

Kidney disease pathways, options and decisions: an environmental scan of international patient decision aids

Anna E. Winterbottom ¹, Andrew Mooney¹, Lynne Russon², Vicki Hipkiss³, Lucy Ziegler⁴, Richard Williams¹, Jeanette Funderup^{5,6} and Hilary L. Bekker^{6,7}

¹Adult Renal Services, Lincoln Wing, St James University Hospital, Leeds, UK, ²Sue Ryder Care, Wheatfields Hospice, Leeds, UK, ³Bradford Renal Unit, Horton Wing, St Luke's Hospital, West Yorkshire, UK, ⁴Academic Unit of Palliative Care, School of Medicine, Leeds Institute of Health Sciences, University of Leeds, Leeds, UK, ⁵Department of Clinical Medicine, Aarhus University Hospital, Aarhus, Denmark, ⁶ResCenPI, Research Centre for Patient Involvement, Aarhus University Central Denmark Region, Aarhus, Denmark and ⁷Leeds Institute of Health Sciences, School of Medicine, University of Leeds, Leeds, UK

Correspondence to: Anna E. Winterbottom; E-mail: a.e.winterbottom@leeds.ac.uk; Twitter handles: @DrAWinterbottom, @BekkerHilary, @finddrup, @LucyZiegler3; @ResCenPI

ABSTRACT

Background. Conservative management is recognized as an acceptable treatment for people with worsening chronic kidney disease; however, patients consistently report they lack understanding about their changing disease state and feel unsupported in making shared decisions about future treatment. The purpose of this review was to critically evaluate patient decision aids (PtDAs) developed to support patient–professional shared decision-making between dialysis and conservative management treatment pathways.

Methods. We performed a systematic review of resources accessible in English using environmental scan methods. Data sources included online databases of research publications, repositories for clinical guidelines, research projects and PtDAs, international PtDA expert lists and reference lists from relevant publications. The resource selection was from 56 screened records; 17 PtDAs were included. A data extraction sheet was applied to all eligible resources, eliciting resource characteristics, decision architecture to boost/bias thinking, indicators of quality such as International Standards for Patient Decision Aids Standards checklist and engagement with health services.

Results. PtDAs were developed in five countries; eleven were publically available via the Internet. Treatment options described were dialysis ($n=17$), conservative management ($n=9$) and transplant ($n=5$). Eight resources signposted conservative management as an option rather than an active choice. Ten different labels across 14 resources were used to name 'conservative management'. The readability of the resources was good. Six publications detail decision aid development and/or evaluation research. Using PtDAs improved treatment

decision-making by patients. Only resources identified as PtDAs and available in English were included.

Conclusions. PtDAs are used by some services to support patients choosing between dialysis options or end-of-life options. PtDAs developed to proactively support people making informed decisions between conservative management and dialysis treatments are likely to enable services to meet current best practice.

Keywords: chronic kidney disease, conservative management, dialysis, kidney failure, patient decision aid, shared decision-making

INTRODUCTION

A notable shift in clinical guidance for managing people with chronic kidney disease (CKD) Stages 4 and 5 [G4+; referred to herein as established kidney disease (EKD)] is to offer conservative management as an active treatment pathway alongside renal replacement therapies, dialysis and transplant [1, 2]. Most kidney services in Europe and North America have established educational programmes to help patients make decisions about their future treatment when their kidney disease is identified as progressing from chronic to EKD [3]. Often known as pre-dialysis education [3, 4], kidney professionals provide information about renal replacement options, focusing on discussions about which options fit best into a patient's life, including haemodialysis (HD) and peritoneal dialysis (PD), with at-home or in-centre options. Conservative management is offered as an active option to manage symptoms arising from failing kidneys in patients meeting certain criteria, e.g. those >75 years of age, with a high level of comorbidity and/or with a poor quality of life [5].

KEY LEARNING POINTS

What is already known about this subject?

- Most kidney services in Europe and North America have established educational programmes to help patients make decisions about their future treatment when their kidney disease is identified as progressing from chronic to established kidney disease (EKD).
- Conservative management is recognized as an acceptable treatment for people with worsening chronic kidney disease; however, patients consistently report they lack understanding about their changing disease state and feel unsupported in making shared decisions about future treatment.
- Patient decision aids (PtDAs) are designed to proactively support people's reasoning when choosing between treatment options. It is unclear if PtDAs are sufficient to help people make informed decisions between conservative management and renal replacement therapy across the longer-term trajectory of kidney disease.

