Kidney Medicine

# Integrating Clinical Reasoning Into a Patient Decision Aid for People Making Conservative Kidney Management and Dialysis Decisions: A User-Centered Intervention Development Design

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**Rationale & Objective:** For older adults with kidney failure, conservative kidney management can provide better quality of life, less treatment burden, and for some, the same length of life benefit. Patient decision making around kidney treatments is complex and emotionally demanding for both patients and health professionals. Resources provided by kidney units about dialysis and conservative kidney management options are frequently not sufficient to support people making reasoned decisions between options. This article describes 2 studies underpinning the development of the Yorkshire Dialysis and Conservative Care Decision Aid.

**Study Design:** Study 1: cross-sectional study using in-depth interview methods; study 2: user-centered iterative design with multiple stakeholders.

**Setting & Participants:** Older adults with kidney failure and health professionals from 3 kidney units in the North of England. Resource development included input from co-applicants, patient and public involvement team, multidisciplinary health professionals, and academics in the United Kingdom and Denmark.

**Analytical Approach:** Thematic analysis was used to analyze the data.

**Results:** Three themes synthesized stakeholder responses: transition to a conservative kidney management pathway, clinical and social indicators for changing kidney care management, and preparation for end-of-life care. The findings informed the patient decision aid content, which was structured with reference to international guidance. There were 16 iterations of the patient decision aid addressing multiple-stakeholder evaluations. People with kidney failure, family members, and kidney professionals agreed the final resource provides accurate, balanced, accessible, and relevant information supporting engagement with the decision between conservative kidney management care and dialysis within the kidney care pathway in the context of their everyday life.

**Limitations:** There was a lack of ethnic diversity in the sample.

**Conclusions:** People with kidney failure must choose between dialysis and conservative kidney management when planning their kidney care. Development of this resource used evidence of professionals' clinical reasoning about kidney disease management. Providing details of the research underpinning patient decision aid development demonstrates why the resource can enhance health literacy and supports shared decision making conversations with people making these difficult decisions.

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People referred to kidney services are becoming older, more frail, and more likely to have comorbid conditions. International guidelines recognize that the kidney supportive care services provided must be relevant to this group.[1] For older adults with kidney failure, conservative kidney management without dialysis can provide better quality of life, less treatment burden, and for some, the same longevity.[2,3] Patient decision making around kidney treatments is complex, involving multiple stakeholders, a progressive disease, and treatment that leads to death if discontinued. Patient information provided routinely by kidney units to involve people with advanced chronic kidney disease (CKD) in making decisions about dialysis and conservative kidney management options is incomplete, difficult to understand, provides inequitable descriptions of the different treatment options, and tends to confound descriptions of conservative management with palliative and end-of-life care.[3-8] Health professionals may not have sufficient resources to proactively support people with advanced CKD in making reasoned decisions about which option best matches their personal priorities as their disease progresses.[9-12]

Patient decision aids are complex interventions that use decision science to structure the health care problem in a way that supports people's ability to make reasoned decisions when there are multiple options and uncertainty of the outcome of each option.[13,14] Decision aids encourage people to make decisions by better understanding the decision problem in the context of the health problem, and presenting information in a way that encourages people to reason about information important to their situation.[15] Decision aids include accurate, evidence-based, and balanced information about all options and their consequences. Many are designed after research has been conducted to understand the necessary content/layout needed by people making these difficult decisions with their health care teams.[13,14] Approximately 25 kidney-related decision aids have been developed, but few present conservative

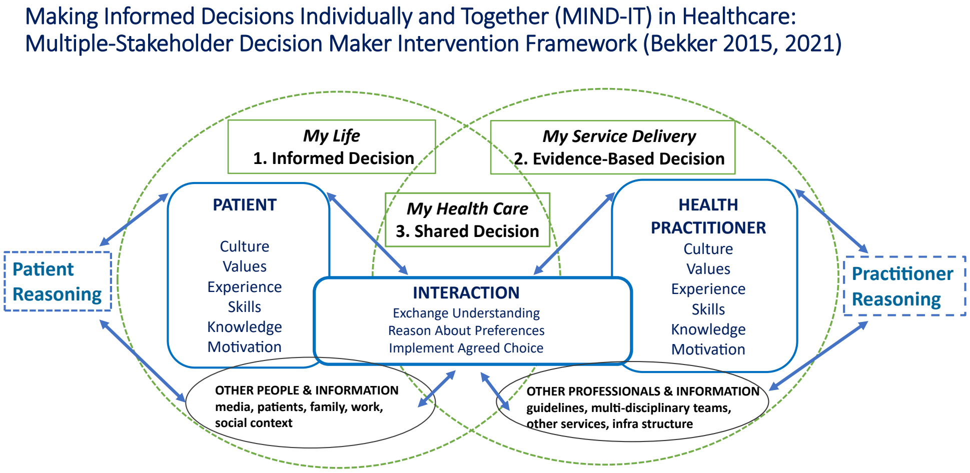

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**Figure 1.** Making Informed Decisions Individually and Together (MIND-IT) in health care: multiple-stakeholder decision maker intervention framework.[48,49]

kidney management and dialysis options so that people with advanced CKD and health professionals can make shared decisions about which pathway best suits both their clinical and personal needs as their kidney disease worsens.[16-18]

