

# Understanding the Low Take-Up of Home-Based Dialysis Through Shared Decision-Making: A Qualitative Study

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## Research Article

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**Title**

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## **Abstract**

### **Background**

Despite home dialysis having many advantages, take-up by people with established renal failure is low in many countries. Previous studies highlight complex social, psychological, economic and health-system obstacles to patients choosing home dialysis. The study explored how people who are pre-dialysis, caregivers and health professionals together navigate common shared decision-making processes, and assesses how this impacts on choice of dialysis, conservative treatment or transplant. .

### **Methods**

This qualitative study took place in Wales, a country within the United Kingdom with a publicly-funded healthcare system. From 5 renal centres, education literature used in patient education was collected and content analysis applied. The theoretical framework was the MAGIC shared decision-model. From February 2019 until data saturation was reached in January 2020, semi-structured interviews with a purposive sample of 51 patients, 41 caregivers and 49 renal professionals were undertaken. Interview data were analysed using framework analysis. Patient and public representatives were involved throughout.

### **Results**

Thematic findings are presented as: Prior knowledge, choice talk, options talk, decision talk. Gaps were found in both knowledge and understanding at every stage of

the decision-making process and amongst all involved. Patients and caregivers came with varying levels of prior knowledge and understanding, which can result in misinformation and biases that contaminate the shared decision-making process. This is not always recognised by renal professionals. Presentation of treatment options through education programmes was often found to be inadequate, biased or poorly understood. Such deficiencies create partialities towards some treatments and, in particular, mitigate against the take-up of home therapies, even when they may be the most appropriate. A logic model and a road map to further evolving clinical practice was developed.

## **Conclusions**

There are critical points in the process at where change could benefit patients. Patients need to be better prepared and their preconceived ideas and misconceptions gently challenged. Healthcare professionals need to update their knowledge in order to provide the best advice and guidance. Shared decision-making processes need to be individually-tailored so that there is more attention paid to the benefits of home based options, and on people who could chose a home therapy but select a different option.

## **Keywords**

dialysis, end stage kidney disease, end-stage renal disease, renal dialysis, home therapies, qualitative, shared decision-making

## 1 Background

The increasing global prevalence of kidney disease and the burden of dialysis on healthcare systems has driven the need to increase home-based dialysis. Home dialysis has a number of advantages compared with in-centre treatment. Frequent and longer haemodialysis is possible at home and can be associated with extended survival rates [1–5]. People with established renal failure (ERF) receiving home dialysis experience better quality of life through greater independence and autonomy [6, 7]. The flexibility of self-management and reduced need to travel to a dialysis centre provides greater opportunities for people to take on occupational and social roles [8]. Home dialysis is more cost-effective in many circumstances [9–11].

Clinical practice guidance in many high-income countries (e.g. the United States of America, Canada, Australia, UK and Europe) state that patients with advanced kidney disease (AKD) who may need renal 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 [12]. Ideally, this should happen through effective shared decision-making [13] as poor decision-making experiences are associated with low treatment satisfaction [14]. Yet, while an estimated 50% of all patients are suitable for peritoneal dialysis and 15% of haemodialysis patients could dialyse at home [15] international evidence finds less than a fifth of dialysis takes place in the home [16]. Barriers to home dialysis have been found to be complex [8]. Practically, home dialysis requires patients to have adequate housing including space for supplies and in the case of home haemodialysis, an affordable and satisfactory

supply of water [17], but studies also find a complex mix of more intractable social, psychological, economic and health-system obstacles to home dialysis [8, 14, 18].

Gaining a better understanding of the factors that impact on treatment choices, and specifically to better understand why so many patients default to centre-based dialysis was the aim of the ‘Dialysis Options and Choices Study’ [19]. This two-year mixed method co-productive study integrated analysis of electronic renal patient records with documentary analysis of pre-dialysis education programmes, interviews with pre-dialysis patients and their families, and interviews with renal professionals, and a health economics analysis of dialysis modalities.

This paper presents findings from the study [19] examining the factors that impact on pre-dialysis choices made by patients. Framed within a model of shared decision-making, we examine existing approaches to pre-dialysis education offered to people. Using qualitative methods we explore what patients, and caregivers 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 are elicited by clinical teams within the shared decision-making process. In the context of diverse service provision within a health-care system, the paper concludes by setting out options to improve health and care practice and services towards meeting the policy intent of increased uptake of home therapies.

## **2 Methods**

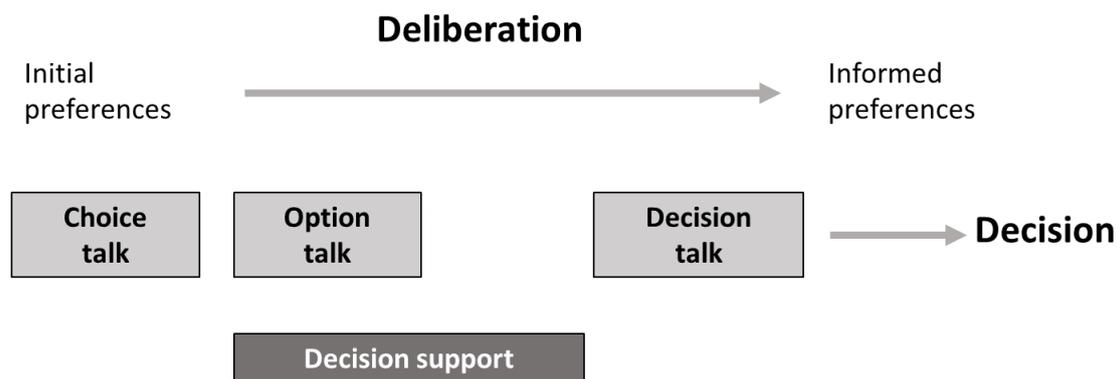
This was a qualitative study using the framework method [20] of data collection and analysis and reported using the Consolidated Criteria for Reporting Qualitative

Studies (COREQ) checklist [21] (Online Appendix 1). A protocol was developed and published elsewhere [19].

## 2.1 Theoretical Framework

The study was informed by theory underpinning the MAGIC (Making Good Decisions in Collaboration) model and intervention designed to test and identify the best ways to embed shared decision making into routine primary and secondary care [22]. Shared decision-making 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 [23]. The MAGIC programme provided a multistage consultation process for decisions - such as dialysis modality - involving a ‘Three-talk model’ for shared decision-making (Figure 1) with the sequence of choice, option and decision talk [13,23].

**Figure 1 A three-talk model for shared decision making [23]**



## **2.2 Setting**

The study took place in Wales, a semi-autonomous country within the United Kingdom with a publicly funded healthcare system. There are five renal centres across the country with services commissioned, monitored and audited by the Welsh Renal Clinical Network (WRCN). Incidence and prevalence of dialysis is higher in Wales than in other parts of the United Kingdom and despite half of patients being suitable for home therapies [24] only 12.9% receive peritoneal dialysis (PD) and only 6.1% home haemodialysis (HHD) [25] with significant variation in patient modality choice across the country. Wales provides an ideal setting for this study being a small but diverse country with a publicly-funded national health system, socio-economic and geographical variation, and a number of renal centres with different systems and practices. Ethical approval for this study was granted by the Wales Research Ethics Committee (Ref. 19/WA/0020).

## **2.3 Patient and Public Involvement (Co-production)**

This was a co-productive study meaning that from inception to dissemination, academics worked together with those who commission, audit, provide and use renal services to improve provision through research. The co-productive approach is reported elsewhere.

