

## CKJ REVIEW

# Decision aids to assist patients and professionals in choosing the right treatment for kidney failure

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## ABSTRACT

**Background.** Kidney services vary in the way they involve people with kidney failure (PwKF) in treatment decisions as management needs change. We discuss how decision-science applications support proactively PwKF to make informed decisions between treatment options with kidney professionals.

**Methods.** A conceptual review of findings about decision making and use of decision aids in kidney services, synthesized with reference to: the Making Informed Decisions—Individually and Together (MIND-IT) multiple stakeholder decision makers framework; and the Medical Research Council—Complex Intervention Development and Evaluation research framework.

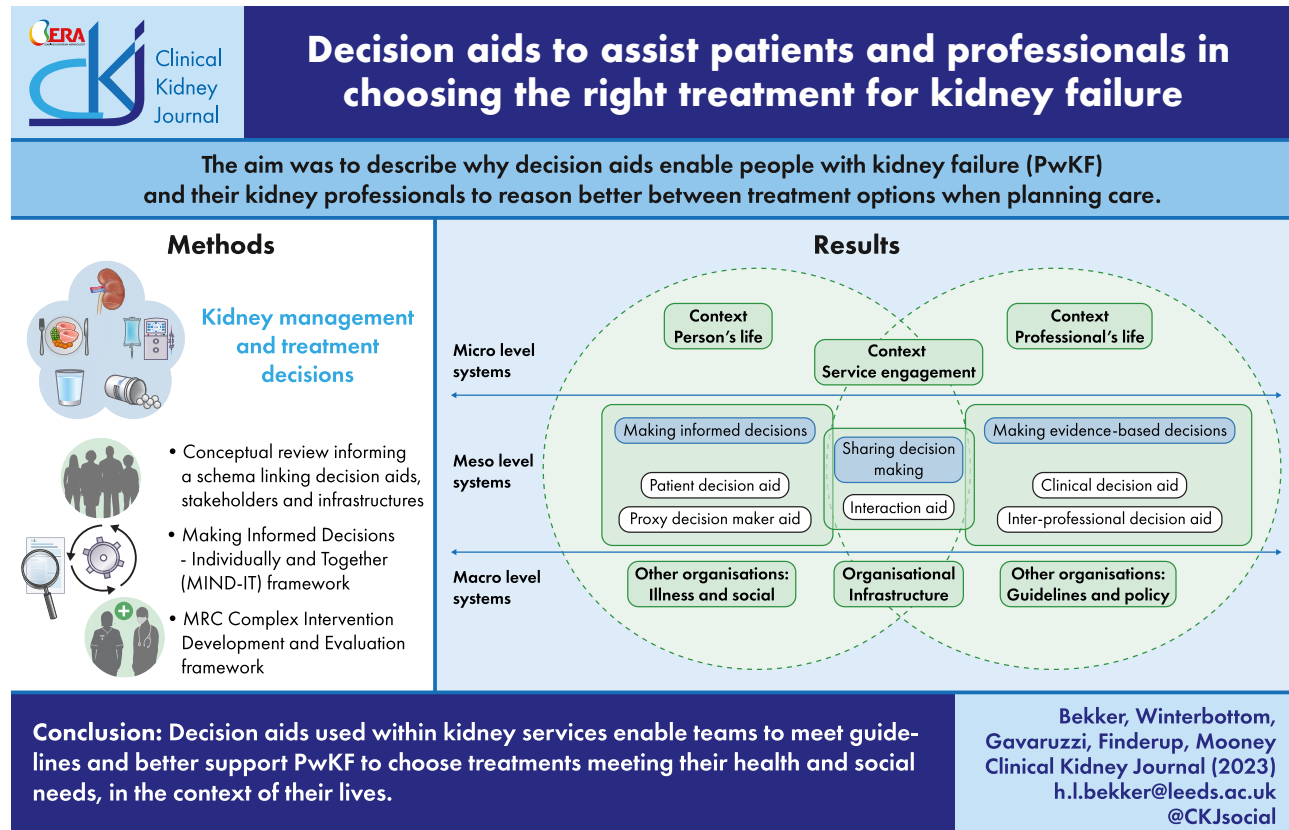
**Results.** This schema represents the different types of decision aids that support PwKF and professional reasoning as they manage kidney disease individually and together; adjustments at micro, meso and macro levels supports integration in practice.

**Conclusion.** Innovating services to meet clinical guidelines on enhancing shared decision making processes means enabling all stakeholders to use decision aids to meet their goals within kidney pathways at individual, service and organizational levels.

Received: 19.1.2023; Editorial decision: 8.6.2023

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## GRAPHICAL ABSTRACT



**Keywords:** kidney treatment, patient decision aids, shared decision making

## INTRODUCTION

This paper provides an overview of why and how decision aids support kidney professionals to involve people with kidney failure (PwKF) in choosing the most clinically appropriate treatment that fits best into their daily life. We describe the use of decision science to (i) analyse current practice and identify factors that boost or bias people's judgments when making decisions between options involving uncertainty and conflicting outcomes, and (ii) inform the structure and content of different types of decision aids developed in healthcare to support patient and professional decision making, individually and together.

We draw on research carried out internationally exploring how PwKF, their families and kidney professionals make treatment decisions along the care pathway, the effectiveness of resources used in kidney services to involve patients in their disease management, and studies developing and evaluating interventions to support patients in making informed, value-based treatment decisions. We refer to a 'decision map' as a way to develop a shared understanding between PwKF, their families and health professionals of discussions about conservative care, dialysis and treatment pathways in the context of making symptom management decisions for kidney failure as treatment needs and people's daily life change over time [1, 2].

We describe two theoretical frameworks for research and quality improvement activities to (i) understand variations in

patient and professional decision making about treatment decisions for kidney failure, (ii) design and evaluate patient decision aids (PtDAs) and shared decision making (SDM) interventions and (iii) inform integration within people's activities when managing kidney failure. The first framework is Bekker's 'Making Informed Decisions Individually and Together (MIND-IT)' intervention framework to help developers represent explicitly the different goals, reasoning and support needs of multiple stakeholder decision makers making the same healthcare decisions [3–6], and the second is the Medical Research Council methodological framework for developing and evaluating complex interventions in healthcare [7, 8].

We suggest next steps for research, quality improvement and practice to encourage kidney services to adopt decision aids in their usual practice, and investigate the impact on patient and service outcomes.