In health care, most decisions involve multiple stakeholders, each with different goals, preferences, experiences, and knowledge[15] (Fig 1). For decision aids to be meaningful, they need to present information reflecting the narratives of all involved in the health care pathway.[19] Few studies provide an in-depth report of the decisional needs of people with advanced CKD and kidney professionals during the kidney decision aid developmental process.[17,18,20-22] Providing evidence of the reasoning processes employed by kidney professionals and people with advanced CKD when planning transitions in care may help identify information critical for communicating about conservative kidney management and dialysis when making shared decisions about long-term kidney disease management.

This article describes the development of the Yorkshire Dialysis and Conservative Care Decision Aid (YoDCA; see Supplementary File) intervention. Development of this decision aid followed a systematic process using guidance on complex intervention development and clinical decision making.[13-15,23] The 5 steps undertaken were[24]

1) Evidence consolidation, including a scoping review of clinical guidelines,[25] patient and health professional surveys of kidney treatment options and disease experience,[26-28] behavioral decision support guidance and frameworks for decision aid development,[29] and author expertise in developing interventions supporting shared decision making between people with advanced CKD and clinical teams in kidney services to guide patient decision making about dialysis,[9,12,30] and designing written information[31,32];
2) Audit and critical review of patient information about conservative kidney management in UK kidney services[10];
3) Quality assessment of international decision aids supporting dialysis and conservative kidney management decision making[16];
4) Patient and health care professionals' views on the experience of managing kidney failure along the disease pathways, and making decisions about conservative kidney management to identify active ingredients to inform the decision aid content (see Study 1);
5) User-centered design methods to develop a decision aid of relevance to multiple decision makers making kidney failure management decisions[32,33] (see Study 2).

The development phase of YoDCA is essential to understand (a) patient experiences of kidney care management and decision making, (b) professional reasoning about the evidence for best treatment and patient assessment of a changing disease state, (c) how service is delivered, and (d) how decision aids will be used in practice.[15] It builds on research methods carried out to develop the Dialysis Decision Aid[34]; the experience of its integration into practice by Kidney Research UK; and its use by people with advanced CKD, kidney professionals, and kidney services since 2014.

## AIM

To develop a decision aid to support people with advanced CKD and their family members making decisions between dialysis and conservative kidney management options.

## OBJECTIVES

- Establish the context(s) in which decisions about conservative kidney management and dialysis management pathways are made from the perspectives of people with advanced CKD and kidney health professionals.
- Develop a decision aid intervention relevant to all decision makers along the kidney supportive care pathway.

## METHODS

### Study 1

#### Design

Survey of people with advanced CKD and multidisciplinary (kidney) health professionals using semistructured interview methods.

#### Ethics

The National Health Service Research Ethics Committee and Health Research Authority favorably reviewed the study on February 19, 2018 (17/LO/2132; 231121).

#### Setting

Three large teaching hospitals in West and South Yorkshire.

#### Sample and recruitment

A purposive sample of adults with advanced CKD (stages 4 and 5) recruited from 1 setting. Eligibility criteria included people who had:

- chosen dialysis or conservative kidney management and were offered both options,
- were yet to start or had commenced dialysis or conservative kidney management,
- had experience of receiving both options.

Those lacking the cognitive capacity to consent to an interview were excluded. Patient participants meeting the inclusion criteria were identified by health professionals in the advanced kidney care clinic, and study information was provided at their next outpatient appointment. A researcher (AW) telephoned participants 1 week after their appointment to arrange an interview. Health professionals were identified by AW as being part of the multidisciplinary team overseeing the care of people with advanced CKD. Kidney care professionals were invited to interview by email.

#### Study materials

Study information sheets, consent forms to inform and recruit participants, and an interview guide for patients with kidney failure (Appendix 1) and health professionals (Appendix 2).

#### Data collection

Semistructured interviews with people with advanced CKD elicited views about how to make sense of kidney disease; how treatment decisions were made; and illness care in the past, present, and future. Health professionals were interviewed separately about how they support patient decisions with transitions in kidney failure between different treatment pathways and discussed training needs. Interviews were conducted by a researcher (AW), lasted no longer than 60 minutes, and took place at home (people with advanced CKD) and on the telephone or in the hospital (health professionals). All participants gave written informed consent to participate.