## **2.4 Data collection**

### **Documentary analysis of patient education materials and practices**

To identify and compare the topics and content, mode of delivery and range of resources used in education programmes to assist patients in dialysis decision making, we collected documents, resources and information on how education is delivered to patients and caregivers. In total, 44 separate booklets and leaflets were collected along with the education pathways followed across the five renal centres. The material was scanned with optical recognition software and imported into Nvivo 11 software (QSR International).

### **Patient and caregiver interviews**

People were eligible for the study if they were adults with AKD and had received formal pre-dialysis education and had, or were in the process of making a choice about treatment. Caregivers<sup>1</sup> were also eligible. Late-presenting patients were excluded. We ascertained the overall number of eligible pre-dialysis patients from the electronic patient record and established other criteria including location, treatment option, eligibility for home therapy and included additional characteristics of interest

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<sup>1</sup> Defined as a close friend or family member - who in the broadest sense - takes responsibility for looking after another person. While the term 'caregiver' is common parlance in this Journal and is used throughout this paper, it is not unproblematic. Many family members in our study did not see themselves as providing health-related care and the possibility of becoming a carer for a dialysis patient could be a barrier to home therapy choice.

in the group (such as gender, age, ethnicity, income, living alone etc.) to establish a sampling frame to ensure the theoretical requirements of the study.

Potential patient participants were identified by team members in each renal centre, provided study information and asked to complete a form consenting to be contacted by a researcher. This process ensured personal data was not shared between institutions. The researchers contacted potential participants, introducing the study, themselves, their roles and were able to answer queries. Further study information and consent to interview forms were sent to participants before interviews were arranged in mutually agreed locations.

Semi-structured interviews of between 30 and 90 minutes took place mainly in participant's homes and in most cases people with AKD were interviewed alongside caregivers.

The interview guide (Online appendix 2) was informed by the 'Three-talk' model (Figure 1) and a review of the literature. It was piloted and refined through discussion within the research team and with partners.

Data collection continued until saturation was reached. Table 1 summarises the sampling and characteristics of participants. No participants were interviewed more than once.

**Table 1 Sample characteristics**

<u>Location</u>	<u>Renal centre 1</u>	<u>Renal centre 2</u>	<u>Renal centre 3</u>	<u>Renal centre 4</u>	<u>Renal centre 5</u>	<u>Totals</u>
Proportion of dialysis patients in Wales	5%	50%	10%	25%	10%	100%
Number of forms received from public	4	30	7	14	15	70
Non-contacts / refusals / cancellations	1	5	2	5	6	19
Number of AKD patients interviewed	3	25	5	9	9	51
Number of family members / caregivers interviewed	3	21	4	7	6	41
Number of professionals interviewed	13	13	11	6	6	49
<b><u>Characteristics of AKD patients interviewed</u></b>						
Living alone	0%	12%	60%	11%	22%	18%
Low income household (<£20k/annum)	67%	36%	80%	44%	78%	51%
Under 50 years of age	33%	24%	0%	22%	22%	22%
Male	67%	44%	60%	44%	44%	47%
Female	33%	56%	40%	56%	56%	53%
<b><u>Characteristics of professionals interviewed</u></b>						
Nephrologists	23%	38%	27%	17%	0%	24%
Specialist renal nurses	31%	46%	36%	67%	50%	43%
Other renal team members	46%	15%	36%	17%	50%	33%
<b><u>Dialysis modality preferences expressed by AKD patients interviewed</u></b>						
Peritoneal dialysis	0%	20%	20%	11%	33%	20%
Home haemodialysis	33%	16%	0%	33%	11%	18%
Unit haemodialysis	67%	36%	80%	22%	44%	41%
Conservative Management	0%	4%	0%	0%	0%	2%
Undecided	0%	24%	0%	33%	11%	20%

## **Professional interviews**

A wide range of health and care professionals involved in supporting patients with AKD in decision-making were encouraged to take part in the study through the WRCN and provided with study information by email. Following the topic guide (Online appendix 3) we undertook semi-structured interviews with individuals, a number of small group interviews with different professional clusters and some whole-team focus groups (Table 1). In all formats we explored the values, preferences, experiences, expectations and anticipated outcomes from a professional perspective of dialysis modality decision-making.

Brief field notes were made after each interview. Interviews were shared between [Initial] and [Initial] experienced male and female qualitative researchers with doctorates, employed by [HE Institution]. Digital recordings of the interviews were transcribed verbatim by a specialist service and uploaded into NVIVO 11 software (QSR International). Codes were created to link participants with each other and with their respective renal centre. While transcripts were not participant-checked, co-production facilitated broader patient and caregiver feedback on the findings.

## **2.5 Analyses**

### **Education material**

We constructed an a priori framework and used content analysis [26] to systematically read and code the material. Sources were classified by renal centre and original source (publisher) and inductively assigned a ‘type’ classification indicating the primary purpose of the information. Using automatic and manual searches content was coded

against a pre-defined list of treatment options - transplant, unit-based haemodialysis (UHD), peritoneal dialysis (PD), home haemodialysis (HHD) and conservative care - and for the 'Three-talk' model for decision-making [13].

## **Interviews**

We used three levels of framework analysis to organise and code interview data.

Framework analysis provides a systematic analysis process that can be replicated by others [27]. Level 1 used a modified version of the 'Three-Talk' model (Figure 2), a decision-making journey which can be viewed from the perspective of the patient, caregiver or professional. Level 2 identified the professionals involved in supporting the decision-making process and the range of treatment options offered and considered. Level 3 was an inductive process of thematic analysis based on important themes identified in a sample of ten initial interviews read line-by-line by [Initial] and [Initial] and discussed with wider co-productive partners. The coding schema was further refined and developed in weekly team meetings and wider stakeholder meetings as data was gathered and coding commenced.

Transcripts were coded by [Initial] and [Initial]. 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. Continuing statistical measures of inter-rater reliability showed an average 92.6% coder agreement and an average Kappa coefficient of 0.58 (which accounts for chance) and is deemed fair to good agreement. Discrepancies between the two coders were resolved through discussion.

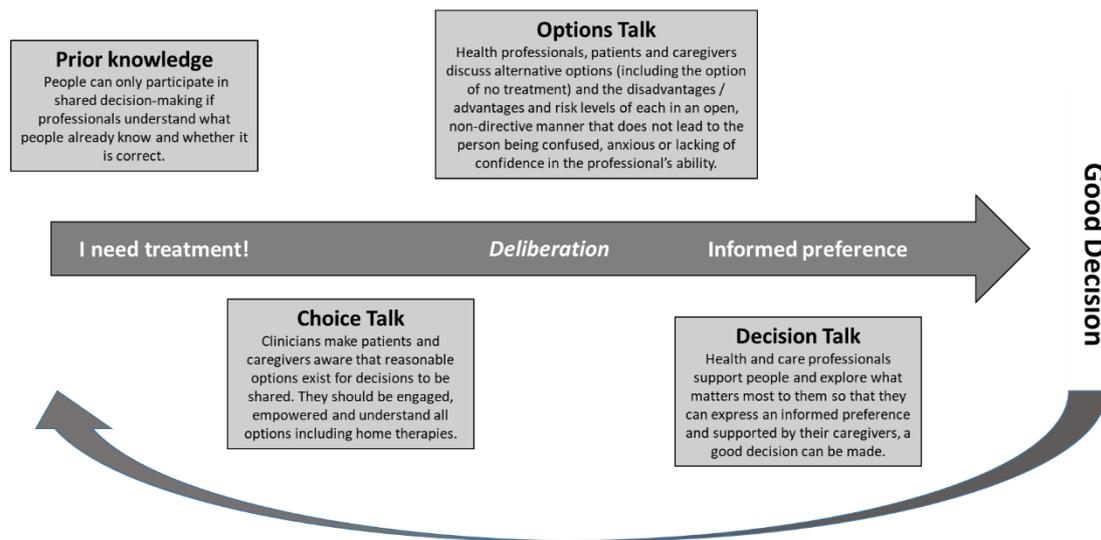
Discussion of findings was ongoing from an early stage in the research process. A wide range of co-productive partners were involved in the interpretation and validation of the findings, subthemes and themes. As part of the wider mixed-method study we routinely integrated the qualitative data with clinical audit and health economics data utilising methodological triangulation to assure validity.