What this study adds?

- Seventeen PtDAs were identified as being designed explicitly to support people with EKD in making treatment decisions. They had at least a standard level of readability and included components encouraging people to think proactively about what mattered to them about their choices and to share their reasoning with health professionals.
- Not all resources were designed to support the conservative management–dialysis decision problem explicitly or supported people making the decision across the trajectory from kidney failure to end-of-life care; there was variation in how conservative management was labelled and positioned within these PtDAs and dialysis options were described.
- These data, the kidney disease pathways, options and decision figure and International Standards for Patient Decision Aids Standards checklist may help structure a PtDA enabling people to explore what is important to them about this changing pathway of care when sharing decisions with kidney professionals.

What impact this may have on practice or policy?

- These findings suggest a conservative management and dialysis decision aid needs to be built on evidence about how people with worsening kidney disease make decisions about their health now, and in the future, and how kidney professionals negotiate the different service pathways to deliver care to patients as their care needs change as their kidneys fail.

The conservative management and renal replacement therapy decision is complex and can be seen as a hierarchy of nested decisions (see [Figure 1](#), adapted from Winterbottom

et al. 2020 [6]) rather than a choice between discrete options [7]. Decision-making takes place in the context of managing a long-term condition, with patients and professionals deliberating about treatment changes over months and years as kidney function stabilizes or continues to decline [8]. Patients may switch or stop treatments as treatments fail, health worsens and life circumstances change [9]. This dynamic context may explain why decision points are not easily identified or discussed and why patients may not be aware their kidney disease is worsening [10] or may not be prepared to make shared decisions about future treatment with kidney professionals [11].

This study critically evaluates the validity of patient decision aids (PtDAs) to support people with kidney disease making informed decisions between conservative management and dialysis options. PtDAs are designed to proactively support people's reasoning between treatment options [12]. PtDAs use evidence from the decision sciences to ensure resources structure explicitly the decision problem, provide accurate and balanced information about all options and their consequences, enable people to evaluate these facts with their own values and reach a decision based on a trade-off of these evaluations. Studies evaluating PtDAs for the choices-between-dialysis decision show they increase patient knowledge and understanding of their kidney disease and their readiness to make a decision, helping them make dialysis decisions aligned with their preferences [8, 13–17]. It is unclear if PtDAs are sufficient to proactively support people's informed decisions between conservative management and renal replacement therapy across the longer-term trajectory of kidney disease [17, 18].

The purpose of this work was to critically evaluate PtDAs developed to support patient–professional shared decision-making between dialysis and conservative management treatment pathways for people with EKD via an environmental scan of resources.

MATERIALS AND METHODS

Design

We used a survey design employing an environmental scan method [19–21] of PtDAs for people with EKD making treatment decisions between dialysis options and/or conservative management. We used systematic review guidance to inform all steps of the search, extraction and synthesis of evidence from the PtDAs [12, 22, 23].

Study context

This study was carried out as part of the Developing the Yorkshire Dialysis versus Conservative-Management Decision Aid (YoDCA) project, funded by Kidney Research Yorkshire, 2017–2019 (ref: YKRF 16-118) [7].

Information sources and search strategies

Four data sources were searched to identify PtDAs:

1. MEDLINE (1996–August Week 4 2019) and PsycInfo (2002–August Week 3 2019) online databases were searched using a combination of the search terms: CKD/