#### Data analysis

Interviews were audio recorded and transcribed. NVivo 12 software (QSR International, 2018) was used to organize and manage the data, which were analyzed using thematic analysis.[35] Analysis was conducted by AW, using a critical realist approach, whereby it is acknowledged that an external reality exists that is knowable and that people's experiences are subjective. Analysis involved a 5-step process including "familiarization with the data," "generation of initial codes," "searching for themes," "refining and reviewing themes," and "defining and labeling themes." Emerging themes were discussed with team members (AEW, HLB, AM) to help identify potential errors, biases, and oversights. Consolidated criteria for Reporting Qualitative studies were followed.[36]

### Study 2 – User-centered iterative design of the YoDCA

Iterative drafts of the resource prototype were produced drawing on evidence and research findings gathered from developmental steps 1-5. To ensure rigor, accuracy, and understandable content, the resource was designed with project team members. At different iterations of the prototype, additional external stakeholder feedback on content, design, and comprehension was sought from expert patients, patient organizations, and health professionals in the United Kingdom and Denmark, to assess the decision aid's face validity and utility. Specific feedback was sought from kidney health care experts to ensure accuracy of statistical and technical procedural information. Feedback from all stakeholders was considered by the team and incorporated into further iterations of the resource. The final decision aid underwent a formal editorial process to improve health literacy levels, and a graphic design team enhanced its appearance. Health literacy was improved by using simple, unambiguous language, providing a glossary and explanation in the text of technical terms, and using decision maps to help people visualize the treatment options within the context of their worsening CKD by considering the visual layout of the information on the page. The Flesch–Kincaid readability formula estimated the United States grade level required to read the decision aid. This was calculated by using the average number of words per sentence and the average number of syllables per word, and to increase the meaningfulness of the score, the grade score is expressed as an age range.[37]

**Table 1.** Study Participants' Demographic Characteristics

| Age | Sex | Treatment Decision (Recorded in Medical Notes) | Ethnicity and Nationality | Underlying Condition(s)/Comorbid Condition(s) | Time Since Referral to Low Clearance Clinic (mo) | eGFR on Referral | eGFR at Interview |
|---|---|---|---|---|---|---|---|
| Late 70s | Male | Conservative care | White, British | Nephrectomy for renal TB, 1950 asbestos exposure plural plaques Hypertension | 5 | 16 | 15 |
| Early 80s | Male | Hemodialysis | White, British | Probable hypertension and age-related glomerulosclerosis | 14 | 9 | 10 |
| Early 80s | Male | Conservative care | White, British | Ischemic heart disease<br>Peripheral arterial disease<br>Long-standing hypertension | 7 | 17 | 23 |
| Early 80s | Female | Hemodialysis | White, British | Long-standing hypertension, Asymmetrical kidneys – right 7.7 cm, left 11.5 cm with reduced<br>cortical thickness right kidney and upper pole left kidney | 9 | 17 | 23 |
| Late 80s | Female | Conservative care | White, British | Unknown | 5 | 13 | 6 |
| Early 80s | Male | Conservative care | White, British | Type 2 diabetes mellitus<br>Right-sided heart failure | 28 | 17 | 8 |
| Mid 70s | Female | Conservative care | White, British | Etiology uncertain<br>Cardiac impairment<br>Atrial fibrillation<br>Hypothyroid<br>Polymyalgia rheumatica<br>Diabetic retinopathy<br>Hypertension | 21 | 15 | 20 |
| Mid 70s | Male | Conservative care | White, British | TIA 2014<br>Probable TIA April 2017<br>Gleason stage IV prostate adenocarcinoma<br>TURP 2014<br>Postoperative hydronephrosis<br>Possible polymyalgia rheumatica | 44 | 25 | 12 |
| Late 70s | Male | Hemodialysis | White, British | Intermediate solid lesion on MRI – no intervention<br>scheduled<br>Ischemic heart disease | 15 | 13 | 30 |
| Late 70s | Female | Conservative care | White, British | Ischemic heart disease<br>Hypertension | 43 | 17 | 9 |
| Early 80s | Female | Conservative care |  | Type 2 diabetes mellitus<br>Hypertension<br>Gout<br>Previous iron deficiency anemia<br>Low level of Vitamin B12<br>History of frequent UTIs | 13 | 12 | 10 |

*Abbreviations*: eGFR, estimated glomerular filtration rate; MRI, magnetic resonance imaging; TB, tuberculosis; TIA, transient ischemic attack; TURP, transurethral resection of the prostate; UTI, urinary tract infection.