### SERVICE NEEDS TO INVOLVE PEOPLE WITH KIDNEY FAILURE IN MAKING THE RIGHT TREATMENT CHOICE

Kidney service frameworks outline the need for services to plan and deliver conservative kidney management (CKM) and end of life care (EoLC) pathways alongside established kidney replacement therapy pathways, i.e. haemodialysis (HD) or peritoneal

dialysis (PD), and kidney transplantation with a deceased or living donor [9–18]. This shift in guidance recognizes explicitly the increased complexity of services in managing kidney failure and challenges the efficacy of established treatments, as (i) patient populations have got older and people are more likely to have comorbidity or frailty issues [19–23] and (ii) advances in technology impact the evidence used to form clinical judgments about care [24–28]. Central to these guidelines is a requirement for services to ensure that patient education, counselling and resources enable PwKF to be involved actively with practitioners in making decisions between these care pathways [29–36]. There are sustained calls for services to change the way kidney professionals inform PwKF about treatment options and prepare them to manage their kidney disease [9–18]. However, these frameworks do not make explicit why current practice is not sufficient in enabling kidney professionals to support PwKF proactively in decision making along the kidney disease care pathway, or which educational interventions impact on practice.

There is by-service variation in the education programmes, counselling and resources provided to inform PwKF about treatment options [15, 21, 30, 31]. Leaflets are essential resources in kidney services, supplementing the advice given by the kidney team to support PwKF and their families in coping with their kidney disease [1, 2, 34–38]. However, leaflets tend to inform patients about an option or procedure to support self-management of symptoms, and its co-ordination of care within a local service [34]. In consequence, PwKF receive two to three leaflets at a time which provide descriptions of each option but do not help people compare across options, or make trade-offs to reach a decision about which option suits their social and clinical needs best [34]. Analysis of leaflet content shows that they tend to be difficult to understand, include judgments aligned to service delivery values, and miss out key information needed to support people to understand their health problem and engage with services along the trajectory of a long-term health condition [34–36]. Patients find exposure to inaccurate, seemingly contradictory and non-relevant information to be detrimental to their experience of care [37].

PwKF and kidney professionals find decision making about kidney disease management complicated and emotionally demanding [32, 37–48]. PwKF report being satisfied with their kidney care but needing more guidance in making treatment decisions about their kidney failure. Despite current education and communication practices, evidence shows consistently that PwKF are not aware of (i) the symptoms associated with having kidney disease or that indicate their kidney disease is worsening, (ii) the different types of treatment options for PwKF and the consequences for their longer-term kidney disease management and (iii) being involved as much as they want to be in making decisions between care pathways. Practitioners report a lack of confidence in their own ability to provide balanced and accurate details of options other than their specialist pathway (e.g. HD versus PD versus CKM and EoLC), and a lack of opportunity for training to broaden their expertise.

Integrating decision aids into kidney services can address these issues within current practice. Developing decision aids to support people to make reasoned or informed decisions between options requires an analysis of the decision environment, investigating the terminology, organizational structures, values, time pressures, constraints and decision making strategies relevant to people in this context [49–54]. Evaluating PwKF's and kidney professionals' experience of services and illness management with an awareness of how people make decisions [55–59], factors biasing judgments [60–62] and components boosting rea-

soning [63–68] helps identify current practices that facilitate, or impair, how people attend to relevant information, make judgments and reason between options. Enabling PwKF to choose the right treatment for their circumstances means ensuring accurate information about all options is accessible in advance of making choices, minimizing how service delivery leaks organizational or other people's values about options, and proactively supporting people to reason about why one option, compared with another, best meets their clinical needs and evaluations of fit within their life [65–67].

## FRAMEWORK FOR UNDERSTANDING THE FUNCTION OF DECISION AID INTERVENTIONS

Decision aids are interventions designed to support people in making hard decisions, such as those where there are uncertain consequences and options have multiple objectives [49–53]. Decision aids help people make decisions well by drawing on theories, methods and evidence from the decision sciences to analyse the decision context and problem, explain how people search and assimilate information during decision making [49–51], and identify what biases people's judgments and what boosts their reasoning [56–64]. Research is used to investigate factors supporting, or hindering, people's reasoning within specific decision environments, and identify components to enhance people's active thinking about the decision problem in differing contexts. The resulting findings are used to make judgments about the structure, content, delivery and implementation of decision aid interventions within the decision context [49–53].

Within healthcare, there are two specific contextual factors identified by the decision analysis literature that are likely to impact on how decision aid developers construct the structure, content and delivery of interventions in this context [49–51, 54].

Firstly, most healthcare decisions are made by multiple stakeholder decision makers, each with their own agency when making the same decision, and each with their own goals. This multiple decision-maker lens means that different decision makers represent and reason about the decision problem in different ways. The frame or scope of the decision problem needs active construction to make explicit and integrate the differences and similarities between decision makers' reasoning. Some 'co' approaches to healthcare and research [69–72] have similar aims in exploring differences in stakeholder perceptions, skills and needs, but tend not to address explicitly issues around decision-maker agency, goal and decision frame [50]. Figure 1 illustrates the MIND-IT framework for developing multiple stakeholder decision-maker interventions in healthcare [3–6]. This framework helps developers consider (i) the different goals of each stakeholder when making the same decision, (ii) the components needed to support the individual reasoning of the PwKF, kidney professional and other people involved in the life of the PwKF and delivery of their care, (iii) the interaction points within the service infrastructure enabling shared understanding and reasoning together about options and (iv) the mechanisms to explain how the intervention may impact on individual decision maker actions, decision maker interactions and context infrastructure from each decision maker's perspective.