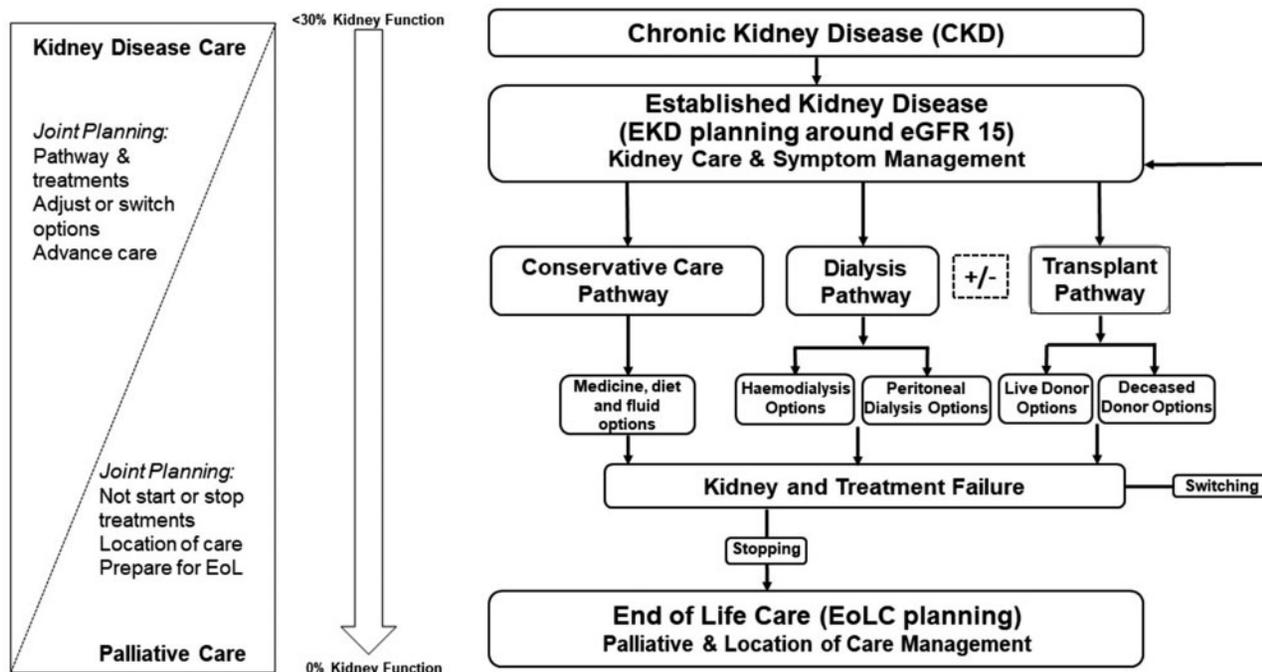


FIGURE 1: Decision map of the kidney disease pathways, options and decisions when managing kidney failure.

- end-stage kidney disease/end-stage renal failure/CKD Stage 5 (disease context), dialysis/conservative management/conservative care (treatment) and decision-making/shared decision-making/decision aid (contact authors for further information);
- open access repositories of PtDAs, e.g. Decision Aids Library Inventory [Ottawa Health Research Institute, Canada (<https://decisionaid.ohri.ca/>)]; UK and US clinical guidelines database [National Institute of Health and Care Excellence (NICE) (<https://www.nice.org.uk/guidance>) and UK clinical trials databases (<https://www.journalslibrary.nihr.ac.uk/#/>; <https://clinicaltrials.gov/>)];
 - international experts in shared decision-making, renal clinicians, authors and collaborators known to specialize in the field of decision-making for patients with EKD were contacted; and
 - reference lists from relevant research studies in the field.

Inclusion/exclusion criteria

Inclusion criteria were PtDAs designed for adults with CKD, aimed at facilitating decisions about conservative management and renal replacement options (HD, PD and transplant) and accessible in English.

Exclusion criteria were resources where the goal was to inform about CKD management (CKD Stages 1–3), end-of-life (EoL) care (advance care and palliative care planning), involvement in care (preparation for talking with health professionals, friends and family), quality improvement and education/communication skills interventions. One PtDA was not available for inclusion [24]. PtDAs were screened for inclusion by A.E.W. and decisions were discussed by A.M. and H.L.B. and independently reviewed by J.F., L.Z. and A.M.

Data extraction form

A data extraction form was developed with reference to PtDA development, evaluation and standards [25–29], decision science reviews of components known to minimize bias and boost active thinking [30–35], explanations of people’s understanding of illness and treatment [36–38] and our prior research [8, 19, 39–44]. It was applied systematically (A.E.W.) to all PtDAs eliciting:

- characteristics: title, publisher, year, country, authors, funders, location (URL), length, stated purpose resource;
- quality indicators: readability [45], endorsed by a third party, developed systematically and/or evaluated, lists evidence/resources used to inform content;
- a description of the health issue: information about the health issue (label and/or symptoms, cause, timeline, consequences, cure and/or control, and emotional responses) and disease trajectory (worsening CKD, pathways of care and quality of life);
- engagement with health services and support: preparation for consultations, shared decision-making with health teams and/or friends and family and/or other services (charity, patient advocacy groups) and preparation for procedures (photos, pictures and diagrams);
- a description of the treatment options and consequences: label and/or procedure, eligibility, prognosis, cure, side effects, impact on lifestyle and stopping or switching options;
- decision architecture to boost/bias thinking: representation decision problem, value elicitation and/or trade-off prompts, decision guidance or ‘metacognition’ statements, other’s stories and experiences, risk presentation; and
- eHealth architecture to boost engagement with resources: portable document format (PDF) and/or interactive

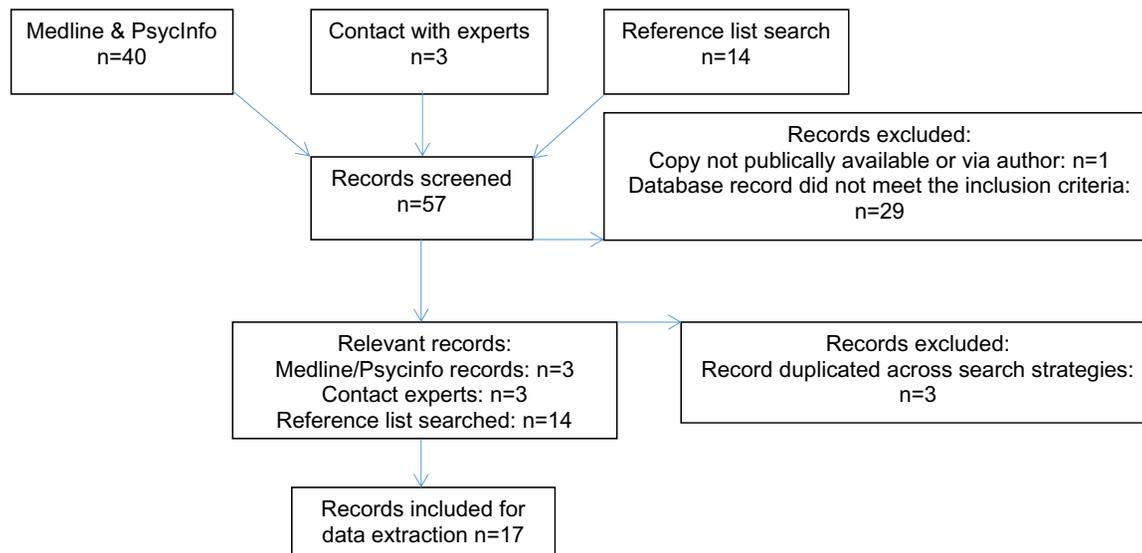


FIGURE 2: Flow diagram for identification of PtDA resources included within the environmental scan of resources.

website, personalized, tailored, orientation, tracking, value prompts, drilling down and timing of use.

Data synthesis and analysis

To critically evaluate the PtDAs, we developed two resource quality grids to synthesize evidence elicited from the data extraction. The grids summarized the active ingredients of the resources with reference to the International Patient Decision Aids Standards (IPDAS) checklist [21, 46] and components known to boost active and minimize biased thinking [19, 25, 41]; each item was scored either 0 (not present) or 1 (present) and a total score was calculated by resource for each grid. Data were managed using SPSS (version 23; IBM, Armonk, NY, USA).

During this analysis phase, we developed a decision map with reference to clinical guidelines [National Institute for Health and Care Excellence (NICE)/Kidney Disease: Improving Global Outcomes (KDIGO)] to represent the key decision points and options for managing kidney failure and progression towards EoL (Figure 1). Drafts of the decision map were discussed with the YoDCA project steering group and kidney service teams in the UK and Denmark and modified to ensure its utility to represent the treatment pathways and decisions within usual care settings. Narrative supported by frequency data is used to address whether or not current PtDAs are designed to proactively support people's reasoning between conservative and dialysis management pathways of care.

RESULTS

Search strategies yielded 57 unique, potentially eligible resources for assessment, with 17 meeting the inclusion criteria after screening (Figure 2). All PtDAs were available in English and four in other languages. Resources varied in length between 1 and 55 pages {mean 13.5 [standard deviation (SD) 14.2]}; the

readability score ranged from difficult to easy [55–89; mean 65.1 (SD 7.71); Flesch readability scale (0–100, difficult–easy; 60+ standard; Table 1].