Themes from findings were first organised according to the stage of decision-making (Table 2) and subsequently into a logic model (Table 3). There is no uniform template for developing logic models, although a common approach involves organising the findings of the qualitative study into chains of events [28] which can inform the development of a road-map for service delivery change (Table 4).

### 3 Findings

Consistent with our methodology, findings are therefore presented within the context of our modified ‘three-talk’ model (Figure 2). More detailed findings with illustrative quotes from interviews are set out in Table 2 under the same headings.

**Figure 2 Modified version of the shared decision making model [13]**



#### 3.1 Prior knowledge

People can only participate in shared decision-making if professionals understand what people already know and whether it is correct. We found a wide variation in patient and caregiver knowledge and understanding from both clinical and other sources prior to them commencing the decision-making pathway (Figure 3)

**Figure 3 Idealised pathway to home therapies**

<b>Stage 1</b>	<b>Patient with AKD is assessed by nephrologist as requiring treatment</b>
<b>Stage 2</b>	<b>Patient provided with information about options (education package)</b>
<b>Stage 3</b>	<b>Patient and their family/caregivers deliberate and express choice of dialysis modality</b>
<b>Stage 4</b>	<b>Consideration by clinical team (with social care input) incorporating the preferences of Patient (and their family/caregivers).</b>
<b>Stage 5</b>	<b>Joint decision made of dialysis modality</b>
<b>Stage 6</b>	<b>Patient is prepared for renal replacement therapy</b>

We observed how influential differing levels of knowledge was in shaping preferences and subsequent treatment choices. Prior knowledge that mitigated against home therapies included poor knowledge and understanding of kidney function, kidney disease, treatment and prognosis; the timing of commencement of the treatment pathway; and experience and acceptance of self-care. Incorrect or outdated knowledge often underpinned deep-seated and often inalienable biases against home therapies (Table 2).

### **3.2 Choice talk**

Choice talk is about making people aware that reasonable options exist. Ideally, the patient and their caregivers are engaged, empowered and understand options including home therapy possibilities. While clinicians and other renal team members attempted to engage patients and caregivers in shared decision-making, the timing, content and methods of treatment choice education varied widely. Where patients did not receive, or understand adequate information about the range of treatments

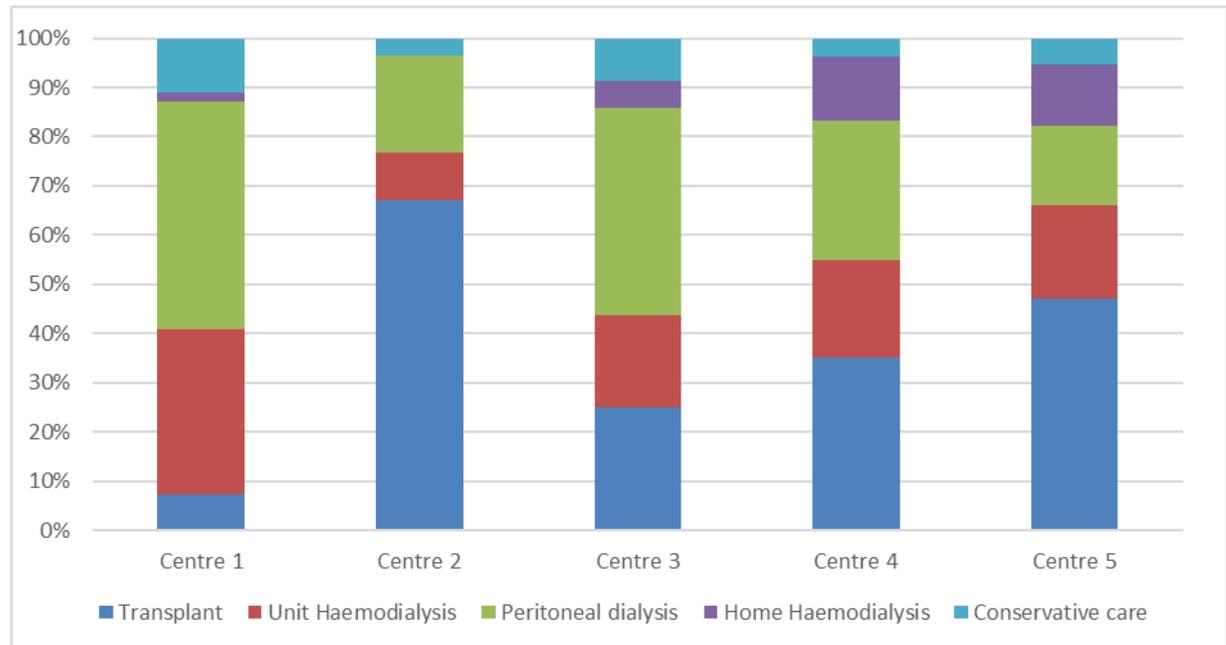
available to them they were left with concerns and expectations not fully addressed and would often default to UHD as the treatment they recognised and which had the most medical support.

A trusting relationship between patient and individual renal team members was important in facilitating choice. Likewise, where caregivers were actively involved in all stages of the process patients found it easier to make decisions and were more likely to choose a home therapy. Exceptions were where caregivers had concerns about their own abilities and responsibilities for home treatment or where patients believed home therapies to be burdensome on caregivers.

**Patient Education material.** Across centres, patients and caregivers were provided with literature to support decision-making. Most was produced locally by health boards or individual centres, the remainder originated from pharmaceutical / healthcare companies or kidney charities. We found considerable variation with less than a third of material containing information about treatment options or information to support choice-making. While all units provided some literature that outlined dialysis options, not all choices were always presented in one document, not all options were given equal weight within the texts and there was inconsistency between centres (Figure 4). Across the literature, of the treatment options mentioned, transplant was cited most frequently (37% of treatment mentions) followed by PD (30%), UHD (19%), HHD (7%) and conservative care (6%).

Although few patients or caregivers interviewed valued literature to inform decision-making compared with face-to-face encounters with health professionals, the lack of focus on home therapies in education material contributes to unnecessary bias.

**Figure 4 Variation of treatment choice content in pre-dialysis patient education literature by renal centre (n=44)**



### 3.3 Options talk

Options talk is about health professionals, patients and wider networks including caregivers discussing alternative options (including the option of no treatment) and the inherent disadvantages / advantages and risk levels of each. It is often seen as the pivotal stage of shared decision-making and where the professional often has no clear preference about the most effective treatment choice.

Despite protocols, we found that amongst health and care professionals, patients and caregivers, home therapies were rarely presumed to be the norm. Clinicians said that

presenting dialysis options was often hindered by a lack or misdirection of resources, staff, heavy workload and time restrictions for consultations. As illustrated in Table 2, barriers to the promotion of home therapies including the expansion of haemodialysis satellite units, patient and caregiver opposition to medical equipment or treatment in the home, concerns about infection risk and potential for social isolation. Perceptions that home therapies are burdensome on family and caregivers was a common theme as were concerns over desegregation of health needs and personal life. Some professionals told us that they lacked the necessary in-depth knowledge of home therapies to offer clarity of options.

### **3.4 Decision talk**

Having been informed of the treatment choices available to them, shared-decision making should involve health professionals supporting patients and exploring what matters most to them so that they can express an informed preference and supported by their caregivers, a good decision can be made.