Secondly, the far-reaching consequences of making healthcare decisions means there is seldom a one-off discrete decision and, importantly, choices made are likely to impact on people's health state [50]. The challenge for those developing decision aids is how to frame or structure the decision problem

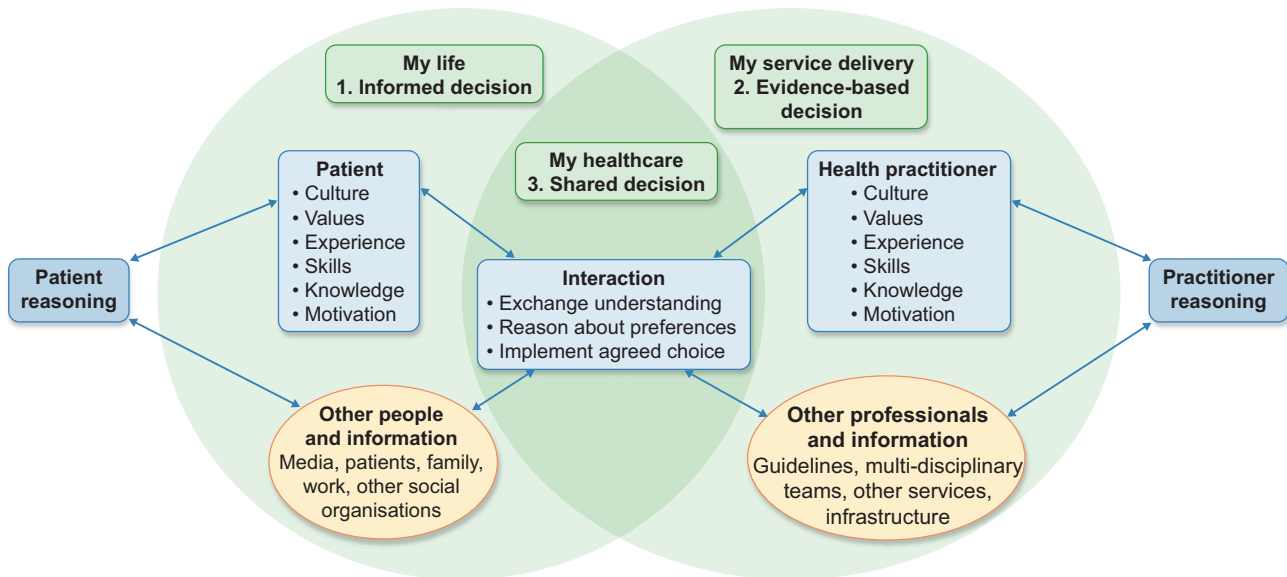


Figure 1: Making informed decisions individually and together (MIND-IT) in healthcare framework [5, 6]: developing interventions supporting multiple stakeholder decision makers [3].

when there are several nested or linked decisions in a management pathway [1, 2, 73–76]. In the context of a chronic health problem that worsens over time, decision aids need to link these nested decisions with the ongoing monitoring and management of the health problem as it, and a person's life, change over time. Figure 2 is a decision map representing the treatment pathway options for PwKF alongside the different types of management decisions kidney professionals make with PwKF as their kidney disease worsens, the effectiveness of treatments to manage symptoms lessens, and their wellbeing and lifestyle needs change over time [76–78]. This figure has been found to be acceptable to PwKF and kidney professionals when sharing their understanding, reasoning and trade-offs between options in the short- and long-term planning of care [77, 78].

## DECISION AIDS SUPPORTING PATIENT ENGAGEMENT WITH HEALTHCARE

The purpose of decision aids is to improve the process of making decisions, encouraging people to consider accurate information about all options and their consequences without bias, evaluate this information in accordance with their values, make a decision based on trade-offs between the options evaluated, and take steps to implement the choice [58, 64, 67, 68, 79, 80].

When developing, implementing and evaluating decision aids to support patient engagement with healthcare, it is useful to think of them as complex interventions [7, 8, 54], involving multiple decision makers (e.g. patients, family members, professionals), each with different goals, values, knowledge, skills and motivations (see Fig. 1) requiring differing types of interventions to meet their needs [69–72], and impacting differentially on, and within, the healthcare infrastructure. The types of decision aids developed to support patient engagement with healthcare include the following:

- Patient decision aids (PtDAs) support people to make informed, value-based decisions between healthcare options [67, 68]. The International Patient Decision Aid Standards (IPDAS) collaboration [80, 81] provides research-informed

guidance on PtDA development, implementation and evaluation [82, 83] such as providing balanced, accurate and accessible facts and figures for all options [84–90] and prompts to elicit people's values [91], being aware of the biasing role of patient stories [92, 93], the development process [94, 95], implementation in practice [96–98] and evaluation methods [99–101]. PtDAs can be integrated into care pathways and delivered either within [102] or outside [103, 104] a consultation to facilitate patient reasoning and engagement with healthcare [65]. There are established short courses run by professional organizations to support inter-professional training and PtDA development, evaluation and implementation interventions, and their role in supporting shared decision making communications between patients and professionals [69, 105, 106].

- Proxy decision maker aids are developed to support a proxy in making healthcare choices with, or on behalf of, a person receiving healthcare who may not be able to participate fully in the decision making process [107–112]. Although some PtDAs enable friends and family members to understand the context of a person's treatment decision, and are often shared by people making the decision when integrating treatments within their daily life [74], the function of a proxy decision maker aid is different. The proxy decision maker aid must be developed to meet the needs of the proxy to make a decision as an advocate for a person receiving the relevant healthcare. The structure and content of such resources are likely to vary according to the relationship of the proxy with the person receiving healthcare (e.g. employed carer, family member or guardian), the health problem and the type of decision. There is less guidance, and more uncertainty, about the components required within a 'good' proxy decision maker aid [111].
- Decision aids supporting patient and professional interactions directly within healthcare pathways to enhance the exchange of information about people's understanding, reasoning and preferences from their different perspectives are most frequently developed as decision aids for use in consultations to enhance SDM communications between patients



