Clinical Kidney Journal, 2023, vol. 16, Suppl 1, i20–i38

https://doi.org/10.1093/ckj/sfad172
CKJ Review

CKJ REVIEW

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

Hilary L. Bekker[1,2,3], Anna E. Winterbottom[1,4], Teresa Gavaruzzi[5], Jeanette Finderup[3,6,7] and Andrew Mooney[1,4]

[1]Leeds Unit of Complex Intervention Development (LUCID), Leeds Institute of Health Sciences, School of Medicine, University of Leeds, Leeds, UK, [2]Department of Public Health, Aarhus University, Denmark, [3]ResCenPI – Research Centre for Patient Involvement, Aarhus University, Aarhus and the Central Denmark Region, Denmark, [4]Renal Unit, St James's University Hospital, Leeds Teaching Hospital Trust, Leeds, UK, [5]Department of Medical and Surgical Sciences (DIMEC), University of Bologna, Bologna, Italy, [6]Department of Renal Medicine, Aarhus University Hospital, Aarhus, Denmark and [7]Department of Clinical Medicine, Aarhus University, Aarhus, Denmark

Correspondence to: Hilary L. Bekker; E-mail: h.l.bekker@leeds.ac.uk

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.

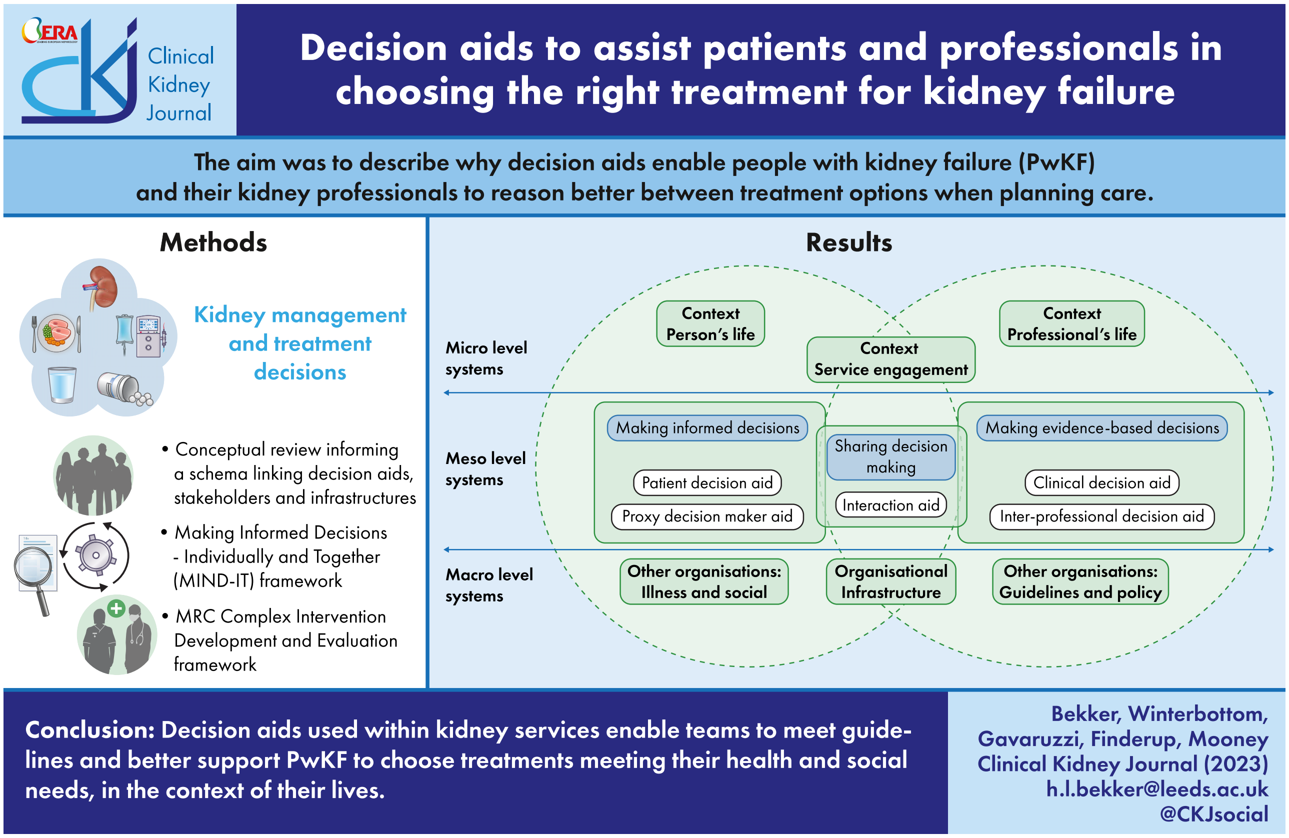
Methods. A conceptual review of findings about decision making and use of decision aids in kidney services, synthesized with reference to: the Making Informed Decisions—Individually and Together (MIND-IT) multiple stakeholder decision makers framework; and the Medical Research Council—Complex Intervention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

GRAPHICAL ABSTRACT



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

The aim was to describe why decision aids enable people with kidney failure (PwKF) and their kidney professionals to reason better between treatment options when planning care.

Methods

Kidney management and treatment decisions

- Conceptual review informing a schema linking decision aids, stakeholders and infrastructures
- Making Informed Decisions - Individually and Together (MIND-IT) framework
- MRC Complex Intervention Development and Evaluation framework

Results

Conclusion: Decision aids used within kidney services enable teams to meet guidelines and better support PwKF to choose treatments meeting their health and social needs, in the context of their lives.

Bekker, Winterbottom, Gavaruzzi, Finderup, Mooney
Clinical Kidney Journal (2023)
h.l.bekker@leeds.ac.uk
@CKJsocial

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 co-morbidity 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 reasoning [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

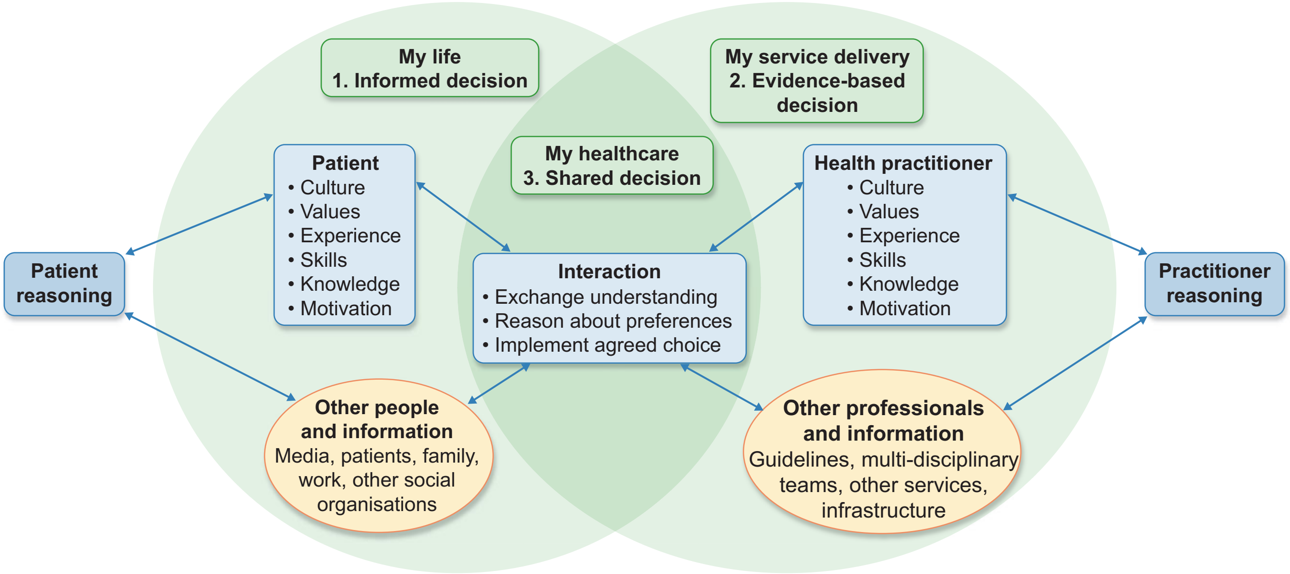


Figure 1: Making informed decisions individually and together (MIND-IT) in healthcare framework [5, 6]: developing interventions supporting multiple stakeholder decision makers [3].