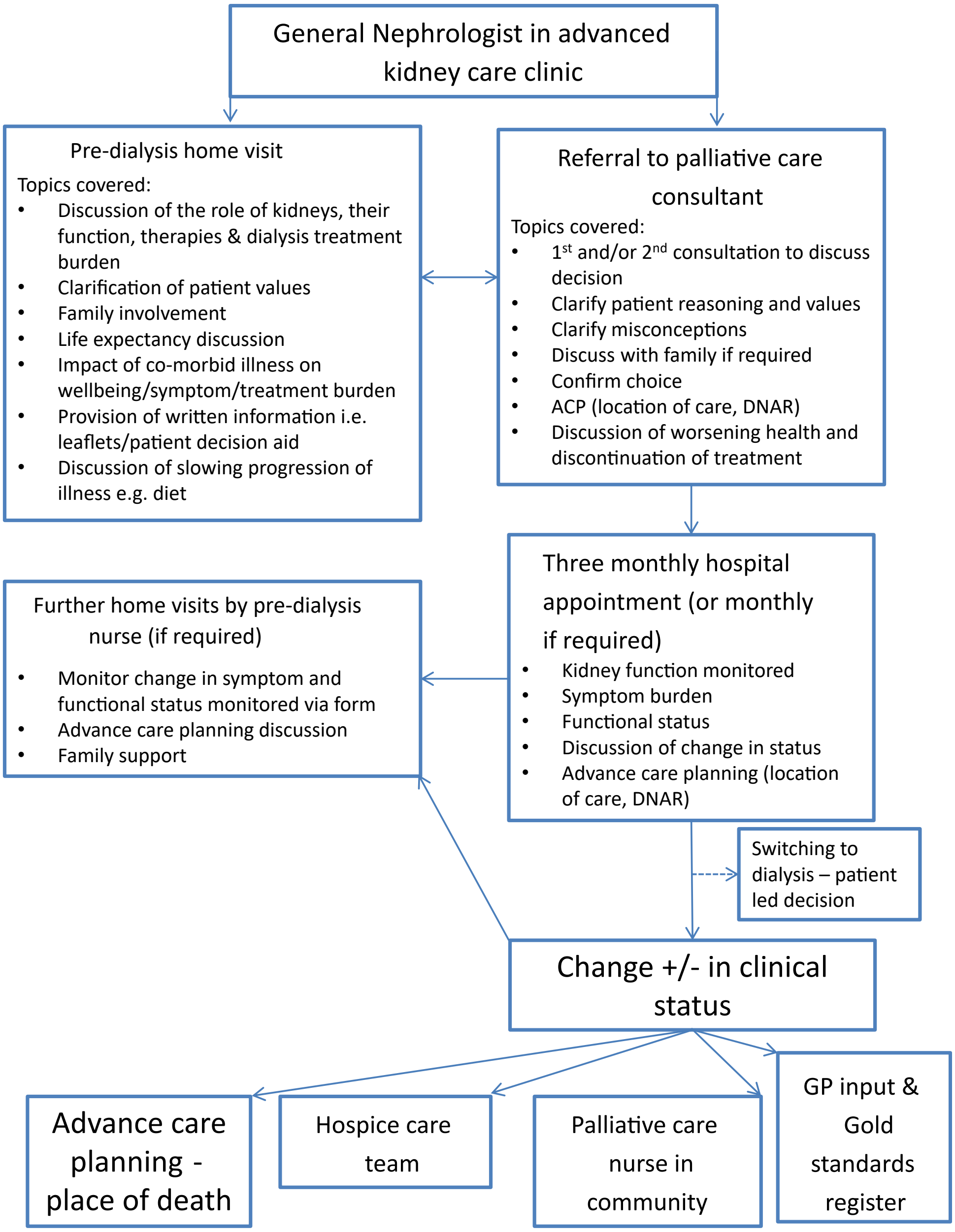

**Figure 2.** Care pathway for providing conservative care in renal study site. ACP, advance care planning; DNAR, do not attempt resuscitation; GP, general practitioner.

## RESULTS

### Findings: Study 1

Eleven people with advanced CKD and 8 health professionals were interviewed between May 2018 and April 2019. Patient characteristics are described in Table 1. Five were women; all were White, British, with a mean age of 82 (range 75-88); and from their medical notes, 8 had chosen conservative kidney management. Interviews were conducted with health professionals including advanced kidney care nurses and palliative, elderly care, and kidney specialists. Three themes are described below.

### *Transition to a Conservative Kidney Management Treatment Pathway*

Health professionals in all kidney units put considerable time and effort into preparing people for a change in their kidney care management as their illness worsens. Each service structured the management of people receiving conservative kidney management differently. Figure 2 describes the structure of a conservative kidney management pathway within one of the study settings.

In all units, people with advanced CKD either continued to attend the same kidney care management clinic, or attendance at a conservative kidney management clinic was within the same department. Health professionals perceived that this care option was minimally disruptive for their patients.