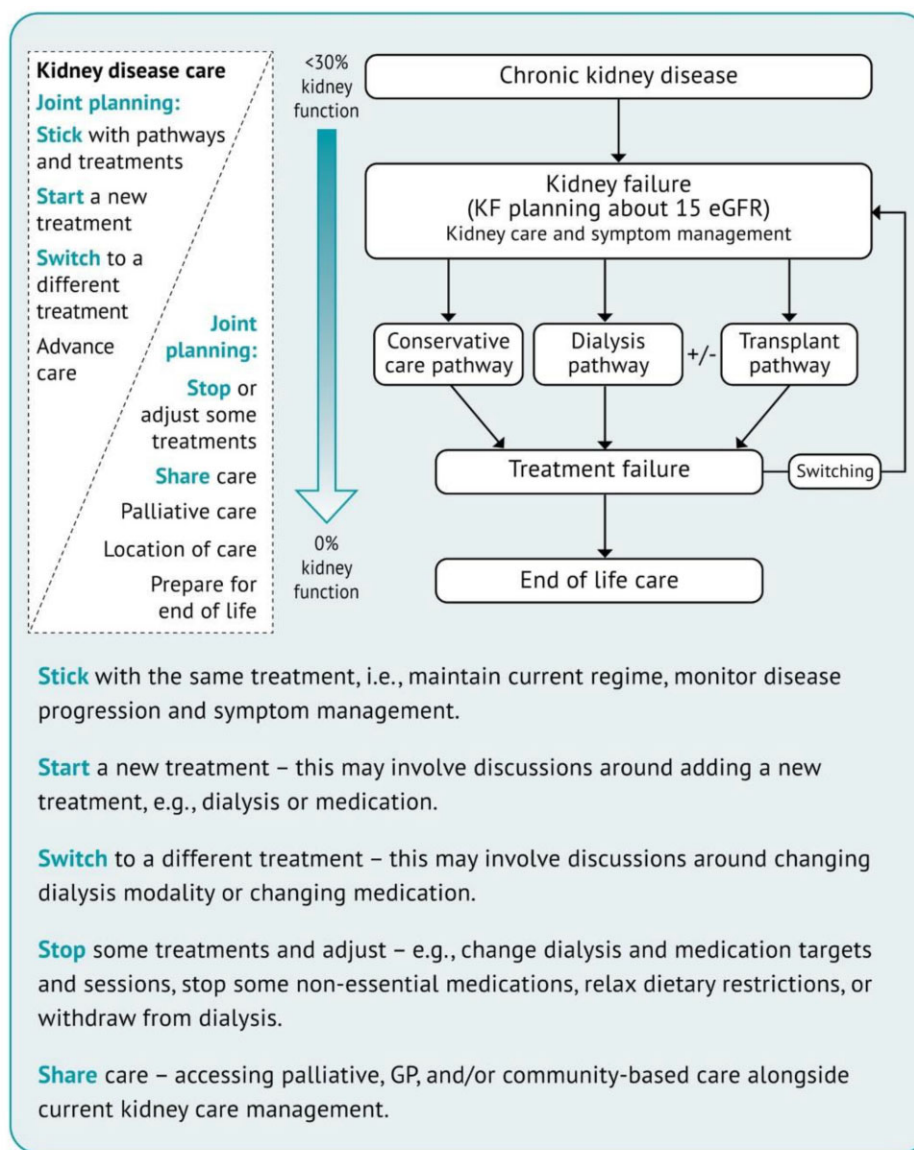


Figure 2: Decision map linking the decision problems with care pathways and worsening kidney disease [1, 2, 76–78].

and professionals when collaborating on choosing health-care [113–121]. There are over 40 models of SDM identifying at least 24 components associated with a SDM process [117], with little consensus internationally on which interventions improve professionals' support of patients in making the right decision [115, 117, 119]. Interventions include the following resources to improve patient–practitioner SDM processes: patient prompts for participation in consultations (e.g. Ask 3 Questions [122, 123], BRAN leaflet [124]); brief decision aids for practitioners for specific decisions (e.g. option grids [125]), evidence summaries and questions to elicit patient preference during a consultation (e.g. decision boxes [126]); and training for professionals in risk communication, SDM and decision aid development [127–130]. There is potential for decision aids to be developed for other touch points within the service infrastructure to support interactions between patients and professionals, and the SDM process, such as a re-design of letters pre and post consultations.

- Clinical decision support (CDS) enhances clinical reasoning and practitioners' ability to deliver evidence-based, valued healthcare [131–133]. Clinical guidelines based on current evidence, computer-based decision support systems and algorithms generated from routinely collected data to personalize care and management plans impact indirectly on the consultation, and patient choice of treatment, via practitioner judgments. Adapting these tools for use in the consultation may support practitioners to share their clinical reasoning explicitly with patients, and enhance the SDM process.
- Inter-professional shared decision making training resources are designed to support collaborative teamwork within and between multi-practitioner teams to deliver a coherent approach to SDM with patients in the workplace [115, 134, 135]. To support patients in making a decision that is right for them, there is a need to investigate further the impact of healthcare organizations and delivery on SDM (e.g.

multi-disciplinary team meetings, referral within and outside organizations).

## WHY PATIENT DECISION AIDS ENABLE KIDNEY SERVICES TO SUPPORT PEOPLE WITH KIDNEY FAILURE'S TREATMENT CHOICES

This section describes components within PtDAs supporting PwKF to make informed, value-based treatment decisions as their kidney disease worsens. Reviews identify about 30 publicly available decision aids [1, 2, 44, 47, 74–78, 136–154] that have been developed and evaluated from research and quality improvement projects in kidney services. Some decision aids are developed by adapting templates or pre-existing frameworks, and others through research with PwKF and kidney professionals to inform the resource's structure, content and implementation [1, 2]. These resources vary in content, responding to local needs, integration within services, and developers' clinical goals and theoretical approach. Some see decision aids as supporting the communication process between patients and health professionals, enhancing the skills of professionals to provide accurate information about all treatment options, their risks and benefits, and of patients to discuss explicitly their experience of illness, preferences for options and values, i.e. the 'Evidence-Based Medicine—Involved Patient' approach [117–119, 148]. Others see them as supporting the reasoning of patients and professionals to evaluate accurate information about all options and consequences in the context of the person with kidney failure's life, and to share their understanding of the trade-offs between clinically and personally relevant outcomes that are important when planning care together, i.e. the 'Multiple Stakeholder Reasoning—Shared Understanding' approach [113–117, 126–129]. The evidence from those evaluated indicates that integrating PtDAs within kidney pathways supports PwKF to make informed, value-based treatment decisions about dialysis and shared decisions with their family and kidney practitioners [2, 74, 137–144, 149, 151, 152, 154–157].

Our approach to developing decision aid interventions for services in the UK and Denmark is guided by (i) decision-science methods to analyse the decision contexts of stakeholders and identify the core elements of the decision problem [49–54], (ii) reviews of services and clinical guidelines supporting the communication processes between practitioners and PwKF to problem solve and plan care that meets the needs of individual PwKF [6, 9–24], (iii) theoretical frameworks representing the introduction of new practices to support active reasoning between management pathways and treatment options as complex interventions that impact on multiple stakeholders' reasoning and service infrastructure [3, 7, 8, 115, 158–162], (iv) research methods to identify the mechanisms in current practice that bias, and boost, PwKF's treatment decision making, and assess the impact of decision aids on enhancing reasoning [58, 73, 92, 93, 163, 164] and (v) the IPDAS collaboration resources guiding the content development and evaluation of PtDAs [80–101].