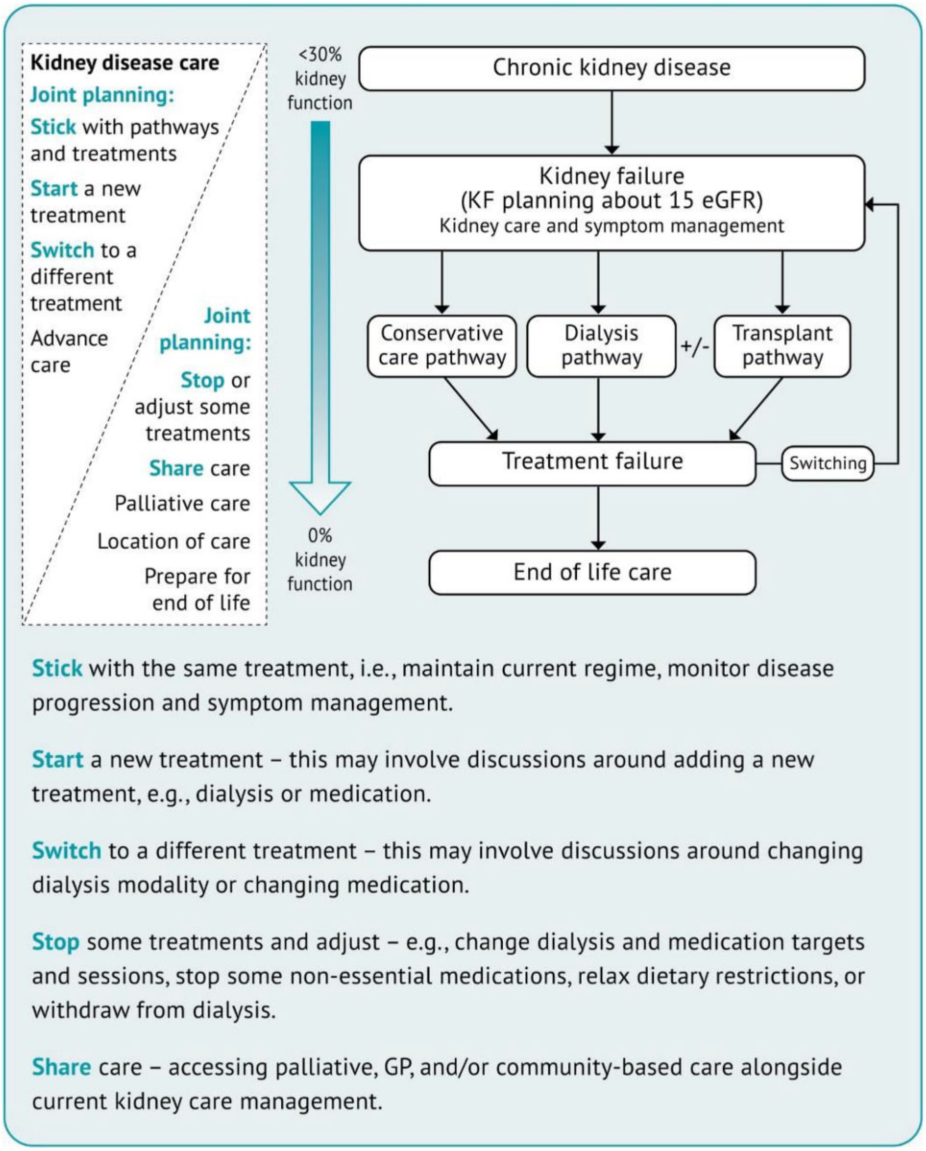
when there are several nested or linked decisions in a management pathway [1, 2, 73–76]. In the context of a chronic health problem that worsens over time, decision aids need to link these nested decisions with the ongoing monitoring and management of the health problem as it, and a person's life, change 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



Stick with the same treatment, i.e., maintain current regime, monitor disease progression and symptom management.

Start a new treatment – this may involve discussions around adding a new treatment, e.g., dialysis or medication.

Switch to a different treatment – this may involve discussions around changing dialysis modality or changing medication.

Stop some treatments and adjust – e.g., change dialysis and medication targets and sessions, stop some non-essential medications, relax dietary restrictions, or withdraw from dialysis.

Share care – accessing palliative, GP, and/or community-based care alongside current kidney care management.

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 healthcare [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, value-led 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 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/AAUHNY.nsf/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 understanding 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

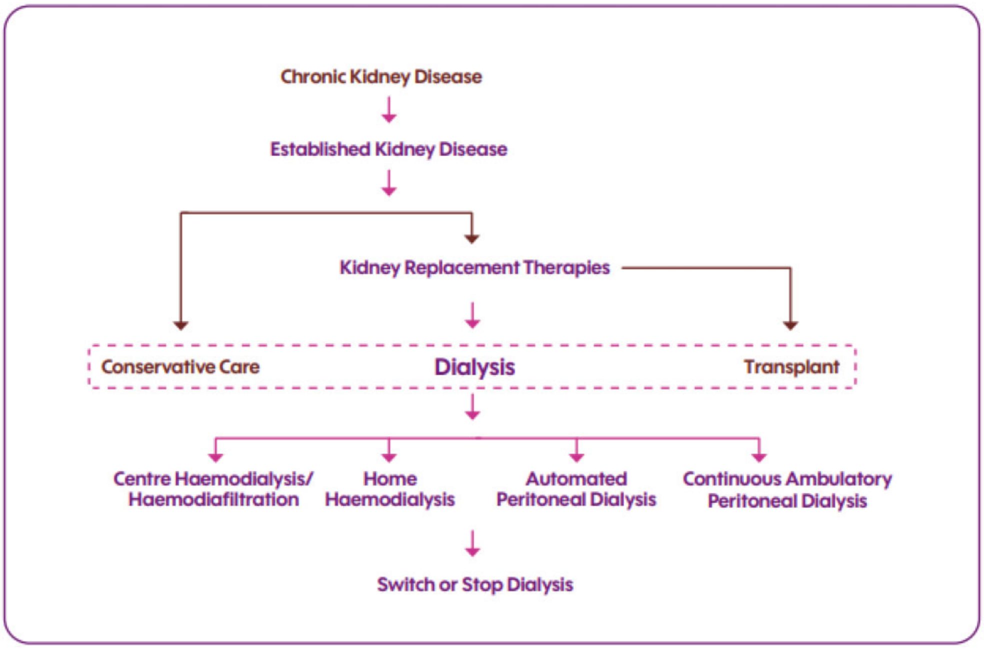
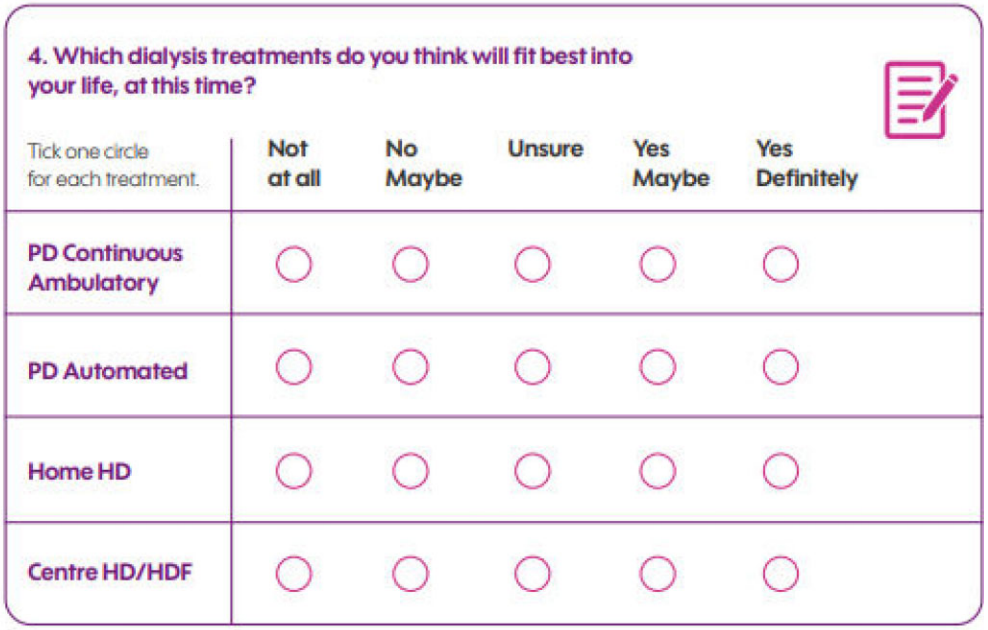


Figure 5: Decision map for dialysis options in the context of treatments for people with kidney failure [76].