While some people with AKD described one main reason for their choice of treatment, others could not articulate clearly why they had opted for a treatment, suggesting the use of heuristics in some cases and in others, deference to clinical authority. Many people with AKD 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 felt unable to make a choice, despite having often known for months or even years that they would need dialysis. In some cases this was linked to strong emotional reactions to ERF leaving them unable to make decisions or too scared to consider

home dialysis. Others were not adjusted psychologically and emotionally to the need for dialysis. Many were anxious while others were depressed. This was not always recognised by professionals and consequently sufficient support was not always available. This in turn impacted on people's ability and confidence to choose home dialysis. Fundamentally we found that when free to make a choice (notwithstanding comorbidities) most people make dialysis choice based on values and lifestyle with little consideration to efficacy of treatment options. This is where we observed some differences in approaches to shared-decision making between clinicians and other renal team members.

**Table 2 Detailed findings and illustrative quotes**

Finding	Illustrative quotations
<b>Prior knowledge and preferences</b>	
<p>Despite attending renal clinics – sometimes for years - patients often had little or no knowledge of kidney disease or treatments.</p>	<p>All I knew about kidneys, was it was something to do with your waterworks. That was it. (P,RC2)</p> <p>I'd been going to [renal clinic] started off maybe every 12 months / nine months. I never even thought of what [dialysis] was. I don't think - I'd heard the word and I'd never thought about it. (P,RC4)</p> <p>It was never explained, "Oh, your kidneys could fail. You'd go on dialysis." I was never told something like that. I was just told, "Your kidneys ain't working properly. You need to do this or you need to do that." (P,RC5)</p> <p>No one has really told me what's caused this, why it's happened. It would've been nice to have known earlier on, say six months ago, that my kidney function was going downhill. All I knew, I was just having blood tests because of my blood pressure tablets. (P, RC2)</p> <p>...sometimes people appear to be listening and they don't take anything in, and then if you ask them the question – even a simple question such as "Do you know why you've come here?" And quite often, they don't, which is a bit sad. Probably a reflection of my communication skills. [Laughs] (CI,RC2)</p>
<p>How and when patients were told that they require treatment varied considerably. In the best cases, people were prepared gently over time. In the worst cases, patients were preparing for dialysis with little knowledge or understanding about how they had got there.</p>	<p>I've been made aware of it all along, really. I've always been aware of the dialysis unit. They know my family history there because my mum was a patient and we've always discussed that at appointments. I think we've always had a chat about how things are going and what the eventuality would be. (P,RC2)</p> <p>I think if, in the beginning, I had been told I would have to have dialysis, that would've helped me better because then it could've been explained as I'm going along. I suppose if I'd had more time in-between when my kidneys failed to go on dialysis, because it was four days / five days. That was such a shock. (P,RC3)</p>

<p>Some knowledge of the disease or treatment options was commonly gained from informal sources such as relatives, neighbours or and was often highly influential.</p>	<p>I didn't know much, but then my mate, he got it [ERF] and he's on dialysis. He has to go to hospital three times a week. So then I did know something about it (P,RC4)</p> <p>I thought about [PD] but for me, I didn't fancy doing that four times a day putting a bag on. At the time, my lifestyle wasn't suited to that. Plus, I heard a rumour that you can get a lot of infections with the pipework in your stomach. A lot of people come off it because they've had infections in the pipes. (P,RC5)</p> <p>My Dad was just about to start PD and then he died. I'm sure it frightened him to death. [Laughs]. I know that's a ridiculous thing for an intelligent person to say but it has stayed with me and put me off [home therapies] a bit. (P,RC2)</p>
<p>Patients and caregivers reported that prognosis (including death) was rarely discussed with clinicians.</p>	<p>I was never told honestly the worst. They need to explain, "This is what's gonna happen if you don't start looking after yourself." I've had doctors saying to me, "Oh, you're gonna die. You're gonna die." And I'm like, "Yeah. You're just saying that just to make me do something." I didn't think they were serious. (P,RC2)</p> <p>I think we're a bit too woolly talking about the serious nature of kidney disease... we're dealing with something which has got a higher mortality than a lot of cancers. Everybody knows that cancer causes people to die. Not many people know that kidney disease does... I'm not sure we are always straight with people. (CI, RC2)</p>
<p>Patients with hereditary kidney disease were more aware, although knowledge could be outdated leading to prejudicial judgements about treatment options.</p>	<p>I have an inherited condition. When my dad went onto dialysis, I was aware of what choices he'd been given and also aware of the type of treatment and all the issues that go with the treatment for the disease and the problems you can have with it (P,RC2)</p>
<p>Many patients and caregivers said that they were not involved in their condition including monitoring or preventative measures that might delay renal decline.</p>	<p>The question I asked every session, every time I saw a doctor for years, was, "Is there anything I can do to stop my kidneys declining?" "No, you just keep doing what you're doing. It's fine." And that's the answer. But I wish there was something I could do to regenerate it (P,RC1)</p> <p>I just kept going for blood tests, but no-one said why... The last one I had which was about two or three months ago, they turned round and said, "Your blood count or your kidney function has gone down, at 19. If this one goes down again we're gonna refer you for dialysis and then kidney transplant," and that's the first I heard of it. (P,RC4)</p>

Choice talk	
<p>The point at which clinicians refer patients for pre-dialysis education is critical.</p>	<p>What it all comes down to is referral time. If they referred them early enough, you've got time to drip-feed the patient, you've got time to talk to the patient at decent intervals about choices and work through steps and maybe bring them round to a home therapy. If they're referring late, you just haven't got that time and that's when they end up on haemo because it's just a default position. (HP,RC3)</p>
<p>People attending group sessions mostly viewed them positively and helpful in decision-making, although some found sessions overwhelming suggesting that the method and timing may not be suited to all.</p>	<p>We went early on, quite early on, with this education meeting. I couldn't take any of it in because I found it far too frightening, these things. And it was like, whoosh. And I'm sure you took it in for those minutes but it was terrifying, the thought of what was there and everything (C,RC3)</p> <p>I went on the education session two years ago where they showed us a film about the dialysis. I didn't take any on it in as I didn't believe that I would ever need it (P,RC4)</p>
<p>Peer delivered aspects are particularly valuable in gaining knowledge and supporting decision-making.</p>	<p>I think the pre-dialysis education has been excellent, actually. We've been up to the dialysis unit in [Location]. We went up there to have a look up there, a group of us. It's very good, this education thing. They've had a few down to talk to us who are on dialysis, dialysis at home and somebody has had a transplant. (P,RC2)</p> <p>The last meeting I went to, I spoke to a girl there. She's doing home dialysis. She does nocturnal. I said then about nocturnal. She said it's marvellous. It's only her and her little boy. So, I said, the only thing, I didn't think I had enough room. She was saying they'd put a Portacabin out in the backyard and things. Of course, since then, it's on my mind. (P,RC4)</p> <p>Talking to other patients helps, what they've been through and a lot of them down there on the home dialysis are a lot older and they're with their wives and their wives get involved and do it all with them so I've been talking with them as well, so what the pros and cons are for them and what they get up to. It's been good. (P,RC4)</p>

