interests in service improvements such as clinics for people with early-stage CKD sometimes called 'low clearance clinics', or improving awareness and integration of conservative management in the dialysis healthcare teams. We aimed to include a spectrum of Nephrologists representing expertise and interests across the kidney health service. Every specialist pre-dialysis nurse in Wales was invited to interview. We also targeted nurse and service managers to ensure that a whole systems perspective was included. The primary purpose of the professional interviews was to unpack biases and other perceived barriers to people opting for home-based therapies. Table 3 and online supplemental appendix 4 provide further details of professional interviews.

### Interviews

Digital recordings of the interviews were transcribed verbatim by a specialist service and uploaded into NVIVO V.11 (QSR International). Codes were created to link participants with each other and with their respective kidney centre. We used the five-stage framework analysis method to organise and code interview data.<sup>40</sup> The 'three-talk model' can be viewed from the perspective of

### Box 1 Patient, public and stakeholder involvement contribution to coproduction of this element

Total numbers: n=44; professionals n=18, patients n=18 and family members n=8.

- ▶ Pre-dialysis shared decision-making meeting: total (n=14); professionals n=8, patients n=4 and family members n=2.
- ▶ Interview input and feedback: total (n=30); professionals n=10, patients n=14 and family member n=6.
- ▶ Developing logic model and road map: total (n=14); professionals n=5, patients n=5 and family members n=4.
- ▶ Additional input was provided throughout via emails, face-to-face meetings and informal conversations with patient and public involvements and kidney professionals.

**Table 1** Participant demographics and treatment decision table

Total number of participants n=56		Total number of patients n=37	
Female	n=30	Female	n=17
Male	n=26	Male	n=20
		Patients chosen treatment	
		UHD	n=16
		HHD	n=9
Age group		CAPD	n=5
Under 30	n=2	APD	n=4
31–39	n=3	Conservative management	n=1
40–49	n=8	Undecided	n=2
50–59	n=9		
60–69	n=19	Time on current kidney replacement treatment	
70–79	n=14	Not started	n=23 (1 conservative management)
80–89	n=1	Under 1 year	n=8
		1–3 years	n=5
Highest qualification			
None	n=9	Kidney service	
Level 1	n=11	Cardiff	n=17
Level 2	n=7	Swansea	n=7
Level 3	n=13	Bangor	n=2
Level 4	n=1	Glan Clwyd	n=5
Level 5	n=5	Wrexham	n=6
Income		Total number of family members	n=19
Less than 20K	n=21	Female	n=13
20K–39K	n=22	Male	n=6
40K–59K	n=13		
More than 60K	n=1		
Ethnicity			
Welsh/English/Scottish/Northern Irish/British	n=56		
Area of deprivation*			
1. Least deprived	n=12		
2.	n=5		

Continued

**Table 1** Continued

Total number of participants n=56		Total number of patients n=37	
3.	n=7		
4.	n=5		
5. Most deprived	n=8		

\*Overall score taken from Welsh Index of Multiple deprivation an online resource to estimate deprivation based on income, employment, Health, Education, Access to Services, Community Safety, Physical Environment and housing [https://wimd.gov.wales/?\\_ga=2.206133845.791407745.1630500908-977393655.1630500908](https://wimd.gov.wales/?_ga=2.206133845.791407745.1630500908-977393655.1630500908).

APD, Automated peritoneal dialysis; CAPD, Continuous ambulatory peritoneal dialysis; HHD, home haemodialysis; UHD, Unit-based dialysis.

the patient, family or professional and was used as the high-level framework to code interview transcripts.

### Rigour

To ensure a satisfactory level of understanding and agreement between coders, four sample transcripts were selected at the start of the process for discussion to ensure consistency. Additional codes of interest were added from a sample of 10 initial interviews, which were read line-by-line by two experienced coders and discussed with the multidisciplinary research team at weekly meetings and at wider stakeholder meetings as data were gathered and coding increased.