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

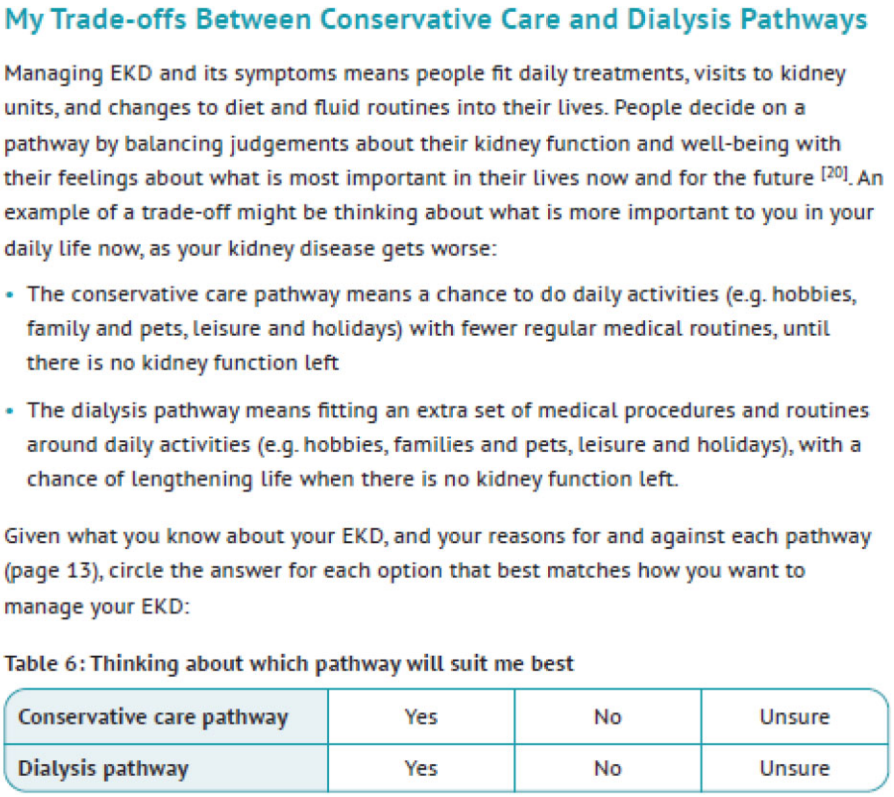
Tick one circle for each treatment.	Not at all	No Maybe	Unsure	Yes Maybe	Yes Definitely
PD Continuous Ambulatory	○	○	○	○	○
PD Automated	○	○	○	○	○
Home HD	○	○	○	○	○
Centre HD/HDF	○	○	○	○	○

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 healthcare 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
	• The patient wants home HD	• The patient wants PD • Children are often most suitable for PD	• The patient wants aAAP • The patient wants PD, but is not able to manage the treatment on his own	• The patient wants CHD • The patient wants HD, but is not able to manage the treatment on his own
Likely barriers	• Failure to provide sufficient access • Has a living donor • Homeless • Brain injury, dementia and recued short-term memory • Not able to use his hands • Blind or a very impaired vision • Cannot be trained to manage the dialysis treatment safely • Short life horizon	• Large hernia that cannot be treated surgically • Comprehensive peritoneal adherents • Ileo- and colostomy • Bricker bladder • Gastric pacemaker • Homeless • Brain injury, dementia and recued short-term memory • Not able to use his hands • Recently (<4 weeks) major abdominal surgery • Cannot be trained to manage the dialysis treatment safely	• Large hernia that cannot be treated surgically • Comprehensive peritoneal adherents • Ileo- and colostomy • Bricker bladder • Gastric pacemaker • Homeless • Recently (<4 weeks) major abdominal surgery	• Failure to provide sufficient access
Possible barriers	• Cardiac: o Heart failure o Arrhythmia o Blood pressure drop • Angina • Endovascular foreign bodies, e.g. pacemaker, heart valve, cardiovascular pump • Diabetes with unexpected hypoglycaemia • Reduced function of his hands o Cerebral: o Uncontrolled psychosis o Uncontrolled anxiety o Uncontrolled epilepsy o Reduced ability to observe physiological symptoms	• Inflammatory or ischaemic bowel disease • Chronic skin infections on abdomen • Severe malnutrition • High-dose immunosuppression • Severe obesity, BMI >35 kg/m^2 • Severe chronic obstructive pulmonary disease and/or emphysema • Blind or a very impaired vision • Reduced function of his hands • Cerebral: o Uncontrolled psychosis o Uncontrolled anxiety o Reduced ability to observe physiological symptoms • Short life horizon	• Inflammatory or ischaemic bowel disease • Chronic skin infections on abdomen • Severe malnutrition • High-dose immunosuppression • Severe obesity, BMI >35 kg/m^2 • Severe chronic obstructive pulmonary disease and/or emphysema	• Conditions where the patient is poorly resistant to ultrafiltration under HD (in some patients with severe heart disease or hypotension) • Endovascular foreign bodies, e.g. pacemaker, heart valve, cardiovascular pump • Short life horizon

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.

REFERENCES

1. Winterbottom AE, Mooney A, Russon L *et al*. Critical review of leaflets about conservative management used in UK renal services. *J Ren Care* 2020;**46**:250–7. https://doi.org/10.1111/jorc.12327
2. Winterbottom AE, Mooney A, Russon L *et al*. Kidney disease pathways, options and decisions: an environmental scan of international patient decision aids. *Nephrol Dial Transplant* 2020;**35**:2072–82. https://doi.org/10.1093/ndt/gfaa102
3. Toft BS, Rodkjaer L, Andersen AB *et al*. Measures used to assess interventions for increasing patient involvement in Danish healthcare setting: a rapid review. *BMJ Open* 2022;**12**:e064067. https://doi.org/10.1136/bmjopen-2022-064067
4. Bekker HL, Mooney AM. Practical aspects of shared decision making: people living with frailty & chronic kidney disease. *Royal Society of Medicine Geriatric Nephrology Symposium* Online: 21 October 2021. https://www.rsm.ac.uk/events/nephrology/2021-22/neq50.
5. Breckenridge K, Bekker HL, Gibbons E *et al*. How to routinely collect data on patient-reported outcome and experience measures in renal registries in Europe: an expert consensus meeting. *Nephrol Dial Transplant* 2015;**30**:1605–14. https://doi.org/10.1093/ndt/gfv209
6. Brown E, Bekker HL, Davison S *et al*. Supportive care: communication strategies to improve cultural competence in shared decision making. *Clin J Am Soc Nephrol* 2016;**11**:1902–8. https://doi.org/10.2215/CJN.13661215
7. Skivington K, Matthews L, Simpson SA *et al*. A new framework for developing and evaluating complex interventions: update of Medical Research Council guidance. *BMJ* 2021;**374**:n2061. https://doi.org/10.1136/bmj.n2061
8. O'Cathain A, Croot L, Duncan E *et al*. Guidance on how to develop complex interventions to improve health and healthcare. *BMJ Open* 2019;**9**:e029954. https://doi.org/10.1136/bmjopen-2019-029954
9. National Institute for Health and Care Excellence (NICE). *Chronic Kidney Disease (Stage 5): Peritoneal Dialysis. Clinical Guideline CG125*. London, UK: NICE, 2011.
10. National Institute for Health and Care Excellence (NICE). *Renal Replacement Therapy and Conservative Management: NICE Guideline NG107*. London, UK: NICE, October 2018. https://www.nice.org.uk/guidance/ng107/resources/renal-replacement-therapy-and-conservative-management-pdf-66141542991301 (26 January 2023, date last accessed).
11. NHS Kidney Care. *End of Life Care in Advanced Kidney Disease: A Framework for Implementation*. London, UK: NHS, January 2015. https://www.england.nhs.uk/improvement-hub/wp-content/uploads/sites/44/2017/11/Advanced-kidney-disease.pdf (26 January 2023, date last accessed).
12. Martinez YV, Benett I, Lewington AJP *et al*.; Committee Guideline. Chronic kidney disease: summary of updated NICE guidance. *BMJ* 2021;**374**:n1992. https://doi.org/10.1136/bmj.n1992
13. Getting It Right First Time (GIRFT). *Renal Medicine: GIRFT Programme National Specialty Report*. London, UK: NHS, March 2021. https://gettingitrightfirsttime.co.uk/wp-content/uploads/2021/09/Renal-Medicine-Sept21k.pdf (26 January 2023, date last accessed).