All PtDAs were designed to complement pre-dialysis consultations, six for use within consultations (PtDAs 4, 6, 7, 8, 16, 17), two for use with caregivers (PtDAs 1, 6) and two for use with a decision coach (PtDAs 8, 16). They were all available as booklets and PDF files and as interactive websites (PtDAs 2, 5, 7, 9, 10, 11, 13–15); additional materials included an audio file (PtDA 3), videos (PtDAs 6, 8), a staff user guide (PtDA 4), drawings (PtDA 6), a patient worksheet (PtDA 3), a development document (PtDA 7) and risk information (PtDA 16).

Less than half published the PtDAs development and/or evaluation research (PtDAs 1, 3–7, 13; Table 2). Six were endorsed by a third party: IPDAS (PtDAs 1, 3, 6, 9, 10, 13), health professional bodies (PtDAs 1, 14) and patient organizations (PtDAs 1, 12, 14; Table 1). One-third provided details about the funder (PtDAs 1, 4, 5, 9–11). Of those describing their developers, 10 included a kidney professional (PtDAs 1, 3, 4, 6, 7, 9–11, 13, 14), 2 primary care professionals (PtDAs 7, 9), 5 a patient or public and patient involvement advocate (PtDAs 1, 3, 5, 6, 14), 5 a pharmaceutical company (PtDAs 1, 4, 7, 13, 14) and 5 a decision scientist or applied health researchers (PtDAs 1, 3, 4, 7, 14).

Framing the decision problem, options and consequences

All PtDAs ($n = 17$) aimed to support dialysis decisions, but their decision focus was different (Table 3). Eight focused on between-dialysis modality decisions (PtDAs 1, 2, 5, 6, 8, 11, 13, 14), five included information about conservative management (PtDAs 1, 2, 5, 6, 14), four focused on dialysis versus conservative management options (PtDAs 3, 9, 10, 16) and five focused on dialysis, conservative management and transplantation

Table 1. Characteristics of PtDAs designed to support patients with CKD in making treatment choices

PtDA ID	Title	Organization	Location	Resource availability	Publicly available	Year published	No. pages ¹	Flesch readability score	Endorsement by third party
1	Dialysis Decision Aid booklet: Making the right choices for you	Kidney Research UK (charity)	UK	Online PDF	✓	2014	55	58.9	✓
2	NHS Rightcare—Established Kidney Failure (Kidney Dialysis) decision Aid.	Totally Health/NHS (healthcare service)	UK	Online PDF	✓	2017	10	63.6	
3	The Choice of Dialysis for the Older Person with End-Stage Kidney Disease: A Decision Aid for Patients	Queensland University of Technology (academic institution)	Australia	PDF and audio CD, worksheet	✓	–	36	70.7	✓
4	'My Kidney's, My Choice'. A decision aid for the treatment of kidney disease.	Kidney Health Australia; Kidney Health New Zealand; Home Dialysis (charity)	Australia and New Zealand	Online PDF, staff handbook, available and adapted by the Canadian Kidney Knowledge Translation and Generation Network (CANN-NET) website	✓	–	15	61.4	
5	Choosing dialysis: empowering patients for choices on renal replacement therapy	Ann Arbor Research Collaborative for Health (not for profit organization)	USA	Interactive website and online PDF	✓	2017	9	68.7	
6	Dialysis Choice	Aarhus University (academic institution)	Denmark	PDF, four videos and a book of photographs/drawings	✓	–	16	70.1	✓
7	Option Grid: Chronic Kidney Disease: treatment options	Option Grid Collaborative: The Dartmouth Institute (academic institution)	UK	Web based and online PDF	✓	2015	1	63.2	
8	Shared End-Stage Renal Patients Decision-Making	The Ottawa Hospital (healthcare service)	Canada	PDF, YouTube video with scripted drama about use of shared decision-making and decision aid	✓	2014	4	67.6	
9	Conservative Kidney Management	Kidney Health Strategic Clinical Network TM of Alberta Health Services, Northern Alberta Renal Programme, Southern Alberta Renal Programme and Alberta Innovates Health Solutions (multi-organization healthcare service)	Canada	Interactive website	✓	2017	3	70.1	
10	Kidney Failure: Should I Start Dialysis?	Healthwise (not for profit organization)	USA	Interactive website and online PDF	✓	–	10	62.6	✓
11	Kidney failure: What type of dialysis should I have?	Healthwise (not for profit organization)	USA	Interactive website and Online PDF	✓	–	14	63.9	✓
12	Dialysis decision aid: Brighton and Sussex University Hospitals NHS Trust	Brighton and Sussex University Hospitals NHS Trust (healthcare service)	UK	Online PDF	✓	2013		62.1	✓
13	My Life, My Dialysis Choice.	Medical Education Institute (not for profit organization)	USA	Interactive website and online PDF	✓	2016	3	88.6	✓
14	The Yorkshire Dialysis Decision Aid	University of Leeds	UK	Research website	✓	2014	11	59.0	✓
15	Established Kidney Failure decision aid—NHS Rightcare	Totally Health/NHS (healthcare service)	UK	Web based and online PDF	✓	2017	6	62.9	
16	Ottawa decision aid: Dialysis versus non-comprehensive dialysis care	The Ottawa Hospital (healthcare service)	Canada	Paper, additional sheets on risk		2016	4	56.3	
17	Renal Treatment Options Grid: comparing treatment options for when your kidneys are not working	The Ottawa Hospital (healthcare service)	Canada	Paper		2014	5	55.4	