Discussion of emerging themes, patterns and tendencies began as soon as data became available to share. We used Lincoln and Guber's four dimension criteria (credibility, dependability, confirmability and transferability) to establish rigour.<sup>41</sup> Examples included a multi-disciplinary team (MDT) of core researchers, PPI involvement in developing data collection tools, purposive sample framework and coproductive analysis and interpretation. Members of the multidisciplinary research team were able to share their expertise and perspectives to help further contextualise data, explain anomalies and advise on ways to fill gaps in the data set. Discrepancies were resolved through whole team discussion. Emerging findings were also presented to PPI/stakeholder groups who had an opportunity to comment and share their expert knowledge (box 1).

### Reflexivity

From a reflexive standpoint, the mixed clinical/academic team believed that home therapy could be an appropriate option for many people who decided against it, and this was clarified in our epidemiological analysis of routinely collected kidney patient data. Wales policy explicitly states that, where appropriate, treatment should be shifted out of hospitals into the communities and towards home and the policy imperative of increasing home dialysis spoke to this agenda.<sup>42</sup> The team also hypothesised that in spite of

**Table 2** Further details of people with CKD and family members' interview selection and processes

Topic guides	Topic guides were informed by the 'three-talk' model and were piloted during initial interviews with PPI involvement. Topic guides were created for people with CKD, family members as well as options for dialysis and included specific probes to help unpack why patients and family members had chosen a specific treatment over and above another treatment. When both people with CKD and family members were interviewed together, specific questions relevant for the family were posed to them and vice versa to help unpick where views and experiences were different and potentially influencing decisions (online supplemental appendix 3).
Interviewees	Interviews were undertaken by male and female researchers with relevant Doctorates who were experienced in interviewing and employed to work on the study. Interviewers had no prior relationship with patients or family members. Some of the professionals were known to one researcher.
Number of interviews	37 interviews covering 37 individual patient cases, with a mix of one to one with patients, family members and joint interviews with patients and their spouse/partner.
Length of interviews	Semistructured between 30 min and 90 min. Participants were interviewed once.
Reasons for decline	Most people who were contacted consented to an interview with some declining due to time available to interview, recent bereavement or health issues. We also were contacted by more people than we had capacity to interview and used a theoretical sampling frame to construct a maximum variation sample.

CKD, chronic kidney disease; PPI, patient and public involvement.

expectations that SDM was operating as business as usual (with one kidney service actually involved in the implementation of SDM across the NHS), SDM had yet to be widely adopted in routine clinical encounters.<sup>32</sup> The team also acknowledged that if following a SDM model, patients came to a treatment decision that they were happy with, then 'SDM' had occurred and the patient had made their choice. Nonetheless, the imperative for this study was to explore decision-making within the entire health system and not just at the clinical/patient interface to explore whether the health system was appropriately focused on SDM and clinicians and patients were fully equipped with all of the information and tools to make a fully informed decision based on the best available evidence. We also acknowledged the local policy imperative to encourage more home dialysis when considered an appropriate option for patients and their families. Frequent face-to-face data analysis and interpretation meetings were convened with team members, key stakeholders and PPI representatives, during which different perspectives were explored and challenged until a consensus was agreed. The researchers who collected data were not known to patients and family members. The researchers were known by many professionals.

## Findings

We present the findings mapped against the adapted MAGIC framework with a focus on the factors that create barriers and enablers to people choosing a home-based treatment from the patient, family member and health-care professionals' perspective. Further details including additional illustrative quotes are presented in online supplemental appendix 5.

### Prior preferences

#### Patients' perspectives

Many people with CKD that we spoke to were asymptomatic and many with symptoms did not always attribute it to their kidney disease. Apathy to disease condition often meant any prior (informal, formal) conversations had little impact on final treatment decisions. Real-life lived experiences impacted on perception of treatment burden, but many people initially catastrophised future treatment, this was especially the case with dialysis.