14. European Dialysis and Transplant Nurses Association/European Renal Care Association. *Supporting Patients Who Opt Not to Have Dialysis or Stop Dialysis: Guidelines for Nurses*. Hergiswil, Switzerland: EDTNA/ERCA, April 2021. https://www.edtnaerca.org/resource/edtna/files/2021-pub-en-supporting-patients-who-opt.pdf (26 January 2023, date last accessed).
15. UK Kidney Association and Kidney Care UK. *Patient Reported Experience of Kidney Care in the UK 2021*. Alton, Bristol: Kidney Care UK, UK Kidney Association, 2021. https://ukkidney.org/sites/renal.org/files/PREM%20report%202021.pdf (26 January 2023, date last accessed) .
16. Davison SN, Levin A, Moss AH *et al.* Executive summary of the KDIGO controversies conference on supportive care in chronic kidney disease: developing a roadmap to improving quality care. *Kidney Int* 2015;**88**:447–59. https://doi.org/10.1038/ki.2015.110
17. Eckardt K-U, Bansal N, Coresh J *et al.* Improving the prognosis of patients with severely decreased glomerular filtration rate (CKD G4+): conclusions from a kidney disease improving global outcomes (KDIGO) controversies conference. *Kidney Int* 2018;**93**:1281–92. https://doi.org/10.1016/j.kint.2018.02.006
18. Diamond LH, Armistead NC, Lupu DE *et al.*; Steering Committee of the Coalition for Supportive Care of Kidney Patients. Recommendations for public policy changes to improve supportive care for seriously ill patients with kidney disease. *Am J Kidney Dis* 2021;**77**:529–37. https://doi.org/10.1053/j.ajkd.2020.09.020
19. Russon L, Mooney A. Palliative and end-of-life care in advanced renal failure. *Clin Med (Lond)* 2010;**10**:279–81. https://doi.org/10.7861/clinmedicine.10-3-279
20. Moss AH. Integrating supportive care principles into dialysis decision making: a primer for palliative medicine providers. *J Pain Symptom Manage* 2017;**53**:656–62.e1. https://doi.org/10.1016/j.jpainsymman.2016.10.371
21. Roderick P, Rayner H, Tonkin-Crine S *et al.* A national study of practice patterns in UK renal units in the use of dialysis and conservative kidney management to treat people aged 75 years and over with chronic kidney failure . Southampton (UK): NIHR Journals Library; April 2015 (Health Services and Delivery Research, No. 3.12). Available from: https://www.ncbi.nlm.nih.gov/books/NBK284925/ doi: 10.3310/hsdr03120
22. Hurst H, Jones E, Ormandy P *et al.* Outcomes and care priorities for older people living with frailty and advanced chronic kidney disease: a multiprofessional scoping review protocol. *BMJ Open* 2021;**11**:e040715. https://doi.org/10.1136/bmjopen-2020-040715.
23. Hole B, Hemmelgarn B, Brown E *et al.* Supportive care for end-stage kidney disease: an integral part of kidney services across a range of income settings around the world. *Kidney Int Suppl (2011)* 2020;**10**:e86–94. https://doi.org/10.1016/j.kisu.2019.11.008
24. van der Veer SN, Couchoud C, Morton RL. The role of kidney registries in expediting large-scale collection of patient-reported outcome measures for people with chronic kidney disease. *Clin Kidney J* 2021;**14**:1495–503. https://doi.org/10.1093/ckj/sfab061
25. Hanson CS, Sautenet B, Craig JC *et al.* Informative for decision making? The spectrum and consistency of outcomes after living kidney donation reported in trials and observational studies. *Transplantation* 2019;**103**:284–90. https://doi.org/10.1097/tp.0000000000002489
26. Tong A, Manns B, Hemmelgarn B *et al.* Establishing core outcome domains in hemodialysis: report of the standardized outcomes in nephrology–hemodialysis (SONG-HD) consensus workshop. *Am J Kidney Dis* 2017;**69**:97–107. https://doi.org/10.1053/j.ajkd.2016.05.022
27. Sautenet B, Tong A, Williams G *et al.* Scope and consistency of outcomes reported in randomized trials conducted in adults receiving hemodialysis: a systematic review. *Am J Kidney Dis* 2018;**72**:62–74. https://doi.org/10.1053/j.ajkd.2017.11.010
28. Major RW, Shepherd D, Medcalf JF *et al.* The kidney failure risk equation for prediction of end stage renal disease in UK primary care: an external validation and clinical impact projection cohort study. *PLoS Med* 2019;**16**:e1002955. https://doi.org/10.1371/journal.pmed.1002955
29. Mooney AF, Winterbottom A, Bekker HL. The importance of expert education in enabling informed, activated patients. *Kidney Int* 2009;**75**:1116–7. https://doi.org/10.1038/ki.2009.33
30. Van Biesen W, van der Veer SN, Murphey M *et al.* Patients' perceptions of information and education for renal replacement therapy: an independent survey by the European Kidney Patients' Federation on information and support on renal replacement therapy. *PLoS One* 2014;**9**:e103914. https://doi.org/10.1371/journal.pone.0103914
31. Combes G, Sein K, Allen K. How does pre-dialysis education need to change? Findings from a qualitative study with staff and patients. *BMC Nephrol* 2017;**18**:334. https://doi.org/10.1186/s12882-017-0751-y
32. Cassidy BP, Getchell LE, Harwood L *et al.* Barriers to education and shared decision making in the chronic kidney disease population: a narrative review. *Can J Kidney Health Dis* 2018;**5**:2054358118803322. https://doi.org/10.1177/2054358118803322
33. Hoekstra B, Amiri F, van Beenen S *et al.* Training and education, what has changed this last decade? *J Ren Care* 2021;**47**:250–4. https://doi.org/10.1111/jorc.12376
34. Winterbottom A, Bekker HL, Conner M *et al.* Evaluating the quality of patient leaflets about renal replacement therapy across UK renal units. *Nephrol Dial Transplant* 2007;**22**:2291–6. https://doi.org/10.1093/ndt/gfm095
35. Winterbottom A, Stoves J, Ahmed S *et al.* Patient information about living donor kidney transplantation across UK renal units: a critical review. *J Ren Care* 2021;**49**:45–55. https://doi.org/10.1111/jorc.12404
36. Morony S, McCaffery KJ, Kirkendall S *et al.* Health literacy demand of printed lifestyle patient information materials aimed at people with chronic kidney disease: are materials easy to understand and act on and do they use meaningful visual aids? *J Health Commun* 2017;**22**:163–70. https://doi.org/10.1080/10810730.2016.1258744.
37. Loiselle M-C, Michaud C, O'Connor A. Decisional needs assessment to help patients with advanced chronic kidney disease make better dialysis choices. *Nephrol Nurs J* 2016;**43**:463–93.
38. Barrett TM, Green JA, Greer RC *et al.* Preferences for and experiences of shared and informed decision making among patients choosing kidney replacement therapies in nephrology care. *Kidney Med* 2021;**3**:905–15.e1. https://doi.org/10.1016/j.xkme.2021.05.011
39. Morton RL, Tong A, Howard K *et al.* The views of patients and carers in treatment decision making for chronic kidney disease: systematic review and thematic synthesis of