> "I think that this works because it's in the same clinic and it's not a huge step…there's a smooth transition, and it feels like we're part of the renal service that they've been in." [advanced kidney care nurse, setting A]

Some health professionals described conservative kidney management as a continuation of kidney disease management, rather than a distinct treatment choice.

> "I try not to label it as anything…[I say] we can care for you by doing everything that we're doing for you now through your medications, through your monitoring, through advice… in collaboration with your GP. So we can give you our full, active care as it is now, or we can escalate the care and add in a dialysis component or a transplant component." [consultant nephrologist, setting C]

This labeling of conservative kidney management as a continuation of kidney disease management was observed in the accounts of people with advanced CKD, who were largely unaware of what the term meant or the transition to a conservative kidney management pathway.

> "[Conservative kidney management is] probably a medical or technical term for saying, "Carry on as you are." [male patient, early 80s, hemodialysis]

The decision of people with advanced CKD to opt for conservative kidney management was framed in terms of the perceived burden of attending regular dialysis appointments, rather than the treatment attributes of conservative kidney management.

> "Yeah. I don't want to be dependent on anything really. I don't mind any operation and stuff, but I don't like the everyday… I don't think there's anything wrong with dialysis. I just don't want to be like that and committed forever" [male patient, late 80s, conservative kidney management]

Health professionals also reflected that they felt their patients with advanced CKD judged conservative kidney management in terms of an absence of dialysis.

> "I present it as an active treatment option, but I fully concede that, from the patients' point of view, some of them could think, "Oh, it's very nice to come along and talk to you girls each week," whatever. I guess, from their point of view, what they're doing is not dialyzing, if that makes sense" [consultant nephrologist, setting A]

Health professionals expressed difficulty in articulating the clinical reasoning underpinning the option of conservative kidney management as a management option for worsening kidney disease. They were aware the information they were providing was influenced by factors that people with advanced CKD experience: other conditions, frailty, age, personal circumstances, and a belief they would likely die from non–kidney-related causes.

> "It is a difficult decision to get over to people cos you're going to talk about treatments that are life-sustaining… but then saying, "Actually, it might not be. If you don't want it, we can do without it." [advanced kidney care nurse, setting B]

### Clinical and Social Indicators for Changing Kidney Care Management

People with advanced CKD described their kidney disease as a long-term health problem that worsened over time. They experienced several comorbid conditions, some related to the cause of their kidney disease, such as hypertension. Some were unaware of their kidney disease until it was detected incidentally via routine blood tests. They described that they were asymptomatic or experienced minor symptoms, such as tiredness and lack of energy, and expressed uncertainty about whether these were caused by their kidney disease, other conditions, or were related to the aging process in general.

> "I just thought, 'Oh, you're getting older, you're 89, and that's it. You're just getting tired.'" [female patient, late 80s, conservative kidney management].

People with advanced CKD also spoke about various medications that controlled their kidney disease symptoms and other conditions but were unable to identify which medication treated which illness. Health professionals discussed the role of symptoms in initiating changes to kidney care management plans. Some health professionals described symptoms of kidney failure so that their patients know how to recognize them and understood that some people with advanced CKD were unable to identify them, which made it difficult to identify a cue to initiate discussions regarding future treatment options.

> "…they're such slow, insidious symptoms that they tend to compensate and not realize, and you get those comments when they start dialysis or undergo transplantation, how poorly they were, they didn't realize at the time." [consultant nephrologist, setting C]

Health professionals described how they make explicit the symptoms of kidney failure with their patients so that they can identify them and seek medical help.

> "…Even the patients who are not [choosing conservative kidney management], who are thinking about dialysis, they will often say, "I only come every three months. How do I know it's got worse?" So I do run through the symptoms quite often with my patients so they know what they're looking out for." [advanced kidney care nurse, setting B]

Symptoms were also used to indicate that the health of people with advanced CKD was declining and that referral to services such as palliative care or a general practitioner would be appropriate.

> "And then the other thing is that, when their level is very low and they're getting lots of symptoms, then we talk about referring them to their local palliative care service because they can't wait three months between appointments." [advanced kidney care nurse, setting A]

Some people with advanced CKD reported restricted mobility and that this impacted their ability to carry out leisure activities, increasing their reliance on family and/or friends to maintain their lifestyle.

> "You find that, doing jobs inside, you can't do t'same [sic] as what you used to be able to do. I used to think nothing of going all round these windows and that all in one go, but I don't do it now." [male patient, early 80s, hemodialysis]

Maintaining regular clinic appointments for those receiving conservative kidney management enabled health professionals to get to know their patient's lifestyles, hobbies, and interests. The ability of people with advanced CKD to perform everyday activities was used as a trigger to change their kidney management pain. Reduced social interaction could indicate treatment should commence or that end-of-life was approaching and a palliative care referral was appropriate.