We draw on resources developed from our research to illustrate components within PtDAs supporting PwKF to make the right treatment choice. These resources are publicly available and endorsed by third party organizations as meeting standards for decision support (<https://decisionaid.ohri.ca/dali/> 2015; 2020) in relation to dialysis and CKM pathways (<https://www.nice.org.uk/about/what-we-do/our-programmes/our-endorsement-programme-has-now-closed#current-endorsed-resources> 2015; 2020). We refer to components within these resources to

illustrate how decision aids can be used to help people think actively about treatment decisions and make trade-offs about what is important to them in terms of the clinical and personal consequences of the available options when planning care with kidney practitioners. Table 1 outlines the active ingredients included in our resources that reduce bias and boost the reasoning of people using these PtDAs, and that support PwKF to engage with sharing their decision making with kidney teams. The resources are:

- The 'Dialysis Decision Aid' (DDA)—available since 2015 (Kidney Research UK; <https://kidneyresearchuk.org/wp-content/uploads/2019/05/KR-decision-Aid-DOWNLOAD.pdf>) developed from the Yorkshire Dialysis Decision Aid (YoDDA) research team [74, 76] accessed directly by PwKF and family members to support decisions about which dialysis option best suits their daily life, and UK renal services to support their education sessions with PwKF; used as part of continuing professional development and peer educator training to illustrate ways of supporting PwKF to make informed decisions between dialysis options. In addition, the YoDDA research informed the three decision aids for PwKF developed by the NHS Right Care Shared Decision Making programme (2012–17) (available via [sdm.rightcare.nhs.uk](http://sdm.rightcare.nhs.uk) between 2013 and 2018); Bekker was commissioned to provide the decision science expertise to the team developing 37 interactive web-based PtDAs, and the team training NHS staff in SDM skills and assessing its impact on patient experience of SDM (the SHARED questionnaire) [138, 165, 166].
- The 'Dialysis Choice' decision aid—available since 2020 (Aarhus University Hospital, Denmark; [https://e-dok.rm.dk/edok/editor/AAUHNHNSF/vLookupUpload/ATTACH-RMAP-BT4EF6/\\$FILE/Dialysis%20Choice%2027082020.pdf](https://e-dok.rm.dk/edok/editor/AAUHNHNSF/vLookupUpload/ATTACH-RMAP-BT4EF6/$FILE/Dialysis%20Choice%2027082020.pdf)); accessed via Danish kidney services as part of an SDM education session; implemented within Danish services using decision coaching skills training with kidney doctors and nurses [139, 140, 143, 144].
- The 'Yorkshire Dialysis and Conservative Care Decision Aid' (YoDCA)—available since 2020; accessed directly by PwKF and family members (Kidney Research Yorkshire; <https://www.kidneyresearchyorkshire.org.uk/yorkshire-dialysis-and-conservative-care-decision-aid/>); used as part of continuing professional development and peer educator training to support PwKF to make informed decisions between renal replacement therapy and CKM pathways in the UK and Denmark [75, 77].
- The 'Difficult Conversations: Talking with People about Kidney Failure, End of Life and Advance Care Planning' booklet—available since 2022 (Kidney Care UK; <https://www.kidneycareuk.org/health-professionals/difficult-conversations/>); accessed directly by kidney practitioners seeking guidance on talking with PwKF about care towards the end of life; currently being integrated into UK and Danish kidney teams through the development of skills training [78].

### Component 1—describing the health problem

To make reasoned decisions between kidney treatments, PwKF need an understanding of kidney disease within the management context and how this changes over time [49, 50]. PwKF report a need for general information about kidney disease, its symptoms and prognosis, how treatments work to manage

Table 1: Linking active ingredients within PtDAs that reduce bias or boost reasoning.

	DDA [76], page no.	Dialysis choice [143], page no.	YoDCA [77], page no.
Decision problem(s) defined (boost health literacy and reasoning)	2, 16, 20, 28	3, 4, 5, 7	2, 9, 13, 14, 18
Health problem(s) and symptoms described (boost health literacy and reasoning)	1–15	4–5	4–8
Kidney disease management described (boost health literacy and reasoning)	9, 26–28	5 (within consultation prompt)	5–8, 11
Balanced, accurate details about pathways (reduce bias and boost health literacy)	16–18, 28	6	9–13
Balanced, accurate details about options (reduce bias and boost health literacy)	8–34	6–11	9–13
Navigation through PtDA (boost engagement with information)	6, 7, 19, 35, 41	2, 3, 4, 7, 14	3, 4, 9, 14, 18, 21
Information summary and decision oversight (boost thinking and health literacy)	13, 16, 20, 21, 28, 30–34, 36–37	3, 5, 6, 12, 13	5, 8, 9, 12, 14, 15, 18
Value and evaluation prompts (boost value-based reasoning and trade-offs)	24, 25, 36, 38, 39	11, 14	11, 13, 16
Decision guidance (boost active thinking and trade-offs)	16–18, 20, 40	4, 6, 15	13, 16, 18–20
Shared reasoning—family/kidney team (boost shared reasoning and care planning)	10, 12, 15, 24, 25, 29, 40	(Within consultation training)	5, 17, 20
Reducing bias in written information	Applied to whole resource	Applied to whole resource	Applied to whole resource
Neutral language—no judgments (e.g. pros/cons, low/high as defined by staff)			
Options presented actively (e.g. conservative management, not non-dialysis)			
Same type of information used for all options (e.g. photos, consequences)			
Quality indicators in written information	Applied to whole resource	Applied to whole resource	Applied to whole resource
Readability of text: 12–14 years of age (literacy)			
Glossary of terms (literacy)			
Consistency in risk presentation (numeracy)			
Inter-professional team (reduce bias/increase clinical utility)			
Involvement of PwKF and family (reduce bias/relevance to PwKF)			
Conflict of interest/funding (reduce bias)			
Clinical evidence and guidelines (reduce bias/increase clinical utility)			
Evidence of PwKF's experiences (boost reasoning/relevance to PwKF)			
Publication date (relevance)			
Research informed and evaluated (relevance)			

kidney disease and managing kidney disease within people's daily lives [13, 15, 41, 30–32, 45, 46, 145]. Information or education about kidney disease and its management appears to be given informally within consultations tailored to the needs of individual PwKF and the expertise of the kidney professional. Clinical guidelines and training update kidney professional expertise in managing people's worsening kidney disease and integrating new treatments into clinical practice [10], but no guidance is provided on what information helps people make sense of their kidney disease. PtDA development standards [80–84, 94, 95] state that the health problem should be described, and provide guidance to enhance generic literacy and numeracy [84–87, 89–91], but little attention is given to what details resources need to enable reasoning about a health problem and engagement with their kidney disease management in the broader clinical context [93].