qualitative studies. *BMJ* 2010;**340**:c112. https://doi.org/10.1136/bmj.c112

40. Murray MA, Brunier G, Chung JO *et al.* A systematic review of factors influencing decision-making in adults living with chronic kidney disease. *Patient Educ Couns* 2009;**76**:149–58. https://doi.org/10.1016/j.pec.2008.12.010
41. Winterbottom AE, Bekker HL, Conner M *et al.* Choosing dialysis modality: decision making in a chronic disease context. *Health Expect* 2014;**17**:710–23. https://doi.org/10.1111/j.1369-7625.2012.00798.x
42. O'Halloran P, Noble H, Norwood K *et al.* Advance care planning with patients who have end-stage kidney disease: a systematic realist review. *J Pain Symptom Manage* 2018;**56**:795–807.e18. https://doi.org/10.1016/j.jpainsymman.2018.07.008
43. Frazier R, Levine S, Porteny T *et al.* Shared decision making among older adults with advanced CKD. *Am J Kidney Dis* 2022;**80**:599–609. https://doi.org/10.1053/j.ajkd.2022.02.017
44. Engels N, de Graav GN, van der Nat P *et al.* Shared decision-making in advanced kidney disease: a scoping review. *BMJ Open* 2022;**12**:e055248. https://doi.org/10.1136/bmjopen-2021-055248
45. Hussain JA, Flemming K, Murtagh FEM *et al.* Patient and health care professional decision-making to commence and withdraw from renal dialysis: a systematic review of qualitative research. *Clin J Am Soc Nephrol* 2015;**10**:1201–15. https://doi.org/10.2215/cjn.11091114
46. Da Silva-Gane M, Farrington K. Supportive care in advanced kidney disease: patient attitudes and expectations. *J Ren Care* 2014;**40**:30–5. https://doi.org/10.1111/jorc.12093
47. Gander JC, Gordon EJ, Patzer RE. Decision aids to increase living donor kidney transplantation. *Curr Transplant Rep* 2017;**4**:1–12. https://doi.org/10.1007/s40472-017-0133-1
48. Tentori F, Hunt A, Nissenson AR. Palliative dialysis: addressing the need for alternative dialysis delivery modes. *Semin Dial* 2019;**32**:391–5. https://doi.org/10.1111/sdi.12820
49. von Winterfeldt D, Edwards W. *Decision Analysis and Behavioural Research*. Cambridge, UK: Cambridge University Press, 1986.
50. von Winterfeldt D. Decisions with multiple stakeholders and conflicting objectives. In: Weber EU, Baron J Loomes G, eds. *Conflict and Tradeoffs in Decision Making*. Cambridge, UK: Cambridge University Press, 2016, 259–99.
51. IL Janis, Mann L. *Decision Making: A Psychological Analysis of Conflict, Choice, and Commitment*. New York, NY: Free Press, 1977.
52. Baron J. *Thinking and Deciding*. 4th edn. New York, NY: Cambridge University Press, 2006.
53. Hammond JS, Keeney RL, Raiffa H. *Smart Choices: A Practical Guide to Making Better Decisions*. Brighton, MA: Harvard Business School Press, 1999.
54. Mazur DJ. *Shared Decision Making in the Physician-Patient Relationship*. Tampa, FL: American College of Physician Executives, 2001.
55. Bekker HL. Using decision making theory to inform clinical practice. In: Elwyn G Edwards A, eds. *Shared Decision Making – Achieving Evidence-Based Patient Choice*. London, UK: Oxford University Press, 2009, 45–52.
56. Chapman GB, Elstein AS. Cognitive process and biases in medical decision making. In: Chapman GB Sonnenberg FA, eds. *Decision Making in Healthcare*. Cambridge, UK: Cambridge University Press, 2000, 183–210.
57. Chapman GB. The psychology of medical decision making. In: Koehler DJ Harvey N, eds. *Blackwell Handbook of Judgement and Decision Making*. Oxford, UK: Blackwell Publishing Limited, 2004, 585–603.
58. Hunink M, Glasziou P, Siegel J *et al. Decision Making in Health and Medicine: Integrating Evidence and Values*. Cambridge, UK: Cambridge University Press, 2001.
59. Schwartz A, Kostopoulou O. Clinical reasoning in medicine. In: Higgs J, Jensen GM Loftus S *et al.*, eds. *Clinical Reasoning in the Health Professions*. 4th edn. London, UK: Elsevier Ltd, 2019, 223–34.
60. Frisch D. Reasons for framing effects. *Organ Behav Hum Decis Process* 1993;**54**:399–429. https://doi.org/10.1006/obhd.1993.1017
61. Kahneman D, Tversky A. Choices, values, and frames. *Am Psychol* 1984;**39**:341–50. https://doi.org/10.1037/0003-066X.39.4.341
62. Keys DJ, Schwartz B. "Leaky" rationality: how research on behavioral decision making challenges normative standards of rationality. *Perspect Psychol Sci* 2007;**2**:162–80. https://doi.org/10.1111/j.1745-6916.2007.00035.x
63. Larrick RP. Debiasing. In: Koehler DJ Harvey N, eds. *Blackwell Handbook of Judgement and Decision Making*. Oxford, UK: Blackwell Publishing Limited, 2004, 316–38.
64. Llewellyn-Thomas HA. Patients' health-care decision making: a framework for descriptive and experimental investigations. *Med Decis Making* 1995;**15**:101–6. https://doi.org/10.1177/0272989X9501500201
65. Bekker HL, Hewison J, Thornton JG. Understanding why decision aids work: linking process with outcome. *Patient Educ Couns* 2003;**50**:323–9. https://doi.org/10.1016/s0738-3991(03)00056-9
66. Bekker HL. The loss of reason in patient decision aid research: do checklists damage the quality of informed choice interventions? *Patient Educ Couns* 2010;**78**:357–64. https://doi.org/10.1016/j.pec.2010.01.002
67. Bekker H, Thornton JG, Airey CM *et al.* Informed decision making: an annotated bibliography and systematic review. *Health Technol Assessment* 1999;**3**:1–156. https://doi.org/10.3310/hta3010
68. O'Connor AM, Rostom A, Fiset V *et al.* Decision aids for patients facing health treatment or screening decisions: systematic review. *BMJ* 1999;**18**:731–4. https://doi.org/10.1136/bmj.319.7212.731
69. Ottawa Hospital Research Institute. *Ottawa Personal Decision Guides*. Ottawa, Canada: Ottawa Hospital Research Unit, October 2022. https://decisionaid.ohri.ca/decguide.html (27 January 2023, date last accessed).
70. Vaisson G, Provencher T, Dugas M *et al.* User involvement in the design and development of patient decision aids and other personal health tools: a systematic review. *Med Decis Making* 2021;**41**:261–74. https://doi.org/10.1177/0272989X20984134
71. Grindell C, Coates E, Croot L *et al.* The use of co-production, co-design and co-creation to mobilise knowledge in the management of health conditions: a systematic review. *BMC Health Serv Res* 2022;**22**:877. https://doi.org/10.1186/s12913-022-08079-y
72. Vargas C, Whelan J, Brimblecombe J *et al.* Co-creation, co-design and co-production for public health: a perspective on definitions and distinctions. *Public Health Res Pract* 2022;**32**:e3222211. https://doi.org/10.17061/phrp3222211
73. Bekker HL, Gavaruzzi T, Summers B *et al. Testing the Added Value of Decision Aid Components to Facilitate Patients Informed Decision Making about Dialysis Treatment*. 34th Annual

Meeting of the Society for Medical Decision Making, Phoenix, AZ, 17–20 October 2012. https://smdm.confex.com/smdm/2012az/webprogram/Paper7104.html

74. Winterbottom AE, Gavaruzzi T, Mooney A *et al.* Patient acceptability of the Yorkshire dialysis decision aid (YoDDA) booklet: a prospective non-randomized comparison study across 6 predialysis services. *Perit Dial Int* 2016;**36**:374–81. https://doi.org/10.3747/pdi.2014.00274

75. Winterbottom AE, Bekker HL, Ziegler L *et al.* The Yorkshire dialysis vs conservative-management decision aid (YoDCA): study protocol. *J Kidney Care* 2018;**2**:179–85. https://doi.org/10.12968/jokc.2018.3.3.179

76. Bekker HL, Winterbottom A, Gavaruzzi T *et al. The Dialysis Decision Aid Booklet: Making The Right Choices for You*. Peterborough: Kidney Research UK, September 2020. https://kidneyresearchuk.org/wp-content/uploads/2019/05/KR-decision-Aid-DOWNLOAD.pdf (27 January 2023, date last accessed).