> "I've got a number of patients that are really into crown green bowling, and I know that they're well when they say, 'I've been', and then they're not so well when they're only watching it, and then, when they don't get there at all, then they must be more poorly. We talk about things like that, saying, 'Look how this has changed in six months.'" [palliative care physician, setting A]

### Preparation for End-of-Life Treatment and Care

People with advanced CKD varied in their desire to discuss what would happen to them as their illness progressed. Some reported acceptance of the prospect of dying and had discussed this with a health professional; others chose not to discuss this matter openly.

> "I've accepted the fact that I'm going to die. You've got to do. What can you do about it? Nothing."…She [the doctor] knows how I feel about it. I said, "I've come to terms with it." You can't put it off. [male patient, early 80s, conservative kidney management]

Health professionals felt they lacked the skills and confidence to engage in end-of-life discussions, particularly for those choosing dialysis.

> "I think it is an area that does kind of fall down… we don't talk to them about end-of-life pre-dialysis…they have high morbidity and high mortality, but they miss out on all the planning and the discussions." [advanced kidney care nurse, setting B]

Health professionals felt that this led to people with advanced CKD to have unrealistic expectations about the benefits of dialysis and that the option of discontinuing treatment and discussing end-of-life topics was raised infrequently during decision making consultations.

> "It's very difficult, but I think some [members of staff] will say, "So you can dialyze for years and years and years." I don't think [patients] ever see the end". [advanced kidney care nurse, setting A].

Despite this, those health professionals who did engage in end-of-life discussions felt that most people with advanced CKD were agreeable to discussing their end-of-life wishes and if they were not agreeable, were quick to indicate this.

> "I've learnt over the years…that often patients are much less anxious and stressed about talking about this sort of thing than we are. And it's us that have the difficult leap to make…If they're not, they'll soon say… But a lot of them really value the chance to talk about things that they've been worried about." [advanced kidney care nurse, setting A]

Some people with advanced CKD had specific questions about how their illness would progress, the option for stopping treatment and the experience of dying from kidney failure.

> "I don't know what the consequences are, how painful it is at the end…For example, if I decide not to have dialysis, at what point will I begin to feel discomfort? Nobody has ever told me this." [female patient, early 80s, hemodialysis]

If these questions were not addressed, once people had started on dialysis, health professionals spoke about the difficulty in initiating conversations about stopping treatment and end-of-life.

> "I guess the group that are getting missed are the ones that are on dialysis but not doing very well and sometimes are getting poorly and spending their lives in and out of hospital... People don't address that then cos it's easier just to say, "We'll see you on Wednesday," rather than, "Actually, this isn't working." [advanced kidney care nurse, setting A].

Others emphasized the importance of introducing end-of-life topics early on, and over a series of conversations as this facilitated revisiting the topic later.

> "I need to bring it up earlier so it's there." So in the first clinic visit…I will say, "One of the things we do in this clinic, as well as focus on you and your quality of life and your symptoms, is prepare for the future. That is called advance care planning, and that's something I'd like to bring up at the next clinic visit." [consultant nephrologist setting B]

**Table 2.** Active Components of the YoDCA

| Decision Support Technique | Function | Location Within Resource (Supplementary File 1) |
|---|---|---|
| Tips to encourage active patient management of kidney failure and slow its progression. | Places future treatments in the context of current kidney disease management. | Page 6 |
| Table of common symptoms of kidney failure. | Makes symptoms explicit to help people understand how their illness may impact on their wellbeing, develop an understanding that their illness may be worsening and may necessitate a change in care as symptoms increase. | Page 8 |
| Decision maps content and structure informed by clinical reasoning of health professionals in describing how their services provide options, how they reason about care plans when tailoring kidney management to a person's circumstance and changing disease state. | The decision problem is 'unpacked' to make explicit the tacit knowledge of kidney professionals about how kidney disease worsens over time, disease management plans change, and the longer-term decision options when current treatments stop working. | Pages 5, 8, 14, 18 |
| Treatment options and consequences – Conservative care is presented as an active treatment option with a structured care plan. | Reduces bias and helps clinical teams to articulate care plans for both options and shared consultations about which fits best into the life of the PwKF and what services can offer. | Pages 11, 12 |
| Attributes of each treatment are made explicit in tables to allow comparisons between options. | | Page 15 |
| Novel information to signpost treatment options as likely to be revisited and change over time, for example, to switch or stop dialysis options. | Shared understanding of disease trajectory, terminology about options, and decision making. | Page 13 |
| Signposting to future management decisions and end-of-life options, presented in an equitable way for both treatment options. | Shared understanding of disease trajectory, terminology about options, and decision making. | Pages 18-20 |
| Explicit decision guidance statements and the use of trade-offs. | Support the PwKF in thinking about the different types of decisions they make when managing their kidney in the context of their life and in considering which option bests suits their life. | Page 11&16 |
| | *Health literacy components* | |
| Content written to address 'people with kidney disease' rather than focus on the individual using the term – 'you.' | Use of the word 'you' encourages a power imbalance and assumes an expert is giving their opinions. Also assumes that it will happen to any person. People may disengage from information if they feel it does not apply to their circumstance. | Throughout document |
| Information about kidney disease and progression structured using the illness representations model of health and illness[39] | Promotes greater understanding of kidney disease and its progression. | Pages 4-8 |