<p>Personalised education provided that empowers people and supports self-care</p>	<p>I think it was delivered in a good way and the staff that delivered it were very good at what they did, but I think the level was quite basic. I think there were some people there of different abilities and it was probably aimed at their level of understanding. So because I already had some knowledge of it anyway, they didn't actually tell me anything that I didn't already know (P,RC2)</p> <p>There are lots of leaflets about the department, if you seek them out. But, you're never given the information. You have to seek it. And I think it would be quite useful. I know every patient is different and everybody's situation is different but there's a lot of information that is very generic. I think that there could be a little brochure that's given to everybody (P, RC3)</p>
<p>Patients who had not received adequate information about the range of treatments available to them, or without explanation, were not given certain choices. This often left them with concerns and expectations not fully addressed. In many of these cases, people were not considering home therapies and perceived unit-based haemodialysis as the 'safe' and default option. It was often the one treatment that they recognised and the intervention they perceived to have the most medical support.</p>	<p>[Clinician] didn't really know about me but he was making these varied judgements about me. He just gave the option of haemodialysis in hospital. He didn't talk about home dialysis, he didn't talk about peritoneal dialysis. That was it. (P,RC2)</p> <p>They said I could have [haemodialysis] at home but I've only got two bedrooms so I need another room, for the chair, a month's supplies. They don't do a week, so it wouldn't work. I didn't want nothing in my stomach. I didn't want to do it overnight. A bit frightening. And I wouldn't stick needles in me. I'd rather go down the hospital and just have them doing it for me. Imagine something went wrong here. (P,RC5)</p>
<p>Decision-making is almost always collaborative. Patients whose families were actively involved in all stages of the decision-making process found it easier to make decisions and were more likely to choose a home therapy.</p>	<p>I liked the sound of doing it at home and [Caregiver] was with me at all the sessions but he kept saying, "Do what you want to do?" but I said, "No, it's got to be a joint decision". He's the one who calls the ambulance. (P,RC2)</p> <p>In all situations, to be fair, there's always been discussions with consultants and nurses that I've got to know and what they think is best, because their opinion is obviously a big opinion. Me and my mum will obviously talk about it to figure out what's best for us. Then me and my mum will probably have a talk with them to try and come to a big decision. (P,RC4)</p>

<p>Where a person’s partner had not been involved in education a lack of shared information made joint decision-making difficult and sub-optimal decisions were reached. This behaviour was observed particularly with men who rationalised their decisions not to share as a desire to protect their partner. In such cases, home dialysis was not considered.</p>	<p>I’ve been nursing my partner for a year and 11 months with cancer. I haven’t been right, myself, for a while but I didn’t say anything to her. She knows now, but when I go down the hospital, my sister’s here (P,RC3)</p> <p>I don’t know how [Wife] feels - I’ve kept everything away from people, you see. My family and everything. How can I say it? I just don’t want them to worry before the time is there. My mate says that’s wrong. I said, “The thing is, it’ll worry her.” I don’t want people worrying before you need to worry. (P,RC5)</p>
<p>Ideas, concerns, and expectations of patients and caregivers are not always fully addressed by health professionals.</p>	<p>I know that the doctors and everyone are under pressure of time... but I would like to see the doctors be more upfront with information. All they do is look at your results, tell you what your results are and say, “Right, we’ll see you in two months’ time.” Really, there’s never any, “How are you? Are you depressed? Are you tired? Are you doing too much? Are you eating the right foods?” Should I know a little bit more about it? Or maybe that is the answer. Perhaps that is ok. But they’re not forthcoming. (P,RC5)</p>
<p>A good relationship between the patient, caregivers and individual MDT members is important in building trust and facilitating choice.</p>	<p>We know that patients will have more of an honest conversation with a nurse than they will with a doctor. They are the constant, so with annual leave clinics, registrars, they change, whereas the nurse will always be the one person who will normally remain consistent. So I think if it’s done right, they have a huge role to play in our education process and empowering our patients to become and to choose the right choice, to help guide them to make the right decision (HP,RC2)</p>
<p>Few people researched dialysis choices online, and of these, most were discerning about the sources of online information.</p>	<p>I haven’t gone to Dr Google because I understand Google. Unless you’re 100% accurate on what you’re asking, you can get all sorts of random stuff. I feel you’ve got to go to the expert for the information. (P, RC4)</p>
<p><b>Options Talk</b></p>	

<p>Despite protocols, there is not a presumption of home therapies as the norm amongst either health professionals, patients or caregivers.</p>	<p>We've got a departmental protocol as to what our approach to the patient should be, and that is fitness for transplant number one. If that's not the case then there's a priority order, home therapy, inpatient therapy and if they're not suitable for any of that, conservative care. Culturally though, I think the default position is unit haemo as far as dialysis goes (CI,RC2)</p> <p>I think when the nurse came over and said about the different types of dialysis, I sort of made my mind up straightaway, it's gonna be the hospital, because I didn't know anything about it. I knew it would've been ages in the end but I thought, in my mind, like he said, if anything went wrong, I was in the hospital. I was there. They could see to me. (P,RC4)</p>
<p>Presenting options can be hindered by a lack or misdirection of resources or staff, heavy workload and time restrictions for consultations</p>	<p>Staffing [is the main barrier to presenting options]. There's two part-timers running the PKD team. We want to get back to things like the education sessions. I've been in the job four years and I've never seen a group session because we haven't had the staff. We've had big issues over the time but it would be great to get back to stuff like that. But it's not going to happen if the team stays as it is. We're just about managing the workload. The doctors don't have much time with the patient in clinic. They get ten minutes. (HP,RC4)</p>
<p>Expansion of haemodialysis satellite units make unit-based treatment more accessible and therefore an easier default position for both professionals and those requiring treatment.</p>	<p>I wanted to do the home dialysis first. It was just seven nights here, 22 boxes delivered every fortnight, the room would be full. The other one was nipping to the [dialysis unit] for five hours, three days a week. At the time, it didn't appeal to me. I thought it would be fine overnight. But then a bit later, I said to my daughter, "It's too much of an intrusion, seven nights a week, so I think I'll ask them if I can go to the unit." It's five minutes away. It's a big difference. It's 15 hours on it instead of 63 or whatever it is (P,RC2)</p>
<p>Health professionals do not always depict options in an open, non-directive manner. This can lead to patients being confused, anxious or lacking of confidence in the professional's ability.</p>	<p>I think personal bias sometimes plays an influence in how patients are counselled towards renal replacement therapy. Lots of the consultants are open to the fact that if they're not as up to speed, for example, in PD, they feel quite uncomfortable having that conversation because they feel they can't answer the questions, and the same for transplant. (HP,RC3)</p>

<p>Differences in clinical outcomes between treatments rarely featured in patient’s and caregiver’s assessments of options.</p>	<p>[I] remember saying to [Renal Consultant], I remember saying to him, “Fine. But you fit [dialysis] into my lifestyle. This has got to fit into my lifestyle. I’m not changing my lifestyle to fit into this.” (P,RC2)</p> <p>I really wanted to go for transplant because of our lifestyle. We’ve got a friend who goes for dialysis three times a week. It really does eat into your lifestyle. Obviously if I have to, I will. (P,RC2)</p>
<p>Self-care procedures were commonly presented as intractable impediments to home therapy including fear of infection and disfigurement from catheters used in peritoneal dialysis and fear or lack of confidence in using needles.</p>	<p>It was because I didn’t want nothing in my stomach. I didn’t want to do it overnight. A bit frightening. And I wouldn’t stick needles in me. I’d rather go down the hospital and just have them doing it for me. Imagine something went wrong here. (P,RC4)</p>
<p>Different health and care professionals have different perceptions of options talk reflecting an imbalance in shared-decision making between paternalism and patient-led decision making.</p>	<p>There’s a danger that if AKD nurses present patients with all the dialysis options, they come to us ready-prepared with a firm decision. That’s not shared decision-making and it might not be what’s best for them. (CI,RC3)</p> <p>With our AKD nurses, it felt like they were offering patients irrelevant choices. You can’t have a transplant if you’re not fit enough to have it, so we should be narrowing down those options and not bewildering patients and focusing in on the options that they actually can physically have. (CI,RC2)</p>
<p><b>Decision talk</b></p>	
<p>Unmet social and care issues (eg. housing, welfare benefits, social isolation) prevent home therapies being considered by patients, caregivers and professionals.</p>	<p>A nurse told me about some options. The doctor / consultant told me as well. About four or five people told me. They gave me a piece of paper, went through all this paper about having [dialysis] at home and I said, “No, I’ll just come down here. I don’t want to frighten my boy. I don’t want him seeing me doing all that in here.” I had to have a second room for the machine but I haven’t got another room (P,RC4)</p> <p>Some of the elderly dialysis patients are lonely; they haven’t got family members so a lot of them find it as a social outing three times a week to the dialysis unit. (HP,RC4)</p>