77. Winterbottom AE, Mooney A, Russon L *et al. A Dialysis and Conservative Care Decision Aid: Living with Kidney Disease – the YoDCA Study Booklet*. Leeds: University of Leeds, July 2020. https://www.kidneyresearchyorkshire.org.uk/yorkshire-dialysis-and-conservative-care-decision-aid/ (27 January 2023, date last accessed).

78. Winterbottom A, Mooney A, Hurst H *et al. Difficult Conversations: Talking with People about Kidney Failure, End of Life and Advance Care Planning*. Leeds: Leeds Teaching Hospital Trusts, November 2022. https://www.kidneycareuk.org/health-professionals/difficult-conversations (27 January 2023, date last accessed).

79. Stacey D, Légaré F, Lewis K *et al.* Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev* 2017;**4**:CD001431. https://doi.org/10.1002/14651858.CD001431.pub5

80. International Patient Decision Aids Standards Collaboration. *International Patient Decision Aids Standards (IPDAS) Collaboration*. Ottawa Hospital Research Unit, May 2019. http://ipdas.ohri.ca/ (26 January 2023, date last accessed).

81. Stacey D, Volk RJ. The International Patient Decision Aid Standards (IPDAS) collaboration: evidence update 2.0. *Med Decis Making* 2021;**41**:729–33. https://doi.org/10.1177/0272989X211035681

82. Elwyn G, O'Connor A, Stacey D *et al.* Developing a quality criteria framework for patient decision aids: online international Delphi consensus process. *BMJ* 2006;**333**:417. https://doi.org/10.1136/bmj.38926.629329.ae

83. Joseph-Williams N, Newcombe R, Politi M *et al.* Toward minimum standards for certifying patient decision aids: a modified Delphi consensus process. *Med Decis Making* 2014;**34**:699–710. https://doi.org/10.1177/0272989x13501721

84. Bonner C, Trevena LJ, Gaissmaier W *et al.* Current best practice for presenting probabilities in patient decision aids: fundamental principles. *Med Decis Making* 2021;**41**:821–33. https://doi.org/10.1177/0272989x21996328

85. Trevena LJ, Bonner C, Okan Y *et al.* Current challenges when using numbers in patient decision aids: advanced concepts. *Med Decis Making* 2021;**41**:834–47. https://doi.org/10.1177/0272989x21996342

86. Hoffmann TC, Bakhit M, Durand M-A *et al.* Basing information on comprehensive, critically appraised, and up-to-date syntheses of the scientific evidence: an update from the international patient decision aid standards. *Med Decis Making* 2021;**41**:755–67. https://doi.org/10.1177/0272989x21996622

87. Martin RW, Brogård Andersen S, O'Brien MA *et al.* Providing balanced information about options in patient decision aids: an update from the international patient decision aid standards. *Med Decis Making* 2021;**41**:780–800. https://doi.org/10.1177/0272989X211021397

88. Thompson R, Paskins Z, Main BG *et al.* Addressing conflicts of interest in health and medicine: current evidence and implications for patient decision aid development. *Med Decis Making* 2021;**41**:768–79. https://doi.org/10.1177/0272989x211008881

89. Yen RW, Smith J, Engel J *et al.* A systematic review and meta-analysis of patient decision aids for socially disadvantaged populations: update from the international patient decision aid standards (IPDAS). *Med Decis Making* 2021;**41**:870–96. https://doi.org/10.1177/0272989x211020317

90. Muscat DM, Smith J, Mac O *et al.* Addressing health literacy in patient decision aids: an update from the international patient decision aid standards. *Med Decis Making* 2021;**41**:848–69. https://doi.org/10.1177/0272989x211011101

91. Witteman HO, Ndjaboue R, Vaisson G *et al.* Clarifying values: an updated and expanded systematic review and meta-analysis. *Med Decis Making* 2021;**41**:801–20. https://doi.org/10.1177/0272989x211037946

92. Bekker HL, Winterbottom AE, Butow P *et al.* Do personal stories make patient decision aids more effective? A critical review of evidence and theory. *BMC Med Inform Decis Mak* 2013;**13**:S9. https://doi.org/10.1186/1472-6947-13-S2-S9

93. Shaffer VA, Brodney S, Gavaruzzi T *et al.* Do personal stories make patient decision aids more effective? An update from the international patient decision aids standards. *Med Decis Making* 2021;**41**:897–906. https://doi.org/10.1177/0272989x211011100

94. Coulter A, Stilwell D, Kryworuchko J *et al.* A systematic development process for patient decision aids. *BMC Med Inform Decis Mak* 2013;**13**:S2. https://doi.org/10.1186/1472-6947-13-S2-S2

95. Witteman HO, Maki KG, Vaisson G *et al.* Systematic development of patient decision aids: an update from the IPDAS collaboration. *Med Decis Making* 2021;**41**:736–54. https://doi.org/10.1177/0272989x211014163

96. Joseph-Williams N, Abhyankar P, Boland L *et al.* What works in implementing patient decision aids in routine clinical settings? A rapid realist review and update from the international patient decision aid standards collaboration. *Med Decis Making* 2021;**41**:907–37. https://doi.org/10.1177/0272989x20978208

97. Jull J, Köpke S, Smith M *et al.* Decision coaching for people making healthcare decisions. *Cochrane Database Syst Rev* 2021;**11**:CD013385. https://doi.org/10.1002/14651858.CD013385.pub2

98. Rahn AC, Jull J, Boland L *et al.* Guidance and/or decision coaching with patient decision aids: scoping reviews to inform the international patient decision aid standards (IPDAS). *Med Decis Making* 2021;**41**:938–53. https://doi.org/10.1177/0272989x21997330

99. Sepucha K, Abhyankar P, Hoffman A *et al.* Standards for universal reporting of patient decision aid evaluation studies: the development of SUNDAE checklist. *BMJ Qual Saf* 2018;**27**:380–8. https://doi.org/10.1136/bmjqs-2017-006986