We found a wide variation in patient knowledge of their own kidney disease, prognosis and potential future treatments and what this might mean for them prior to them commencing the SDM pathway. How and when people recalled that they were told they required treatment varied considerably. We frequently found that a

**Table 3** Professional interviews further details

Topic guide	Online supplemental appendix 4 outlines the professional interview content at a high level and includes a topic guide and tools in the form of case studies to help unpick bias codeveloped with PPI input.
Location	Place of work for healthcare professionals to fit in with clinical commitments and existing meeting schedules, whereby professionals met in clusters.
Number of interviews	Four semistructured interviews individually, two small group interviews with professionals in the same role (eg, consultants, pre-dialysis nurses) and three whole team focus groups.

PPI, patient and public involvement.

previous legitimate experience such as a family member having dialysis influenced initial preferences. More often it was outdated or inaccurate information picked up from informal sources such as social media or an individual perspective, fear of the unknown, irrational concerns of the magnitude of treatment burden or that dialysis would transform them into being a burden that was highly influential on their initial preferences towards UHD. People who started dialysis in an emergency obviously had no prior preferences, but conversations about switching to a home-based option were met negatively. Most people's initial image of dialysis was of dialysis in a hospital.

### Family perspectives

As with people with CKD, family members often had a previous experience leading to a bias to UHD and most assumed that dialysis only happened in a hospital. On the whole, the family perspective was lacking at these early stages. Many factors influenced this, the person with CKD not wanting to worry the family, they had not been involved in routine clinics or the realities of kidney failure were also not well understood by the family.

### Healthcare professionals' perspectives

Despite many professionals' enthusiasm for home-based treatments, there were inconsistencies, and not all professionals viewed the high number of people on UHD as a problem. Those who were trying to improve access to home dialysis cited an embedded culture, lack of motivation for change fuelled by staffing pressure as key barriers. Healthcare professionals acknowledged a hierarchy in treatments (transplant, home, UHD) in their protocols but in reality expressed challenges in 'delivering the home part consistently across the service' (consultant).

### Choice talk—highlighting that reasonable options exist

#### Patient perspectives

Often the number of choices combined with the ways they were sometimes presented became a barrier (rather than a facilitator) to people initially choosing home. Information days, meeting other patients and peer to peer support were mostly viewed as valuable and reassuring but not necessarily helpful in deciding a future treatment option—especially home dialysis. UHD was the treatment all people initially recognised. This combined with feeling overwhelmed, confused and with little or no opportunities to follow-up their concerns led many to exclude home-based options, often almost immediately. We found that many people's initial discussions about future treatment were not retained to long-term memory. This included discussions over a longer time and special visits designed specifically to discuss all available treatments. Even when starting discussions for future treatments, many patients struggled to modify their behaviours and proactively engage in SDM. Many requested more personalised information and support led by healthcare professionals. Visual graphs, self-monitoring apps, opportunities to ask questions and confidence in sharing their expectations,

goals and values were common features in experiences, leading to choosing home dialysis.

### Family perspectives

We frequently found family members taking a back step at initial discussions about future treatments—preferring to push the patient forward as the person the conversations were about. At the same time, family members reported chronic anxiety and frustration at their partners 'for not taking things seriously' (wife of patient). On the whole, the family member had done more reading and internet searches than the person with CKD at this stage. Those with younger families had started to consider impacts on children and what this might mean for them but had not spoken to anybody about it, including their partner. Throughout families tended to worry more than people with CKD. This led to a significant bias from the outset for UHD as it was almost always viewed as the safer option for their relative and for them.

### Healthcare professionals' perspectives

Professionals cited good rapport and drip feeding of information as critical to starting good SDM. At the same time, professionals reported difficulty in predicting disease progression as a key barrier to starting conversations. Many professionals suggested that current protocols in presenting initial options were unhelpful and that they were seeking to change how choices are initially presented. Many reported ongoing frustration with trying to get their patients to accept their disease and engage in more healthy behaviours (which may delay need for future treatment). They also reported health system issues such as short clinic times, inconsistent messaging, lack of research evidence on best dialysis options and lack of up to date communication training for key staff as barriers to starting conversations leading to good SDM. People who started UHD with little or no warning quickly integrated the routine of the dialysis unit as the norm and altering their views towards a home-based dialysis was highly challenging for healthcare professionals.