The Self-Regulation Model of Illness Cognition and Behaviour, also known as the Common Sense Model or Illness Representation and Coping Theory [159], provides an explanation of how people make sense of their illness and reason about ways to manage it over time. We use this framework to identify elements needed to support people's understanding of their kidney disease and its management, and their reasoning about treatment within the context of their lives. Our resources draw on evidence about and descriptions of kidney disease and its management from clinical guidelines, research on how PwKF and professionals manage and cope with kidney disease, existing resources and multiple stakeholder PtDA development teams to populate our

descriptions of kidney disease and its management. The content of these descriptions is structured to ensure accurate and accessible information about the following elements is included:

- Identity—provide a label for the illness, and describe its symptoms.
- Cause—explain the cause of the illness, and symptoms.
- Timeline—describe whether or not the illness is acute or chronic, and its duration.
- Consequence—describe the impact of the illness on people's physical, social and psychological wellbeing.
- Control—how to manage the illness, and how treatments work.

By adapting this framework for health problems arising from having a chronic disease, rather than a curable illness, we provide an accurate and relevant description of the health problem, promoting a shared understanding of kidney disease and its management over time acceptable to PwKF, family members and kidney professionals. To support a shared understanding of other stakeholder perspectives, developers need to integrate evidence from different sources to address these core elements, making explicit the links between clinical terminology and health service frameworks, and experiences of engaging with kidney services and managing kidney disease in daily life [93]. For example, many terms used clinically for the different stages of kidney disease that are central to clinical judgments are not helpful labels to PwKF. Our patient partners identified the label 'chronic kidney disease' as meaningful when talking



Figure 3: Picture prompts to discuss symptoms during treatment decision making consultations [144].

about health problems associated with a loss of kidney function and ‘established kidney disease’ for health problems associated with failing kidneys. These labels were acceptable to both PwKF and kidney professionals as a way to recognize that the kidney disease is getting worse, representing a transition point in planning care. PwKF found it helpful to know about the range of symptoms associated with kidney disease, what caused them and how they are managed [74]; kidney nurses found the visual prompts of symptoms [144] helpful when talking with PwKF about their kidney disease management (see Figs 3 and 4). The timeline and consequence elements enabled the integration of acceptable information about kidney disease worsening, treatments failing and signposting to advance care plans, palliative options and EoLC.

### Component 2—describing the decision problem

Essential to the design of PtDAs is a description of the decision problem [49–51]. The updated IPDAS review papers [81] provide guidance about PtDA development processes [95], using evidence to inform content [87], ensuring a balanced presentation of options and their consequences [86], describing risk and uncertainty [84, 85], eliciting patient values [91], decision guidance and coaching [97, 98], and implementation [96]. However,

little detail is provided on how developers should identify and structure the decision problem to support reasoning about relevant treatment options and their consequences in the context of managing a health problem [54]. The clinical context for managing the disease and symptoms of PwKF is complex, with many types of clinical decisions, across different care pathways and in conjunction with other health needs. Providing accurate and balanced information about all available options without framing the decision problem is unhelpful to PwKF [120, 164] and may explain why some studies report PwKF being overwhelmed by information. In addition, this approach lacks clinical utility for some kidney professionals as it is seen as incongruous with judgments about the effective management of PwKF based on their specific disease and health profile.

Through our decision aid research for kidney failure treatments, we developed decision maps from analysing [74–78]: how PwKF make decisions between dialysis modalities, and conservative care and dialysis; and how kidney professionals make clinical judgments about conservative care, dialysis, transplant options, palliative options and EoLC when managing PwKF. Our analysis of the context of managing long-term conditions with changing health states generated five decision types used by people when reasoning about healthcare options and management plans (see Fig. 2), which are known as the ‘Five Ss’:





Figure 4: Picture prompts to discuss what is important to people during treatment decision making consultations [144].

sticking with the same treatment regimen, starting a new treatment (or stepping-up treatment), switching to a related treatment, stopping a treatment and sharing care with another type of health professional. Explicitly embedding these decision types throughout our resources helps PwKF and kidney professionals share their understanding and views about the types of decisions to make, future treatment options and changes in health states, within the context of their current management and experience of illness.

The decision maps provide a way to represent the pathway and treatment options in the context of managing worsening kidney disease that is acceptable to PwKF, family members and kidney professionals in both UK and Danish renal services. The maps provide a structure that enables the decision problem to be represented (e.g. decisions between dialysis options), associated or nested decisions to be signposted (e.g. switching or stopping dialysis) and awareness of other options to be made explicit (e.g. transplant) (Fig. 5). We use the decision maps throughout our PtDAs to guide people through the resource; they highlight where PwKF are in the process of making a decision between options, and how this decision problem fits into the kidney disease management context. This visual summary provides a prompt for PwKF and kidney practitioners to share their understand-

ing about other options or pathways, clarify reasoning about the best option at this point in time and discuss implications for subsequent options.

Once the decision problem is defined, the PtDA has a purpose, for example, to support decision making between (i) conservative care and dialysis pathways, (ii) dialysis options, (iii) switching or stopping dialysis options, (iv) dialysis and transplant pathways, (v) living or deceased donor transplant options and (vi) kidney disease treatment and EoLC options. The PtDA can be populated with accurate information presented in a way that minimizes the cognitive effort needed to process details, reduces bias, boosts active thinking, encourages people to consider what is important to them and prepares them to discuss their reasoning with family and kidney professionals [1, 2, 34, 35, 74–78].