100. Sepucha K, Abhyankar P, Hoffman A *et al*. Explanation and elaboration of the standards for universal reporting of patient decision aid evaluations (SUNDAE) guidelines: examples of reporting SUNDAE items from patient decision aid evaluation literature. *BMJ Qual Saf* 2018;**27**:389–412. https://doi.org/10.1136/bmjqs-2017-006985
101. Trenaman L, Jansen J, Blumenthal-Barby J *et al*. Are we improving? Update and critical appraisal of the reporting of decision process and quality measures in trials evaluating patient decision aids. *Med Decis Making* 2021;**41**:954–9. https://doi.org/10.1177/0272989x211011120
102. Bekker HL, Thornton JG, Hewison J. Applying decision analysis to facilitate informed decision making about prenatal diagnosis for Down syndrome: a randomised controlled trial. *Prenat Diagn* 2004;**24**:265–75. https://doi.org/10.1002/pd.851
103. Shourie S, Jackson C, Cheater FM *et al*. A cluster randomised controlled trial of a web based decision aid to support parents' decisions about their child's measles mumps and rubella (MMR) vaccination. *Vaccine* 2013;**31**:6003–10. https://doi.org/10.1016/j.vaccine.2013.10.025
104. Wong SS, Thornton JG, Gbolade B *et al*. A randomised controlled trial of a decision-aid leaflet to facilitate women's choice between pregnancy termination methods. *BJOG* 2006;**113**:688–94. https://doi.org/10.1111/j.1471-0528.2006.00930.x
105. Ottawa Hospital Research Institute. *Patient Decision Aids*. Ottawa, Canada: Ottawa Hospital Research Unit, October 2022. https://decisionaid.ohri.ca/ (26 January 2023, date last accessed).
106. Society of Medical Decision Making. *Education and Career Tools*. Albany, New York: Society for medical Decision making, 2020. https://smdm.org/hub/education-career-tools (26 January 2023, date last accessed) .
107. Shepherd V, Wood F, Griffith R *et al*. Development of a decision support intervention for family members of adults who lack capacity to consent to trials. *BMC Med Inform Decis Mak* 2021;**21**:30. https://doi.org/10.1186/s12911-021-01390-4
108. Lord K, Livingston G, Cooper C. A systematic review of barriers and facilitators to and interventions for proxy decision-making by family carers of people with dementia. *Int Psychogeriatr* 2015;**27**:1301–12. https://doi.org/10.1017/S1041610215000411
109. Jackson C, Cheater FM, Reid I. A systematic review of decision support needs of parents making child health decisions. *Health Expect* 2008;**11**:232–51. https://doi.org/10.1111/j.1369-7625.2008.00496.x
110. Boland L, Kryworuchko J, Saarimaki A *et al*. Parental decision making involvement and decisional conflict: a descriptive study. *BMC Pediatr* 2017;**17**:146. https://doi.org/10.1186/s12887-017-0899-4
111. Boland L, Graham ID, Légaré F *et al*. Barriers and facilitators of pediatric shared decision-making: a systematic review. *Implement Sci* 2019;**14**:7. https://doi.org/10.1186/s13012-018-0851-5
112. Shepherd V, Wood F, Robling M *et al*. Development of a core outcome set for the evaluation of interventions to enhance trial participation decisions on behalf of adults who lack capacity to consent: a mixed methods study (COnSiDER Study). *Trials* 2021;**22**:935. https://doi.org/10.1186/s13063-021-05883-5
113. Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). *Soc Sci Med* 1997;**44**:681–92. https://doi.org/10.1016/s0277-9536(96)00221-3
114. Makoul G, Clayman ML. An integrative model of shared decision making in medical encounters. *Patient Educ Couns* 2006;**60**:301–12. https://doi.org/10.1016/j.pec.2005.06.010
115. Stacey D, Légaré F, Pouliot S, Kryworuchko J *et al*. Shared decision making models to inform an interprofessional perspective on decision making: a theory analysis. *Patient Educ Couns* 2010;**80**:164–72. https://doi.org/10.1016/j.pec.2009.10.015
116. Lin GA, Fagerlin A. Shared decision making: state of the science. *Circ Cardiovasc Qual Outcomes* 2014;**7**:328–34. https://doi.org/10.1161/circoutcomes.113.000322
117. Bomhof-Roordink H, Gärtner FR, Stiggelbout AM *et al*. Key components of shared decision making models: a systematic review. *BMJ Open* 2019;**9**:e031763. https://doi.org/10.1136/bmjopen-2019-031763
118. Elwyn G, Laitner S, Coulter A *et al*. Implementing shared decision making in the NHS. *BMJ* 2010;**341**:c5146. https://doi.org/10.1136/bmj.c5146
119. National Institute for Health and Care Excellence (NICE). *Standards Framework for Shared-Decision-Making Support Tools, Including Patient Decision Aids. Corporate Document ECD8*. London: NICE, June 2021. https://www.nice.org.uk/corporate/ecd8 (26 January 2023, date last accessed) .
120. Wieringa TH, Rodriguez-Gutierrez R, Spencer-Bonilla G *et al*. Decision aids that facilitate elements of shared decision making in chronic illnesses: a systematic review. *Syst Rev* 2019;**8**:121. https://doi.org/10.1186/s13643-019-1034-4
121. Scalia P, Durand MA, Berkowitz JL *et al*. The impact and utility of encounter patient decision aids: systematic review, meta-analysis and narrative synthesis. *Patient Educ Couns* 2019;**102**:817–41. https://doi.org/10.1016/j.pec.2018.12.020
122. Shepherd HL, Barratt A, Trevena LJ *et al*. Three questions that patients can ask to improve the quality of information physicians give about treatment options: a cross-over trial. *Patient Educ Couns* 2011;**84**:379–85. https://doi.org/10.1016/j.pec.2011.07.022
123. Shepherd HL, Barratt A, Jones A *et al*. Can consumers learn to ask three questions to improve shared decision making? A feasibility study of the ASK (AskShareKnow) Patient-Clinician Communication Model(®) intervention in a primary health-care setting. *Health Expect* 2016;**19**:1160–8. https://doi.org/10.1111/hex.12409
124. Choosing Wisely UK. *Shared Decision Making Resources*. London: Choosing Wisely, 2020. https://www.choosingwisely.co.uk/shared-decision-making-resources/ (26 January 2023, date last accessed) .
125. Elwyn G, Lloyd A, Joseph-Williams N *et al*. Option grids: shared decision making made easier. *Patient Educ Couns* 2013;**90**:207–12. https://doi.org/10.1016/j.pec.2012.06.036
126. Giguere AM, Labrecque M, Haynes BR *et al*. Evidence summaries (decision boxes) to prepare clinicians for shared decision-making with patients: a mixed methods implementation study. *Implement Sci* 2014;**9**:144. https://doi.org/10.1186/s13012-014-0144-6
127. Légaré F, Bekker H, Desroches S *et al*. How can continuing professional development better promote shared decision-making? Perspectives from an international collaboration. *Implement Sci* 2011;**6**:68. https://doi.org/10.1186/1748-5908-6-68
128. Légaré F, Politi MC, Drolet R *et al*. Training health professionals in shared decision-making: an international

environmental scan. *Patient Educ Counsel* 2012;**88**:159–69. https://doi.org/10.1016/j.pec.2012.01.002