Some professionals said they wanted to promote more home-based options and avoid mention of UHD in the conversation but felt they had to discuss everything to avoid potential repercussions of not presenting all available options and/or accusations of bias.

### Options talk—detailed discussions of pros and cons

#### Patient perspectives

Very few people distinguished any difference in treatment in terms of health or lifestyle benefits at this stage—they viewed all options as the same. Most people expressed that they wanted their treatment to fit around them and their lifestyle (often cited as the main benefit of a home-based treatment), but this meant different things to different people. Many people said that UHD was the ideal in this respect as they 'could drop in on the way home from work, go on the machine and pick up something for dinner on the way home, and have four free days then' (patient).

Fears over self-administering treatment leading to disfigurement, infections and social isolation were also cited as key barriers for home-based treatment.

### Family perspectives

Many family members in particular spouse/partners had anxieties about their potential responsibilities and their potential changed/or changing role into a carer although this was not always initially recognised by them. Even in cases where patients had expressed a preference for home, family members expressed concerns that they would not have been able to manage especially if something went wrong. In the majority of these cases, patients put their own views aside and went with the preferred option for the family. We frequently saw families identify home dialysis as ‘*something else for them to do*’ (wife of patient) and viewed UHD as welcomed respite. However, this time was often taken up with general housekeeping and planning around patients additional healthcare needs. Although some patients felt the same it was mostly the family members who could not reconcile the vision of ‘turning their house into a hospital’ as well as the wish to separate dialysis from the home and home life.

### Healthcare professionals’ perspectives

Despite many professionals’ enthusiasm for home-based therapies, they reported ongoing challenges with translating this into practice. They often cited time with patients as a barrier, but when discussed in detail, this was more often coupled with other health system issues such as delays in home dialysis training, staff training, changes of mind not being picked up or actioned on, the role and function of the MDT, comorbidities leading their patients onto complex care pathways of which they have little control over. Some professionals told us that they lacked the necessary in-depth knowledge of specific home therapies to offer clarity and further support.

Some professionals shared how challenging it was to get people to come to terms with and understand the benefits of longer times on dialysis. ‘The world is speeding up everything is getting quicker and we expect things nearly instantly these days. Unfortunately evidence shows that slower, gentler dialysis is better but we really struggle to get people to see that and when you have this ‘4 hour option’ outside the door...’ (consultant).

Nobody considered costs when discussing different options. Cost and cost-effectiveness (from any perspective) was never a consideration when having discussions about available treatment options with patients and their families.

### Decision talk—making the decision

#### Patient perspectives

While some people described one main reason for their choice of treatment, others could not articulate clearly why they had opted for one treatment over another. Some people with CKD described a gradual process of decision-making and reflected on the benefit of being able to make

their choice over a period of time. Others said that the decision was made in one conversation but could rarely articulate the benefits of their decision or the harms of the options that they had discounted. A high number of people felt unable to make a final decision, despite having conversations for months or even years with their healthcare professionals. Many people had not yet even adjusted to the fact that they would need kidney replacement treatment and reported unmet psychological and social care needs. These needs were observed to create barriers to decision-making as they were often perceived as the most urgent or pressing demands that needed addressing before a decision could be made (such as the suitability of their housing or the lack of social support). It was also not uncommon for people to change their mind from a home-based therapy to UHD at this stage. Defaulting to UHD was the easiest option with perceived minimal upheaval at an especially distressing time.

#### Family perspectives

Likewise, we observed family members with unmet psychological or social care needs, resulting from their anxieties associated with their relative going into kidney failure. Financial pressures and welfare concerns were the most frequently cited and again this led to a diversion from making (or being involved in) decisions. This in turn led to a high preference for UHD to ease immediate burdens, avoid home adjustments while ensuring that their relatives’ health was being looked after. This also gave the impression of freeing up time to adjust for current and future changing circumstance.