*Abbreviations*: PwKF, person with kidney failure; YoDCA, Yorkshire Dialysis and Conservative care Decision Aid.

Similarly, health professionals described introducing the idea of discontinuing dialysis over a number of consultations or discussing end-of-life conversations at hemodialysis review clinics.

> So we might say… "It's clear that you could do with a bit more support at home."…You're just gently easing into the question of perhaps cutting back on your dialysis or stopping altogether. [consultant nephrologist setting C]

## Study 2 – Intervention Development

Sixteen iterations of the resource and over 20 versions of the decision map were produced. Initial drafts were developed by 2 project team members with expertise in decision science (AEW, HLB). Decision support techniques[38,39] and interview data informed components relevant to this health context that would support the health literacy of people with advanced CKD to integrate making care decisions based on what is important to their lives, as their kidney disease and health worsen (Table 2).[40]

Project team members including an expert patient partner in research, kidney nurses (in the United Kingdom and Denmark), a palliative care physician, palliative care health services researcher, consultant nephrologist (plus 5 international stakeholders [people with advanced CKD and academic and kidney health professionals]) gave further feedback on a prototype and/or specific elements of the resource. The UK Renal Registry and a national patient charity advised on statistical information. Feedback was positive and acknowledged the value in using the decision aid to supplement face-to-face consultations (Table 3). Changes to the decision aid as a result of feedback from all stakeholders included: referencing advance care planning

**Table 3.** Stakeholder Feedback on YoDCA

| | Stakeholder Comment |
|---|---|
| Content | *"So pleased to see both conservative care and switching/stopping dialysis included." [staff]* |
| Layout | *"What's really nice about this is that you've got each treatment option side by side by side so that you can compare each one." [staff]* |
| Supporting decision making | *"It is a well-structured booklet which aims to explain to 'new' kidney patients the assurance of being able to still have a meaningful life within the confines of kidney failure with options they will find comfortable to live with." [PwKF]* |
| Integration into services | *"I think that's important because we know they only retain about 30% of what we talk to them in a consultation. So to have something that they can say, "Oh, this is what they mentioned" or to jog their memory has got to help." [staff]* |
| Sharing information with family members | *"Do you think that that information gets passed on to relatives, that they read it as well? I think it does… I think a decision aid that gives them the opportunity to ask more questions and to raise these sorts of things." [staff]* |
| Readability | *"The tone throughout is very good and no 'fanciful words or acronyms' are used to confuse anyone making it is very understandable." [PwKF]* |

*Abbreviations*: PwKF, person with kidney failure; YoDCA, Yorkshire Dialysis and Conservative care Decision Aid.

earlier in the decision map, including information on "supportive care," reconsideration of nomenclature around "kidney disease," rewording the description of life expectancy, additional terms in the glossary, including information that considers the impact of multimorbidity on treatments, and rewording information about dying from kidney failure.

### Resource Description

The YoDCA is an open access booklet available via Kidney Research Yorkshire's website (https://www.kidneyresearchyorkshire.org.uk/yorkshire-dialysis-and-conservative-care-decision-aid/), (see Supplementary File). Its purpose is to (a) help people determine which treatment option (dialysis or conservative kidney management) suits them best in the context of fitting in with their lifestyle, and (b) support discussions with health professionals about transitions in kidney failure management including symptom control, identifying worsening illness, end-of-life care preferences, and treatment decisions that consider people's lifestyle, values, and individual medical history. The booklet is for use as part of routine kidney care education about treatment options, or independently with people with advanced CKD, families, and/or carers. The Flesch–Kincaid readability score is 9, and it is deemed readable by people aged 14-15 years.[37] The decision aid is included in the Decision Aid Library Inventory as meeting all International Patient Decision Aid Standards (IPDAS) criteria describing a decision aid and for lowering the risk of making biased decisions.[40] It is endorsed by the National Institute for Health and Clinical Excellence (NICE) as accurately reflecting recommendations on kidney replacement therapy and conservative kidney management.[25]