Our PtDAs include prompts enabling PwKF to think explicitly about their reasons why one option suits their daily life better than another. When referred to within consultations, these prompts enable PwKF and kidney professionals to share their reasoning about options and consider the trade-offs when planning care (Figs 6 and 7). When integrating PtDAs into practice, additional resources to support kidney professionals' reasoning within their teams may be needed, for example, a CDS resource

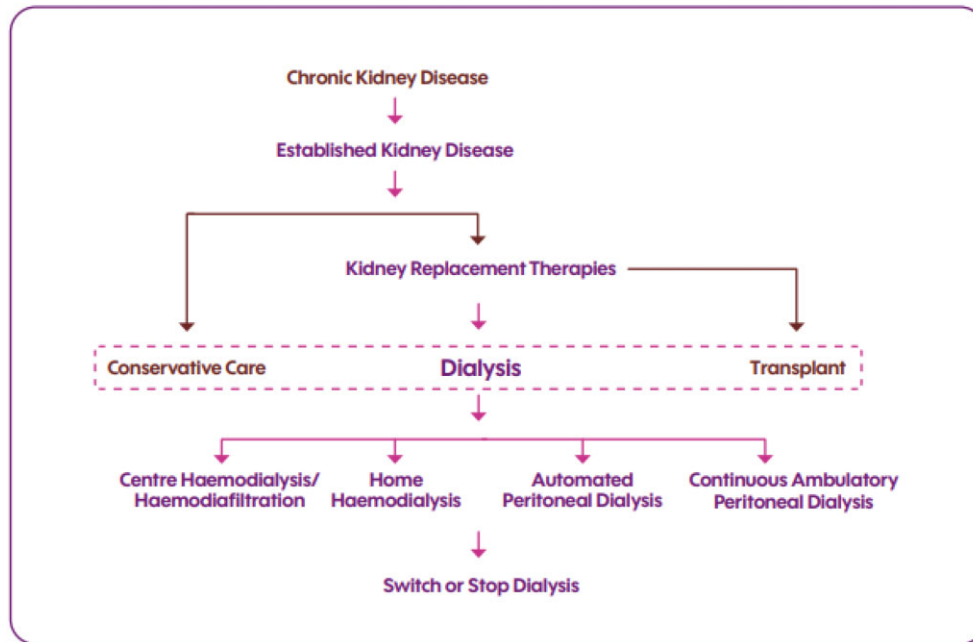


Figure 5: Decision map for dialysis options in the context of treatments for people with kidney failure [76].

**4. Which dialysis treatments do you think will fit best into your life, at this time?**

Tick one circle for each treatment.

	Not at all	No Maybe	Unsure	Yes Maybe	Yes Definitely
PD Continuous Ambulatory	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
PD Automated	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Home HD	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Centre HD/HDF	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Figure 6: Prompt to share reasoning about preferred dialysis option [76].

to aid clinical reasoning and explanations for trade-offs between the clinical and social needs of PwKF (Table 2), and targeted decision coaching communication skills resource [6, 78].

### Component 3—implementing decision aids within kidney care pathways

Essential to implementing complex interventions within practice are (i) an understanding of the context within which these complex interventions will be integrated, (ii) an awareness of

the different components or active ingredients within the intervention and (iii) an investigation of the barriers and facilitators to the adoption of different components by multiple stakeholders across different services within healthcare systems [7, 8, 40, 49, 50, 158, 161, 162]. Reviews of decision aid research identify the following as mechanisms associated with their integration into practice [167–169]: co-production of decision aid content and use in the pathway; training health professional teams in informed decision making and SDM awareness and communication skills; preparing and prompting patients to

## My Trade-offs Between Conservative Care and Dialysis Pathways

Managing EKD and its symptoms means people fit daily treatments, visits to kidney units, and changes to diet and fluid routines into their lives. People decide on a pathway by balancing judgements about their kidney function and well-being with their feelings about what is most important in their lives now and for the future [20]. An example of a trade-off might be thinking about what is more important to you in your daily life now, as your kidney disease gets worse:

- The conservative care pathway means a chance to do daily activities (e.g. hobbies, family and pets, leisure and holidays) with fewer regular medical routines, until there is no kidney function left
- The dialysis pathway means fitting an extra set of medical procedures and routines around daily activities (e.g. hobbies, families and pets, leisure and holidays), with a chance of lengthening life when there is no kidney function left.

Given what you know about your EKD, and your reasons for and against each pathway (page 13), circle the answer for each option that best matches how you want to manage your EKD:

Table 6: Thinking about which pathway will suit me best

Conservative care pathway	Yes	No	Unsure
Dialysis pathway	Yes	No	Unsure

Figure 7: Decision guidance supporting trade-offs between conservative kidney management and dialysis options [77].

engage with resources; senior-level endorsement and support for changes in practice; and measurement demonstrating improvement in service delivery and patient experience. Even when these mechanisms are adopted, kidney services vary as to whether or not they adopt decision aid interventions in their practice [74, 148, 169]. Below are observations from our experience that helped sustain the use of our decision aids in practice:

- Integrate within existing practices—PwKF already have ways to seek support to manage their kidney disease in their daily life, and professionals have established methods of involving PwKF with diverse needs effectively in their kidney disease management. Our interventions are designed to complement or enhance existing ways in which PwKF and kidney professionals engage with services by (i) improving the quality of the information used to inform PwKF about treatment options and (ii) providing additional skills to scaffold difficult conversations between PwKF and kidney professionals to share reasoning about options when planning care. Services integrate these resources in different ways to innovate their offer, building on their expertise and current practices to engage PwKF in making choices that best meet their clinical and social needs. Working with individuals and organizations who are finding innovative approaches to enhance their service delivery and experience of care is essential to integrating decision aids in services to innovate what they offer through different organizational structures, and identifying additional resources to address other unmet needs.
- Facilitate access to resources via different pathways for dissemination—our decision aids can be accessed directly

by PwKF and kidney professionals when searching for ways to innovate practice. Our decision aids are endorsed by kidney professional and PwKF charitable organizations, and signposted within service guideline documents and decision aid repositories. Our decision aid research is disseminated via professional educational materials (e.g. workshops, conference presentations and peer-reviewed publications) and used to inform kidney professional training. Having feedback from all those individuals and organizations involved in supporting PwKF in making treatment decisions is essential to updating these decision aids and ensuring their relevance across clinical and social contexts, and infrastructures.

### IMPLICATIONS FOR KIDNEY SERVICE GUIDELINES, RESEARCH AND QUALITY IMPROVEMENT

After almost 30 years of research, decision aid resources are seen as supporting services to engage people proactively in their health and illness management [119]. However, the field needs to evolve as we investigate the complexities of how and why these multiple decision maker interventions work within the health-care context. It is essential that services are able to recognize and replace any of their education practices that may still be biasing the judgments of PwKF when making treatment decisions, and discouraging them from evaluating relevant information of importance to their daily life (Table 1). Kidney services are likely to benefit from integrating patient decision aids within practice, one of the few types of generic resources known to

Table 2: Example of a clinical reasoning prompt linking service guidelines with PwKF's clinical indicators and preferences.