#### Healthcare professionals’ perspectives

Some professionals commented on health systems and processes undermining or undoing their SDM. ‘*So, I can council my patients for years, we get to know them and have detailed discussions, overtime they are all prepped and ready for PD, then they go off to the multi-disciplinary team or to start preparations etc and the next time I see them they are on the unit. It is one thing to say shared decision-making another thing entirely to actually make it work*’ (consultant). Often professionals were asked at this stage, ‘*what would you do, which treatment would you go for*’ (pre-dialysis specialist nurse) and it was something many felt challenging to manage. Healthcare professionals also reported frustrations trying to explain to people the urgent need to make a decision and engage with those who were proactively delaying treatment.

There were inconsistencies with commissioners and patient perspectives on home-based treatments throughout the pathway. The increasing number of options were consistently marketed as a triumph, ‘home-based dialysis is brilliant we can fit it to anybody’s needs, they get longer better dialysis and so will feel better and live longer. It’s cheaper for the NHS, for the patient and family as they have the freedom to live the life they want to lead, what’s not to love!’ (correspondence with service commissioners). However, when given the choice, people were still defaulting to a standard treatment and very few

people discussed their decision as a ‘no-brainer for home’ (correspondence with PPIs not in the Welsh system). Even people who had chosen home-based treatment still expressed doubt and visible concerns about their decision and uncertainty about the future.

The perceived safety of UHD, the respite offered by dialysis free days and the capacity of their staff to act as surrogate families as well as social hubs made implementing pre-dialysis SDM exceptionally difficult for healthcare professionals. Health system issues (as well as the health of the person) meant that what people initially chose was not necessarily where they ended up.

### Logic model stages, moderators and outcomes of getting onto a home therapy and road map development with recommendations

The above findings were presented at a wider PPI meeting (box 1), where quotes were mapped alongside the three-talk model (figure 1). Facilitated discussion identified six tangible stages of the SDM pathway, with moderators and outcomes, which was refined and presented as a logic model (table 4) and these were mapped alongside the identified barriers and facilitators from the multiple perspectives in the interviews. At this stage, the logic model was refined and shared via email and follow-up consultations with clinical members of the research team, a PPI group and selected members of the MDT (including kidney social workers and psychologists) to highlight what they saw as the intermediate and long-term outcomes for people getting onto home dialysis. The road map outlining service improvement recommendations (table 5) was co-produced alongside the logic model of stages, moderators and outcomes of getting onto a home therapy and aimed to highlight key findings in a structured way with actionable recommendations. The road map and logic model aimed to be applicable to all kidney services regardless of their configuration.

## DISCUSSION

### Statement of principal findings

CKD was not well understood by many people living with kidney disease and their family members. Health systems and various clinical pathways into secondary care made it challenging to implement SDM between patients and professionals as intended. SDM was inconsistent and often too generic to be helpful for patients, family members or professionals. The changed/changing needs of people with CKD or the needs of the family as future treatment plans were developed with professionals were not well understood. The focus on providing (important) but largely clinically focused information missed opportunities to better manage expectations, identify goals and engage patients in good SDM. Family members worried more than patients, and this tended to lead towards a strong bias for UHD. People with CKD and family members defaulted to the perceived simplest option

(UHD), often to pick up their unmet psycho/social care needs.

Complex care pathways meant that what people chose was not necessarily a reflection of where they ended up. Sometimes people appeared to land on a home-based option more by luck than judgement as few people could discern with any real certainty the benefits of their option or crucially the harms of hospital-based dialysis on quality of life, survival and sustainable services.<sup>17 43</sup>

### IMPLICATIONS FOR CLINICIANS AND POLICYMAKERS

Options for home dialysis are increasing. PD and HHD can both be done during the day or overnight. People have the freedom to switch between day and night dialysis and even choose the length of time they dialyse and how many times per week. The benefits of this—cited by so many senior healthcare professionals, commissioners and advocates—are not translating into increases in people on a home therapy.