## DISCUSSION

This article describes research to identify stakeholder views on making decisions about conservative kidney management and dialysis when a person's kidney disease worsens. The findings informed the content, structure, and components included within a decision aid intervention for people with advanced CKD who are choosing between dialysis and conservative kidney management. The resource aligns with clinical guidance on providing an integrated approach to kidney (supportive) care management, conservative kidney management, and renal replacement pathways.[25] Information is presented in a way that represents the needs of all stakeholders to understand the pathway, separate care and management from key decisions and pathways, and share decision making about future kidney management. This resource uses both the clinical reasoning of health professionals making decisions about kidney disease management to structure the decision problem and health context, and the lived experience of people with kidney failure who are considering dialysis and conservative kidney management options. It provides a shared language to support consultations between people with advanced CKD and health professionals to discuss changes to their experience of health, to understand how they can actively manage their illness, and to think about changing treatments and future care plans that are important to them as their kidney failure worsens. Providing the details of decision aid development allows for transparency in the research process and ensures that the resource is based on the needs of all stakeholders in the decision making process.

Three key findings were integrated into the decision aid. First, the insidious nature of CKD makes it difficult for people to accept the need to make a decision about dialysis or conservative kidney management.[12] Our findings are congruent with other studies demonstrating that some people cannot identify symptoms of their kidney failure as distinct from the aging process and other conditions.[41] The resource makes explicit symptoms of kidney failure that may indicate declining health status and the opportunity to switch or adjust treatments over time. It is challenging to develop a decision aid for a chronic illness that gradually worsens when a person's social circumstances, lifestyle, treatment preferences, and service provision of treatment options may change from the point at which a care plan is agreed on and implemented.[15] This was addressed in our resource by presenting the decision problem within the context of a long-term illness, aided by a decision map, showing treatment pathway options alongside the different types of management decisions that health professionals make as a person's kidney disease worsens.

Second, we found a disconnect between kidney services' structure of transitions between management pathways and the ability of people with advanced CKD to recognize changes in their care plans. Although health professionals talk about their clinical reasoning for making conservative kidney management and dialysis decisions and the links to disease progression, people with advanced CKD who must make these decisions are focused on (not) taking up an option (dialysis) rather than managing their kidney disease in the context of their life and worsening health.[42,43] In YoDCA, we present conservative kidney management as an active treatment with attributes comparable to dialysis and distinct from end-of-life kidney care. Framing conservative kidney management as an active treatment option and making explicit a choice between options not only meets national guidelines[25] but is less likely to bias people's preferences[42] and may enable people with advanced CKD to feel supported and cope better with their ongoing kidney failure.[43] Notably, ensuring the same type of information is presented about each option is essential to providing balanced information to support people's reasoning. Our patient decision aids do not include pictures of treatments because few resources present the same type of picture for each option, or the same details, meaning the presentation is not equitable. Furthermore, as people have different experiences about health care and treatment, they are likely to respond differentially to pictures, which may bias their processing of information and reasoning. Third, people with advanced CKD reported uncertainty about how their disease would progress and wanted more information about discontinuing treatment and what would happen as their kidney disease worsens.[44] Health professionals recognized that the opportunity to discuss end-of-life and discontinuing treatment for patients choosing dialysis, is often limited. Health professionals also report feeling unskilled and unconfident and avoid conversations about prognosis and end-of-life for fear of upsetting their patients.[45] Despite this, older adults report a willingness to engage in end-of-life discussions, often doing so with their spouse and/or family member in the absence of a health professional.[46] Those health professionals in our study who did broach such discussions, reflected that people with advanced CKD were often less upset than they anticipated. YoDCA provides terminology and a way of reasoning about decisions acceptable to both people with advanced CKD and health professionals with experience in making these decisions. To make explicit future management decisions and end-of-life options, YoDCA presents this information equitably for both dialysis and conservative kidney management options (eg, in the decision maps).

Inherent to qualitative research is the small sample size. Findings must be interpreted taking into account the lack of diversity in the ethnic background of the participants; however, our patient participants are typical of those with kidney failure in terms of how they described their comorbid conditions, symptoms, conditions that led to kidney failure, and disruption to their everyday activities that they experienced.[47] Sample diversity may be improved by working closely with staff teams to understand the local population, producing study information in a variety of formats, provide information that challenges assumptions about taking part in research, and the use of translators to conduct interviews.

The perspectives of multiple decision makers making decisions between conservative kidney management or dialysis as kidney disease worsens were integrated into the decision aid intervention, YoDCA. Feedback from kidney units using the resource has been positive, and ongoing research is investigating the use of the resources "active ingredients," for example, the decision map, within consultations as part of a shared decision coaching intervention.

## SUPPLEMENTARY MATERIAL

### Supplementary File (PDF)

Yorkshire Dialysis and Conservative care Decision Aid (YoDCA)

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