<p>Some ERF patients told us that they did not feel unwell and therefore saw no need to make a decision. In such circumstances we often found people received UHD in lieu of a decision.</p>	<p>I haven't heard of a timescale for dialysis. I've been informed that now is the time to be told about the options and to think about it, because if I went for the peritoneal options, there are checks that need to be done. But I still feel fine. Do I need to make that decision now? Can I make that decision when the kidney is on its way? (P,RC2)</p> <p>[The clinician] said "When your GFR gets to this, when you feel like that or your symptoms get worse you'll need dialysis." So it was all stuff that was in the future and I couldn't predict when that would happen so you can sort of brush it to one side and it's not real. (P,RC5)</p>
<p>In mainly older people, ingrained deference to clinical authority can result in an unwillingness to participate in shared decision-making and a default to UHD. Such deference can be compounded by poor cognition, low health literacy and confidence.</p>	<p>Oh yeah, they told me all about that [dialysis options]. They just looked at me and said, "What do you want to do?" I said I don't know and they said, "You haven't thought?" I said, "No, don't talk about it. I don't want to talk about it. I'm just staying where I am [UHD]." I said, "I just don't want to be messed about." (P,RC3)</p>
<p>While most multi-disciplinary renal teams contain a psychologist, we heard that many people experiencing difficulties did not feel they needed such support, nor did professionals always assess the wider impact of treatment decision-making on people's lives.</p>	<p>They didn't understand why I didn't want dialysis. I was going through it then – it wasn't depression but I did have a personality change. I was going to die and that was it. I think they could do a lot more... There is no counsellor in the department that I know of. I'm not sure I would go to the counsellor but I'm sure there are people who'd like counselling. (P,RC5)</p> <p>This is the only disease I've ever had where there is no future in sight. All there is is a straight line, and that is causing me some mental problems, both in terms of sleeping and in terms of my attitude to where I go because, as I say, I'm a golfer. I've been around the world golfing, been a lucky boy. Now, I can no longer go abroad. I can't go for holidays; I can't go for golf trips. Been married for 35 years but my wife died. I'm now on my own and I see no future. As such, I've found the dialysis scenario very, very restricting. (P,RC3)</p>
<p>C=Caregiver, P=Pre-dialysis patient, Cl=Clinician, HP=Other health professional, RC=Renal centre</p>	

**Table 3: Logic model**

Stage of Home Therapy pathway		Positive moderators	Negative moderators	Intermediate process outcome	Long term outcome
Stage 1	Patient is assessed by nephrologist as requiring treatment	Family and / or caregivers fully involved	Limited consultation time and / or opportunity	Patient and caregivers understand the clinical need for treatment	Patient and caregivers empowered by a good understanding their health condition.
		Over time and appropriately, clinicians prepare patient and caregivers for the future.	Patient is not informed of, or does not understand consequences of no treatment, or delays in treatment		
Stage 2	Person provided with information about options (education package)	Family and / or caregivers fully involved		Patient and caregivers engaged, empowered and understands options including home therapy options	Patient and caregivers are equipped to make an informed treatment choice.
		Appropriate resources available (staff time, accessibility of clinics, travel time for home visits)	Late referral or sudden deterioration requires hurried decision-making (NICE guidance is 1 year in advance)		
		Good relationship between patient, caregivers and individual MDT members	Nurses have poor understanding of treatment options, and options that comorbidities allow.		
		Patient and caregivers have some pre-existing knowledge of chronic kidney disease and treatment options (may also be negative)	Patient and caregivers have poor understanding or acceptance of their condition. Prognosis (including death) not discussed.		

		Clinicians have high communication skills so that person's preference for information is discussed (e.g. amount and format)	Clinicians may have their own agenda eg. may be pressed for time to get through patient cases.		
		Mix of informal and formal approaches	Bias (overt or unconscious) towards particular therapies in education literature and / or face-to-face sessions		
		Personalised education provided that empowers people and supports self care.	Patient and caregivers suffer from information 'overload'		
		Information delivered consistently, in a range of formats.	Prior knowledge informs heuristic decision-making		
		Consistent peer-delivered information	Caregivers and / or family not fully involved, or have their own needs and concerns which impact on decision making.		
		Equipoise achieved (making the correct range of options available and listing them in a logical sequence and in sufficient clarity so that persons perceive the opportunity to take part in the decision).	Ideas, concerns, and expectations of person (and family/caregivers) not fully addressed		
<b>Stage 3</b>	<b>Patient and caregivers deliberate and express choice of dialysis modality</b>	Presumption of home therapies as the norm	'Abandonment' - professionals offer information about choices but no guidance	Patient makes a choice supported by their family/caregivers	Patient (who is deemed medically suitable) chooses a home therapy (if not appropriate person moves to a different

		Positive image of home therapies	Patient is unable to make a decision and defers to 'experts'		pathway).
		Patient's cognitive abilities are accounted for in supporting decisions - including home therapies	Negative psychological factors of home therapy eg. fear and anxiety		
		Patient and caregivers have positive exposure to other home therapy patients and their family/ caregivers	Unmet social and care issues (eg. housing, welfare benefits, social isolation) prevent home therapies being considered by either Patient and caregivers or professionals.		
		Patient has 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 patient's caregivers and health and social care professionals	Language, terminology and complexity of options affects decision making capabilities of person		
		Fewer options lead to easier decision-making.	Medical efficacy of treatment options not considered by patient		

Stage 4	<b>Consideration by Clinical team (with social care input) incorporating the preferences of patient and caregivers.</b>	Renal multi-disciplinary team work with social care and voluntary agencies work together to overcome clinical barriers to home therapies	Multi-disciplinary team resource and time constraints	Multi-disciplinary renal team decision to support patient with a home therapy	Patient is supported by the whole multi-disciplinary renal team in their choice of an appropriate home therapy
		Health and social care professionals work together to overcome social barriers to home therapy	Risk aversion by health professionals		
		All multi-disciplinary team members are well-trained and knowledgeable about home therapies	Clinician bias against patient attributes eg. social situation, learning disability or frailty		
		Impact of alternative decisions with regard to the values and lifestyles of person with AKD fully considered	Clinician bias towards certain therapies		
Stage 5	<b>Joint decision made of dialysis modality</b>	Sub-optimal accomodations reached through shared decision-making	Delays to decision.	Patient, caregivers and professionals recognise that a good decision has been made.	Patient is ready to be prepared for a home therapy
		Option open to review decision in the future	Restricted opportunities for home therapy training or poor quality training		
		Action plan agreed and arrangements made for follow-up	Changing health and social circumstances		
Stage 6	<b>Patient is prepared for renal replacement therapy</b>	Preparation, and commencement of, home dialysis happens speedily.	Patient may change their mind.	Home therapy is facilitated	Patient embarks on a home therapy

		Positive and timely communication with patient and caregivers.	Poor coordination between agencies (eg. health and social care) in facilitating home dialysis.		
		Ongoing, coordinated health and care support for patient and caregivers			

## 4 Discussion

This is the first qualitative study to look in depth at the shared decision-making process in this context and with this particular lens. The study is largescale, informed by theory, used a purposive sampling frame and explored multiple perspectives that were co-produced by patients and the public and wide ranging key stakeholders. 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 an epidemiological analysis of renal patient data published elsewhere and the findings presented here. There would seem to be broad acceptance in clinical guidance, in our interviews with renal professionals and from previous studies [e.g. 29–31], that choice of dialysis modality should be made through a process of shared decision-making. While other studies have examined structural issues, general support, and patient attitudes to home therapies [6, 8, 18], the process of decision making in the context of home dialysis, has not been examined in detail. Previous studies [see 32] have noted the role that information plays in dialysis choice, but evidence from this study goes further. By framing findings within a recognised model we show how people with AKD and their caregivers behave through the decision-making process, as well as observing and understanding the perceptions and behaviours of health and social care professionals along the same continuum. We find gaps in knowledge and understanding at every stage of the decision-making process and amongst all those involved.