	Home HD	PD (without assistance)	PD (assisted)	PD/HD at centre
Likely barriers	<ul style="list-style-type: none"> <li>• The patient wants home HD</li> <li>• Failure to provide sufficient access</li> <li>• Has a living donor</li> <li>• Homeless</li> <li>• Brain injury, dementia and recued short-term memory</li> <li>• Not able to use his hands</li> <li>• Blind or a very impaired vision</li> <li>• Cannot be trained to manage the dialysis treatment safely</li> <li>• Short life horizon</li> </ul>	<ul style="list-style-type: none"> <li>• The patient wants PD</li> <li>• Children are often most suitable for PD</li> <li>• Large hernia that cannot be treated surgically</li> <li>• Comprehensive peritoneal adherents</li> <li>• Ileo- and colostomy</li> <li>• Bricker bladder</li> <li>• Gastric pacemaker</li> <li>• Homeless</li> <li>• Brain injury, dementia and recued short-term memory</li> <li>• Not able to use his hands</li> <li>• Recently (&lt;4 weeks) major abdominal surgery</li> <li>• Cannot be trained to manage the dialysis treatment safely</li> </ul>	<ul style="list-style-type: none"> <li>• The patient wants aAAP</li> <li>• The patient wants PD, but is not able to manage the treatment on his own</li> <li>• Large hernia that cannot be treated surgically</li> <li>• Comprehensive peritoneal adherents</li> <li>• Ileo- and colostomy</li> <li>• Bricker bladder</li> <li>• Gastric pacemaker</li> <li>• Homeless</li> <li>• Recently (&lt;4 weeks) major abdominal surgery</li> </ul>	<ul style="list-style-type: none"> <li>• The patient wants CHD</li> <li>• The patient wants HD, but is not able to manage the treatment on his own</li> <li>• Failure to provide sufficient access</li> </ul>
Possible barriers	<ul style="list-style-type: none"> <li>• Cardiac: <ul style="list-style-type: none"> <li>◦ Heart failure</li> <li>◦ Arrhythmia</li> <li>◦ Blood pressure drop</li> </ul> </li> <li>• Angina</li> <li>• Endovascular foreign bodies, e.g. pacemaker, heart valve, cardiovascular pump</li> <li>• Diabetes with unexpected hypoglycaemia</li> <li>• Reduced function of his hands</li> <li>◦ Cerebral: <ul style="list-style-type: none"> <li>◦ Uncontrolled psychosis</li> <li>◦ Uncontrolled anxiety</li> <li>◦ Uncontrolled epilepsy</li> <li>◦ Reduced ability to observe physiological symptoms</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Inflammatory or ischaemic bowel disease</li> <li>• Chronic skin infections on abdomen</li> <li>• Severe malnutrition</li> <li>• High-dose immunosuppression</li> <li>• Severe obesity, BMI &gt;35 kg/m<sup>2</sup></li> <li>• Severe chronic obstructive pulmonary disease and/or emphysema</li> <li>• Blind or a very impaired vision</li> <li>• Reduced function of his hands</li> <li>• Cerebral: <ul style="list-style-type: none"> <li>◦ Uncontrolled psychosis</li> <li>◦ Uncontrolled anxiety</li> <li>◦ Reduced ability to observe physiological symptoms</li> </ul> </li> <li>• Short life horizon</li> </ul>	<ul style="list-style-type: none"> <li>• Inflammatory or ischaemic bowel disease</li> <li>• Chronic skin infections on abdomen</li> <li>• Severe malnutrition</li> <li>• High-dose immunosuppression</li> <li>• Severe obesity, BMI &gt; 35 kg/m<sup>2</sup></li> <li>• Severe chronic obstructive pulmonary disease and/or emphysema</li> </ul>	<ul style="list-style-type: none"> <li>• Conditions where the patient is poorly resistant to ultrafiltration under HD (in some patients with severe heart disease or hypotension)</li> <li>• Endovascular foreign bodies, e.g. pacemaker, heart valve, cardiovascular pump</li> <li>• Short life horizon</li> </ul>

The table is indicative and based primarily on experience-based knowledge. The PwKF's overall situation must be considered when reasoning about treatment options, and include their kidney disease indicators, comorbidities, preferences and service infrastructure constraints.

BMI, body mass index; aAAP, assisted automated or continuous ambulatory PD; CHD, Centre HD.



enhance the health literacy of PwKF and enable them to make informed, value-based decisions together with their practitioners. The skills needed to integrate decision aids into practice and support other trade-offs about which options fit best into PwKF's lives complement the more established medical sociological approaches to within-consultation communication skills and patient involvement practices [74, 97, 98, 139].

One area for further exploration concerns the association between PtDAs and their impact on clinician reasoning, individually and in teams. We found PtDAs contain different types of information when development is led by different specialists, indicating that specialists deliver care according to their specialist decision frame or care goal and their different service lens [2]. Certainly, the content of our PtDAs was broadened when we assimilated the expertise of different types of professionals who manage PwKF, such as kidney professionals with different dialysis expertise, general practitioners, geriatricians, palliative care physicians and allied health professionals [76–78]. A second area for decision-science research is the impact of clinical risk prediction models and personalized risk algorithms on clinician and patient judgments [170]. It is unclear whether and how these risk figures boost or bias people's reasoning, and how they affect the mechanisms needed to make informed, value-based decisions individually and with others [28, 133].

Adopting PtDAs designed to impact on multiple stakeholder decision making will enable services to support PwKF in making the right treatment choice to suit their clinical and personal needs. The structure of PtDAs helps PwKF and kidney professionals focus on the information needed to make decisions about kidney replacement therapy, conservative management and end of life options prior to integrating care plans to manage their kidney disease along the care pathway [171]. Providing accurate and balanced details about the decision problem, its options and their consequences in a written form to support active thinking will begin to standardize education about these treatment pathways across services. Training on decision coaching is likely to support the integration of PtDAs by kidney teams in their educational portfolio, and help to address variations in the organization of local services. Ideally, kidney services are moving towards the integration of measures to capture meaningful individual-level PwKF experiences of making shared treatment decisions with kidney practitioners and indicators of enhanced management decisions [5, 24]. These data are essential for services to audit innovation, identify variations in practice, and carry out research to design and evaluate evidence-informed interventions impacting on the patient experience and quality of care.

## FUNDING

This article was published as part of a supplement made possible by Fresenius Medical Care.

## AUTHORS' CONTRIBUTIONS

All authors contributed to the project development, design, methods and dissemination of the research underpinning this review, and associated decision aid outputs. All authors contributed to the final manuscript.

## CONFLICT OF INTEREST STATEMENT

None declared.

## DATA AVAILABILITY STATEMENT

No new data were generated or analysed in support of this research.

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