In terms of implementing SDM across the kidney service, the challenges have been similar to those documented elsewhere, including complex health service configurations, lack of engagement across system levels, confidence from healthcare professionals and general health literacy of the public.<sup>44–46</sup> In this study, we also observed that SDM was not routinely implemented alongside protocols that explain treatment options in a hierarchy. Therefore, SDM in pre-dialysis services is on trajectory to nothing and like other studies have shown, SDM on its own achieves nothing.<sup>47</sup> Although no healthcare professionals expressed that they felt UHD was better or that they were biased to UHD very few people saw or expressed the fact that over 80% of the dialysis population are all on the same type of dialysis as a problem. Healthcare professionals are under pressure, health systems struggle to cope with demand and are increasingly picking up unmet social care needs but unless people across the multiple levels accept the barriers to home dialysis as a problem then SDM (including the various tools, training and support packages) is likely to have little impact.

### STRENGTHS AND WEAKNESSES OF THE STUDY

This was an in-depth qualitative investigation into SDM in the context of pre-dialysis decision-making, across a country wide diverse population and five kidney services. The study was largescale, informed by theory, used a purposive sampling frame to address known gaps and explored multiple perspectives: patients, family members and healthcare professionals. Data collection was completed before the COVID-19 pandemic. We originally planned to interview a minimum of 30 patients and 30 family members. In reality, we interviewed more patients<sup>37</sup> and fewer carers<sup>19</sup> than planned. As Wales is a predominately white population, Black and Minority Ethnic (BAME) perspectives are a noted gap.



**Table 4** Logic model of stages, moderators and outcomes of getting onto a home therapy

Stages of getting onto a home therapy	Positive moderators	Negative moderators	Intermediate process outcome	Long-term outcome
Stage 1 Person with CKD is assessed by nephrologist as requiring treatment	<p>Family and/or caregivers fully involved</p> <p>Over time and appropriately, clinicians prepare patient and families for the future.</p>	<p>Limited consultation time and/or opportunity</p> <p>Patient and families are not informed of or does not understand consequences of no treatment or delays in treatment</p>	Patient and families understand the clinical need for treatment	Patient and families empowered by a good understanding of their health condition and future prognosis
Stage 2 Person provided with information about options (SDM education package)	<p>Family and/or caregivers fully involved</p> <p>Appropriate resources available (staff time, accessibility of clinics, travel time for home visits)</p> <p>Good relationship between patient, family members and whole MDT members</p> <p>Patient and family members have some pre-existing knowledge of chronic kidney disease and treatment options (may also be negative)</p> <p>Clinicians have high communication skills, so that person's preference for information is discussed (eg, amount and format)</p> <p>Mix of informal and formal approaches</p> <p>Personalised education provided that empowers people and supports self-care.</p> <p>Information delivered consistently, in a range of formats.</p> <p>Consistent peer-delivered information, updated and reviewed</p> <p>Equipoise achieved (making the correct range of options available and listing them in a logical sequence and in sufficient clarity, so that people perceive the opportunity to take part in the decision)</p>	<p>Late referral or sudden deterioration requires hurried decision-making (NICE guidance is 1 year in advance)</p> <p>MDTs have poor understanding of treatment options and options that comorbidities allow</p> <p>Patient and family have poor understanding or acceptance of their condition. Prognosis (including death) not discussed</p> <p>Clinicians may have their own agenda, for example, may be pressed for time to get through patient cases.</p> <p>Bias (overt or unconscious) towards particular therapies in education literature and/or face-to-face sessions</p> <p>Patient and family members suffer from information 'overload'</p> <p>Prior knowledge informs heuristic decision-making</p> <p>Caregivers and/or family not fully involved or have their own needs and concerns, which impact on decision-making</p> <p>Ideas, concerns and expectations of person (and family/caregivers) not fully addressed</p>	Patient and families engaged, empowered and understands options including home therapy options	Patient and families are equipped to make an informed treatment choice
Stage 3 Patient and families deliberate and express choice of dialysis modality	<p>Presumption of home therapies as the norm</p> <p>Positive image of home therapies</p> <p>Patient and families' cognitive abilities are accounted for in supporting decisions—including home therapies</p>	<p>'Abandonment'—professionals offer information about choices but no guidance</p> <p>Patient is unable to make a decision and defers to 'experts'</p> <p>Negative psychological factors of home therapy, for example, fear and anxiety</p>	Patient makes a choice supported by their family/caregivers	Patient (who is deemed medically suitable) chooses a home therapy (if not appropriate, they move to a different pathway)