129. Müller E, Strukava A, Scholl I *et al.* Strategies to evaluate healthcare provider trainings in shared decision-making (SDM): a systematic review of evaluation studies. *BMJ Open* 2019;**9**:e026488. https://doi.org/10.1136/bmjopen-2018-026488
130. Stiggelbout AM, Pieterse AH, De Haes JC. Shared decision making: concepts, evidence, and practice. *Patient Educ Couns* 2015;**98**:1172–9. https://doi.org/10.1016/j.pec.2015.06.022
131. Sutton RT, Pincock D, Baumgart DC *et al.* An overview of clinical decision support systems: benefits, risks, and strategies for success. *npj Digit Med* 2020;**3**:17. https://doi.org/10.1038/s41746-020-0221-y
132. Craddock M, Crockett C, McWilliam A *et al.* Evaluation of prognostic and predictive models in the oncology clinic. *Clin Oncol (R Coll Radiol)* 2022;**34**:102–13. https://doi.org/10.1016/j.clon.2021.11.022
133. Sharma V, Ali I, van der Veer S, Martin G *et al.* Adoption of clinical risk prediction tools is limited by a lack of integration with electronic health records. *BMJ Health Care Inform* 2021;**28**:e100253. https://doi.org/10.1136/bmjhci-2020-100253
134. Légaré F, Brière N, Stacey D *et al.* Implementing shared decision-making in interprofessional home care teams (the IPSDM-SW study): protocol for a stepped wedge cluster randomised trial. *BMJ Open* 2016;**6**:e014023. https://doi.org/10.1136/bmjopen-2016-014023
135. Dogba MJ, Menear M, Brière N *et al.* Enhancing interprofessionalism in shared decision-making training within homecare settings: a short report. *J Interprof Care* 2020;**34**:143–6. https://doi.org/10.1080/13561820.2019.1623764
136. NHS Right Care. *Embedding Shared Decision Making in the NHS.* London, UK: NHS Shared Decision Making Programme and Totally Health Ltd, 2013.
137. Prichard A, Thomas N. The option grid: a shared decision-making tool for renal patients. *J Ren Nurs* 2013;**5**:6–11. https://doi.org/10.12968/jorn.2013.5.1.6
138. Durand M-A, Bekker HL, Casula A *et al.* Can we routinely measure patient involvement in treatment decision making in chronic kidney care? A service evaluation in 27 renal units in the UK. *Clin Kidney J* 2016;**9**:252–9. https://doi.org/10.1093/ckj/sfw003
139. Finderup J, Jensen JKD, Lomborg K. Developing and pilot testing a shared decision-making intervention for dialysis choice. *J Ren Care* 2018;**44**:152–61. https://doi.org/10.1111/jorc.12241
140. Finderup J, Jensen JD, Lomborg K. Shared decision-making in dialysis choice has potential to improve self-management in people with kidney disease: a qualitative follow-up study. *J Adv Nurs* 2021;**77**:1878–87. https://doi.org/10.1111/jan.14726
141. Fortnum D, Smolonogov T, Walker R *et al.* 'My kidneys, my choice, decision aid': supporting shared decision making. *J Ren Care* 2015;**41**:81–7. https://doi.org/10.1111/jorc.12100
142. Fortnum D, Grennan K, Smolonogov T. End-stage kidney disease patient evaluation of the Australian 'my kidneys, my choice' decision aid. *Clin Kidney J* 2015;**8**:469–75. https://doi.org/10.1093/ckj/sfv050
143. Finderup J, Dam Jensen J, Lomborg K. *Dialysis Choice.* Aarhus, Denmark: Aarhus University Hospital, June 2020. https://e-dok.rm.dk/edok/editor/AAUHNY.nsf/vLookupUpload/ATTACH-RMAP-BT4EF6/$FILE/Dialysis%20Choice%2027082020.pdf (27 January 2023, date last accessed).
144. Finderup J, Dam Jensen J, Lomborg K. Evaluation of a shared decision-making intervention for dialysis choice at four Danish hospitals: a qualitative study of patient perspective. *BMJ Open* 2019;**9**:e029090. https://doi.org/10.1136/bmjopen-2019-029090
145. Erlang AS, Nielsen IH, Hansen HOB *et al.* Patients experiences of involvement in choice of dialysis mode. *J Ren Care* 2015;**41**:260–7. https://doi.org/10.1111/jorc.12141
146. Buur LE, Finderup J, Søndergaard H *et al.* Shared decision-making and planning end-of-life care for patients with end-stage kidney disease: a protocol for developing and testing a complex intervention. *Pilot Feasibility Stud* 2022;**8**:226. https://doi.org/10.1186/s40814-022-01184-z
147. Buur LE, Finderup J, Søndergaard H *et al.* Mapping the empirical evidence on patient involvement interventions in patients with end-stage kidney disease making end-of-life care decisions: a scoping review protocol. *JBI Evid Synth* 2022;**20**:1537–44. https://doi.org/10.11124/jbies-21-00090
148. Amir N, McCarthy HJ, Tong A. A working partnership: a review of shared decision-making in nephrology. *Nephrology* 2021;**26**:851–7. https://doi.org/10.1111/nep.13902
149. Patzer RE, McPherson L, Basu M *et al.* Effect of the iChoose Kidney decision aid in improving knowledge about treatment options among transplant candidates: a randomized controlled trial. *Am J Transplant* 2018;**18**:1954–65. https://doi.org/10.1111/ajt.14693
150. Emory University. *iChoose Kidney*. Atlanta, Georgia, USA: Emory University, June 2018. https://ichoosekidney.emory.edu/ (27 January 2023, date last accessed).
151. Ozdemir S, Choong LHL, Gan SWS *et al.* Patient decision aid development for older adults with end-stage kidney disease in Singapore. *Kidney Int Rep* 2021;**6**:2885–96. https://doi.org/10.1016/j.ekir.2021.08.027
152. Engels N, van der Nat PB, Ankersmid JW *et al.* Development of an online patient decision aid for kidney failure treatment modality decisions. *BMC Nephrol* 2022;**23**:236. https://doi.org/10.1186/s12882-022-02853-0
153. Murphy E, Burns A, Murtagh FEM *et al.* The prepare for kidney care study: prepare for renal dialysis versus responsive management in advanced chronic kidney disease. *Nephrol Dial Transplant* 2021;**36**:975–82. https://doi.org/10.1093/ndt/gfaa209
154. Green JA, Ephraim PL, Hill-Briggs FF *et al.* Putting patients at the center of kidney care transitions: PREPARE NOW, a cluster randomized controlled trial. *Contemp Clin Trials* 2018;**73**:98–110. https://doi.org/10.1016/j.cct.2018.09.004
155. Damschroder LJ, Zikmund-Fisher BJ, Ubel PA. The impact of considering adaptation in health state valuation. *Soc Sci Med* 2005;**61**:267–77. https://doi.org/10.1016/j.socscimed.2004.11.060
156. Stiggelbout AM, Voel-Voogt E. Health state utilities: a framework for studying the gap between the imagined and the real. *Value Health* 2008;**11**:76–87. https://doi.org/10.1111/j.1524-4733.2007.00216.x
157. Pieterse AH, Stiggelbout AM. What are values, utilities, and preferences? A clarification in the context of decision making in health care, and an exploration of measurement issues. In: Diefenbach M, Miller-Halegoua S Bowen D, eds. *Handbook of Health Decision Science*. New York, NY:

Springer, 2016, 3–13. https://doi.org/10.1007/978-1-4939-3486-7_1

158. Beauchamp A, Batterham RW, Dodson S *et al.* Systematic development and implementation of interventions to optimise health literacy and access (Ophelia). *BMC Public Health* 2017;**17**:230. https://doi.org/10.1186/s12889-017-4147-5
159. Leventhal H, Phillips LA, Burns E. The common-sense model of self-regulation (CSM): a dynamic framework for understanding illness self-management. *J Behav Med* 2016;**39**:935–46. https://doi.org/10.1007/s10865-016-9782-2
160. Ley P. *Communicating with Patients: Improving Communication, Satisfaction and Compliance*. London, UK: Croom Helm, 1988.
161. Damschroder LJ, Reardon CM, Widerquist MAO *et al.* The updated consolidated framework for implementation research based on user feedback. *Implement Sci* 2022;**17**:75. https://doi.org/10.1186/s13012-022-01245-0
162. Murray E, Treweek S, Pope C *et al.* Normalisation process theory: a framework for developing, evaluating and implementing complex interventions. *BMC Med* 2010;**8**:63. https://doi.org/10.1186/1741-7015-8-63
163. Winterbottom A, Bekker HL, Conner M *et al.* Does narrative information bias individual's decision making? A systematic review. *Soc Sci Med* 2008;**67**:2079–88. https://doi.org/10.1016/j.socscimed.2008.09.037
164. Winterbottom AE, Bekker HL, Conner M *et al.* Patient stories about their dialysis experience biases others' choices regardless of doctor's advice: an experimental study. *Nephrol Dial Transplant* 2012;**27**:325–31. https://doi.org/10.1093/ndt/gfr266
165. NHS Right Care. *Measuring Shared Decision Making – A Review of Research Evidence: A Report for the Shared Decision Making Programme in Partnership with Capita Group Plc*. London, UK: National Health Service, Department of Health, 2012.
166. NHS Right Care. *Your Health, Your Decision – Evaluation & Output Report of the AQuA Workstream within the National Shared Decision Making Programme*. London, UK: National Health Service, Department of Health, 2013.
167. Légaré F, Adekpedjou R, Stacey D *et al.* Interventions for increasing the use of shared decision making by healthcare professionals. *Cochrane Database Syst Rev* 2018;**19**:CD006732. https://doi.org/10.1002/14651858.cd006732.pub4
168. Waddell A, Lennox A, Spassova G *et al.* Barriers and facilitators to shared decision-making in hospitals from policy to practice: a systematic review. *Implement Sci* 2021;**16**:74. https://doi.org/10.1186/s13012-021-01142-y
169. Zeuner R, Frosch DL, Kuzemchak MD *et al.* Physicians' perceptions of shared decision-making behaviours: a qualitative study demonstrating the continued chasm between aspirations and clinical practice. *Health Expect* 2015;**18**:2465–76. https://doi.org/10.1111/hex.12216
170. Craddock M, Crockett C, McWilliam A *et al.* Evaluation of prognostic and predictive models in the oncology clinic. *Clin Oncol (R Coll Radiol)* 2022;**34**:102–13. https://doi.org/10.1016/j.clon.2021.11.022
171. Griffioen IPM, Rietjens JAC, Melles M *et al.* The bigger picture of shared decision making: a service design perspective using the care path of locally advanced pancreatic cancer as a case. *Cancer Med* 2021;**10**:5907–16. https://doi.org/10.1002/cam4.4145

Received: 19.1.2023; Editorial decision: 8.6.2023