Importantly, when joining the decision-making process, patients and caregivers come with varying prior knowledge and understanding of both kidney disease and treatment options. Clinicians and other health professionals do not always check, or recognise levels of prior knowledge and/or understanding which allows misinformation and

biases to infect the entire decision-making process. While this is recognised in some decision-making models [13] it is rarely reflected in renal-specific guidance.

Meanwhile, we observe how the presentation of treatment options through education programmes is not always adequate or unbiased. We find that knowledge gaps create barriers to good decision-making, they reduce choice, undermine patient and caregiver autonomy and reduce opportunities for self-determination. Unsurprisingly, we see how such deficiencies create biases towards some treatments and in particular, we find that this mitigates against the take-up of home therapies.

Through identifying factors that are enablers and barriers to the take-up of home therapies (Table 2), our findings suggest a number of changes to service configuration and clinical practice. We set out a 'road-map' for such changes in Table 4 which while applicable primarily to the study setting, contain many universal principles. These include; kidney 'early-education' for a wider group of renal patients and caregivers; reviewing dialysis education materials and programmes; encouraging patient engagement and activation; improving renal professional's knowledge of treatment options; moving away from a medical model of results; and providing better social and psychological support throughout the process. By reducing misinformation and biases and involving patients and caregivers fully in both care choices and activities, we believe that fewer will default to UHD and more will choose a home therapy.

**Table 4 Road map for service delivery change to increase uptake of home dialysis**

1.	<p><b>A presumption of home therapies</b> through the clinical pathway adopted by all, including consultants, nurses, other members of renal MDTs, managers and commissioners, and reflected in education.</p>
2.	<p><b>‘Early’ education for ERF patients and caregivers.</b> 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 ERF (even mild/moderate kidney disease), the importance of blood pressure control, smoking cessation, weight loss etc. For some people with clearly progressive kidney disease (e.g. young patients with polycystic kidneys or type 1 diabetes) who need dialysis and transplant information at earlier eGFRs, 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).</p>
3.	<p><b>Re-design education packages</b> 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 multi-disciplinary renal team members 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 caregivers in recognition of their crucial role in decision-making.</p>
4.	<p><b>Encourage patient engagement and activation at an early stage</b> rather than wait until the time of decision making and then expecting people to become active in their own care. For example, a two-way patient portal which both delivers education/information updates/patient results/clinic letters to the patient, but also lets the patient upload information which is important to their care e.g. Blood pressure/ weight/key symptoms.</p>
5.	<p><b>Update knowledge of home therapies</b> to ensure that clinicians and all renal MDT members have the in-depth <i>and up-to-date</i> knowledge needed to discuss options in detail with patients and caregivers.</p>

6.	<p><b>Move away from purely medical/results focus.</b> Shared-decision making requires a holistic understanding of the patient and caregivers – their social circumstances, support networks, their values and preferences as well as their medical needs. Clinicians often have a disease focussed 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 multi-disciplinary renal teams would be important in delivering change.</p>
7.	<p><b>Social and psychological support.</b> 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 (e.g. validated questionnaires); they need to draw upon specialist renal social work and psychologist capacity; and be able to sign-posting to appropriate external support.</p>

## 5 Conclusions

People with AKD are not being adequately educated about the most appropriate treatment options for them or the benefits, outcomes or costs of the different options. Too many are 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. Study findings are important as they highlight the critical points in the decision-making processes where changes to practice can potentially bring about better shared decision-making and outcomes with patients. People with AKD need to be better prepared and their preconceived ideas and misconceptions gently challenged. Healthcare professionals need to update their knowledge on contemporary renal 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.

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## List of abbreviations

AKD	advanced kidney disease
COREQ	Consolidated Criteria for Reporting Qualitative Studies
ERF	established renal failure
HHD	home haemodialysis
MAGIC	Making Good Decisions in Collaboration
PD	peritoneal dialysis
UHD	unit-based haemodialysis
WRCN	Welsh Renal Clinical Network

## **Declarations**

### **Ethics approval and consent to participate**

All methods used in the study were carried out in accordance with relevant guidelines and regulations. All participants gave informed consent. Patients, carers and professionals were given detailed written information on the study and were asked to sign a consent form indicating their willingness to participate. Anonymity was assured to all participants. Participants retained the right at all times to withdraw from the study and patients were assured that withdrawal would have no impact on their current or future treatment.

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

### **Consent for publication**

Not applicable.

### **Availability of data and materials**

The data used and/or analysed during the current study are available from the corresponding author on reasonable request subject to the usual consents and ethics committee/GDPR requirements to maintain confidentiality and anonymity of participants.

### **Competing interests**

None

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## **Authors' contributions**

DD acquired, analysed and interpreted the data, and drafted the manuscript.

GR was significantly involved in the conception and design of the research, interpreting the data, and was a major contributor in writing the manuscript.

LM acquired, analysed and interpreted the data, and made a contribution to revisions of the manuscript.

GW was significantly involved in the conception and design of the research, was involved in acquiring and interpreting the data, and made a contribution to revisions of the manuscript.

JC was significantly involved in the conception and design of the research, interpreting the data, and made a contribution to revisions of the manuscript.

JN was significantly involved in the conception and design of the research, oversight of data collection and analysis, drafting and revisions of the manuscript.

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The authors acknowledge the invaluable contribution made by [XX] undertook coding of transcripts, synthesised data and provided summaries of data.

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Online appendix 1: COREQ checklist

Online appendix 2: Interview Topic Guide – People with AKD and families / caregivers

Online appendix 3: Interview Topic Guide – Renal professionals

# Figures

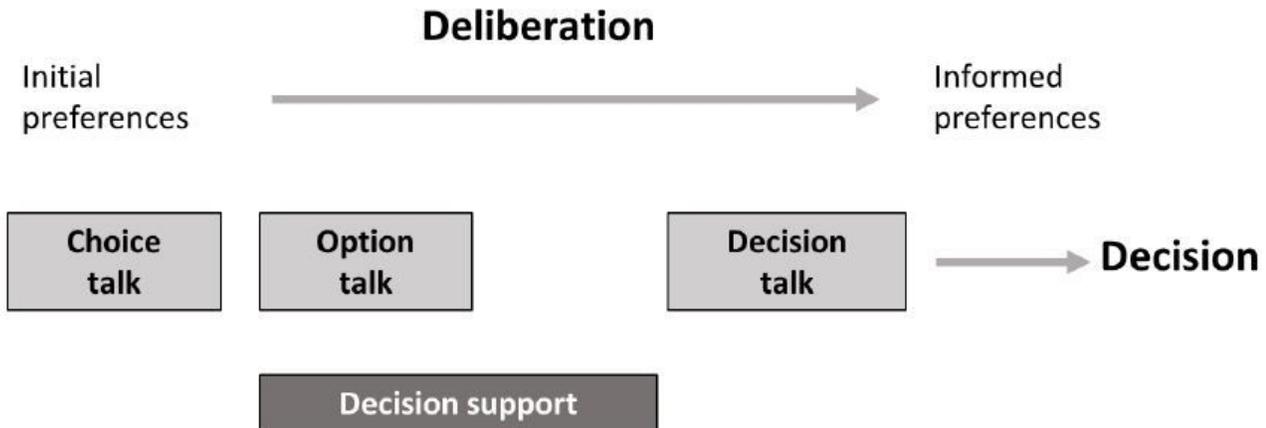


Figure 1

A three-talk model for shared decision making [23]