Continued

Table 4 Continued

		Patient and families have positive exposure to other home therapy patients and their family/caregivers	Unmet social care issues (eg, housing, welfare benefits, social isolation) prevent home therapies being considered by either patient, families or professionals		
		Patient and family have a supportive and suitable home environment	Because patient may not feel unwell, they maintain previous behaviour and avoid making decisions		
		Decision is made or negotiated in partnership with patients, family and health and social care professionals	Language, terminology and complexity of options affect decision-making capabilities of person		
		Fewer options lead to easier decision-making	Medical efficacy of treatment options not considered by patient		
Stage 4	Consideration by Clinical team (with social care input) incorporating the preferences of patient and families.	MDTs work with social care and voluntary agencies work together to overcome non-clinical barriers to home therapies  Health and social care professionals' work together to overcome social barriers to home therapy  All MDTs are well trained and knowledgeable about home therapies  Impact of alternative decisions with regards to the values and lifestyles of person with CKD fully considered	MDT resource and time constraints  Risk aversion by health professionals  Clinician bias against patient attributes, for example, social situation, learning disability or frailty  Clinician bias towards certain therapies	MDT decision to support patient with a home therapy	Patient and family are supported by the whole MDT team in their choice of an appropriate home therapy
Stage 5	Joint decision made of dialysis modality	Settlements and/or compromises reached through shared decision-making.  Option open to review decision in the future  Action plan agreed and arrangements made for follow-up	Delays to decision  Restricted opportunities for home therapy training or poor quality training  Changing health and social circumstances	Patient, families and professionals recognise that a good decision has been made.	Patient and families are ready to be prepared for a home therapy
Stage 6	Patient and families are prepared for kidney replacement therapy	Preparation, and commencement of, home dialysis happens speedily  Positive and timely communication with patient and families.  Ongoing, coordinated health and care support for patient and families	Patient may change their mind  Poor coordination between agencies (eg, health and social care) in facilitating home dialysis.	Home therapy is facilitated	Patient embarks on a home therapy

CKD, chronic kidney disease; MDT, Multi-disciplinary team; NICE, National Institute for Health and Care Excellence; SDM, shared decision-making.

### Strengths and weaknesses in relation to other studies

While studies have examined structural issues, general support and patient attitudes to home therapies,<sup>48–50</sup> the process of SDM in the context of better understanding barriers to home dialysis has not been examined in detail. By framing findings within a recognised model, we show

how people with CKD and their family members behave through the decision-making process as well as observing and understanding the perceptions and behaviours of healthcare professionals along the same continuum. Likewise, Tong and colleagues report that the language used with patients about kidney disease is often alien

**Table 5** Road map and recommendations for service delivery change to increase uptake of home dialysis

1. A presumption of home therapies through the clinical pathway adopted by all, including consultants, nurses, other members of MDT, managers and commissioners, and reflected in education.
2. 'Early' education for people with CKD and families. Talking to people about dialysis too early may lead to unnecessary anxiety, particularly for many patients who will never require dialysis, but 'early' education can focus on the basics of kidney disease, the consequences of CKD (even mild/moderate kidney disease), the importance of blood pressure control, smoking cessation, weight loss, etc. For some people with clearly progressive kidney disease (eg, young patients with polycystic kidneys or type 1 diabetes) who need dialysis and transplant information at earlier eGFR blood tests, early education would help them come to terms with treatment and early-identify barriers to home therapy. This would also assist in patient activation and engagement (see below).
3. Redesign education packages, so that patients rely less on unreliable or industry-sponsored resources. This is likely to be a mixture of online material, group discussion (delivered by peers where possible) and one-to-one sessions. All MDTs have a key role in identifying which education package is best suited for each patient, but the content should be standardised regardless of how or who delivers it. Education packages should also fully engage the family in recognition of their crucial role in decision-making.
4. Encourage patient engagement and activation at an early stage rather than wait until the time of decision-making and then expecting people to become active in their own care. For example, two-way patient portals, which both deliver education/information updates/patient results/clinic letters to the patient and also let the patient upload information, which is important to their care (eg, blood pressure/weight/key symptoms) and viewed by patients.
5. Update knowledge of home therapies to ensure that clinicians and all kidney MDT members have the in-depth and up-to-date knowledge needed to discuss options in detail with patients and family members.
6. Move away from purely medical/results focus. Shared decision-making requires a holistic understanding of the patient and family members' needs—their social circumstances, support networks, their values and preferences as well as their medical needs. Clinicians often have a disease-focused model of history-taking, so that understanding of the patient is based mainly on blood results and comorbidity, and treatment choices may be based on clinical outcomes (such as survival). An appropriate clinic template, sufficient clinic time and training for MDTs would be important in delivering change.
7. Social and psychological support. A high burden of anxiety (and likely depression) that is unrecognised by clinical teams will impact on decision-making. There are tools that clinicians could use to aid in identifying these symptoms (eg, validated questionnaires); they need to draw on specialist kidney social work and psychologist capacity; and be able to sign-post to appropriate external support.

CKD, chronic kidney disease; eGFR, Estimated Glomerular Filtration Rate; MDT, Multi-disciplinary team.

and frightening, and the barriers to home dialysis are complex.<sup>51 52</sup> This study adds more by highlighting the different experiences and perspectives of SDM and barriers to home dialysis. Sometimes, different perspectives expressed near identical views and frustrations, for example, family members and professionals both reported similar challenges engaging patients to take their kidney disease seriously, engage in SDM and generally in more healthy behaviours. This suggests that the family could potentially be reconfigured as a facilitator to improve uptake of home dialysis if they were more proactively involved and their unmet needs were addressed.

### Suggestions for future research and unanswered questions

A new health system wide reorganisation supported by a comprehensive overhaul of patient education materials needs to be developed and implemented to ensure consistent practice across Wales supplemented by a trial to examine its effectiveness. Any such trial would need to be a step wedge design with gradual introduction of the new system and associated enhancements into each subsequent dialysis service. This will be an important next step as although many SDM tools and guidance are in operation (and more are constantly being produced), few have been robustly tested at a system level, from the multiple perspectives and alongside specific service change targets. NICE has recently updated their SDM guidance and is collating existing SDM interventions.<sup>53</sup> Future research should take account of these developing resources to ensure consistency, translatability, shared

goals and evidence-based practices are developed and adhered to.

### CONCLUSION

People with CKD are not being adequately prepared or educated about the most appropriate treatment options for them or the benefits, harms, outcomes or costs of the different options. Patients and family members are too reliant on information or misconceptions gained from sources with varying accuracy and credibility. Healthcare professionals lack the skills to individually tailor the decision-making process for each person and some are not familiar with using shared decision models to inform their conversations with patients. Patients and professionals need greater awareness of the relative costs and benefits of different treatment options to inform their SDM processes.

Study findings are important as they highlight the critical points in the decision-making processes, where changes to practice can potentially bring about better SDM and outcomes with patients. People with CKD need to be better prepared and their preconceived ideas and misconceptions gently challenged. Healthcare professionals need to update their knowledge on contemporary kidney therapies in order to provide the best advice and guidance. Healthcare practitioners can use the logic model and road map to clinical change to benchmark and improve their own practice.

Twitter Jane Noyes @janenoyes

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#### ORCID iDs

Jane Noyes <http://orcid.org/0000-0003-4238-5984>

Gareth Roberts <http://orcid.org/0000-0003-4496-6539>

James Chess <http://orcid.org/0000-0001-8805-6962>

Leah Mc Laughlin <http://orcid.org/0000-0003-0185-6639>

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