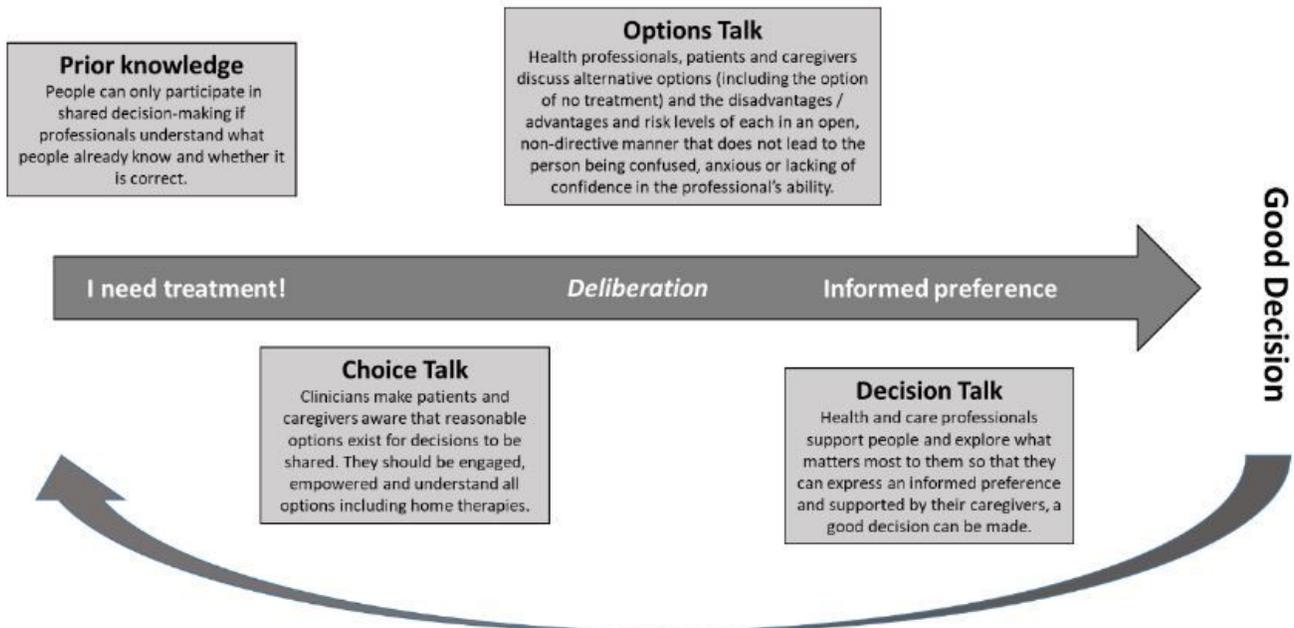


Figure 2

Modified version of the shared decision making model [13]

Stage 1	Patient with AKD is assessed by nephrologist as requiring treatment
Stage 2	Patient provided with information about options (education package)
Stage 3	Patient and their family/caregivers deliberate and express choice of dialysis modality
Stage 4	Consideration by clinical team (with social care input) incorporating the preferences of Patient (and their family/caregivers).
Stage 5	Joint decision made of dialysis modality
Stage 6	Patient is prepared for renal replacement therapy

Figure 3

Idealised pathway to home therapies

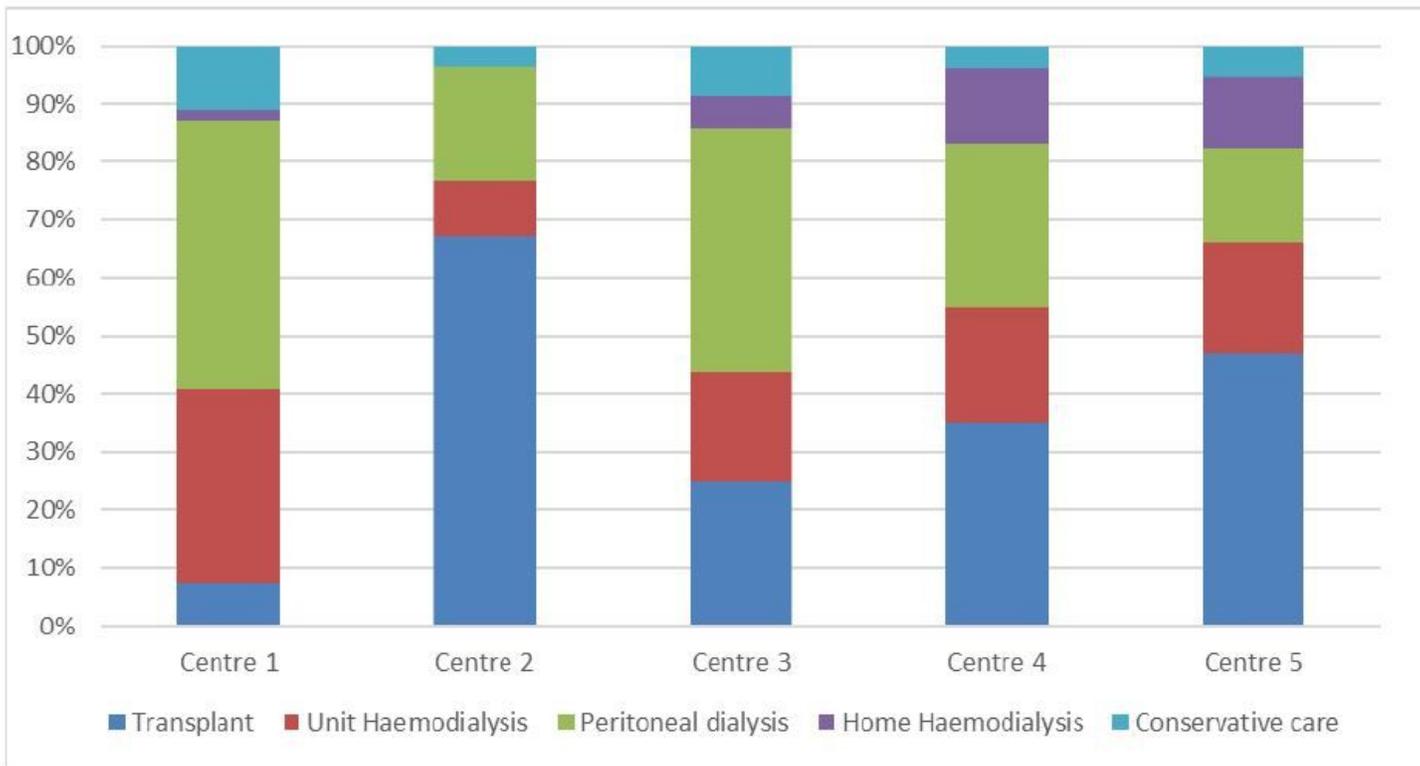


Figure 4

## Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [App1COREQChecklist.pdf](#)
- [App2PatientCarerTopicGuide.pdf](#)
- [App3ProfsTopicGuide.pdf](#)