Table 2. Overview of studies piloting and/or evaluating a selection of decision aids ($n = 7$)

Decision aid ref no.	Title	Treatment options	Sample	Theoretical background/developmental framework	Study design	Outcome variables	Findings
1	Dialysis Decision Aid booklet: Making the right choices for you	Four dialysis options—Home HD Hospital Dialysis, Automated PD, Continuous Ambulatory PD	105 Usual Care and 84 + decision aid patients	Review of clinical guidelines, service frameworks and existing patient information; patient and professional surveys of dialysis choices and kidney disease experience using decision analysis and behavioural decision support guidance	Prospective, randomized pre- and post-test with historic controls	Sample and clinical characteristics, patient-reported health-related QoL (EQ-5D); usefulness of information: ease to read, understanding of illness, treatments and choices, sufficient to make a decision, satisfaction with care; use of decision aid. Decision-making processes: control over choice, sharing decision with and views of others, difficulty in refusing Doctor recommendations, dialysis choice preference, knowledge, perceived seriousness and risk complications, Brief Illness Perception	Patients valued receiving decision aid, 96% read it on their own, and/or shared with family (72%). Decision aid participants had higher scores for understanding kidney disease, reasoning about options, feeling in control, sharing decision with family than usual care group. Decision aid study uptake by staff ~45%
3	A Decision Aid for Patients: The choice of dialysis for the older person with End-Stage Kidney Disease. Study Protocol	Dialysis versus conservative management	Study ongoing	Ottawa decision support framework	Single-blind randomized controlled trial	Decision regret scale, decisional conflict scale, knowledge: quality of life; preparation for decision-making; clinical characteristics	Study ongoing
4	My Kidneys, My Choice	Transplantation, dialysis (HD, PD, continuous ambulatory PD, automated PD) conservative care	National distribution of decision aid to patients; training provided to over 2000 health professionals. Feedback from 100 health professionals; 100 patients	Concept development, engagement of relevant stakeholders, international literature review, structured brainstorming, document development and critical review; review of IPDAS guidelines	Patient survey; prospective quasi-experimental design with a one-group pre-test/post-test Health Professional: online survey	Patient evaluation: knowledge, fears, decision-making Health Professional: use of decision aid, intention/barriers to use, supporting the understanding of options, assisting understanding of the patients' priorities and for supporting decision-making	Health Professionals: New Zealand 55% of units use DA—18% are planning future use; Australia—25 Health Professionals use decision aid, Health Professionals report decision aid: supported understanding of: options, patients' priorities' and decision-making.

5	Choosing dialysis: empowering patients for choices on renal replacement therapy	HD versus PD	70 control group: 63 intervention group	Literature review, US Renal Data System data, results from previous studies by research team, a multi-stakeholder panel reviewed and refined decision aid, IPDAS checklist	Randomized controlled trial	Treatment preference, decisional conflict, decision self-efficacy, preparation for decision-making and knowledge	Formal consumer research—ongoing Improved knowledge, better preparation for decision-making and reduced decisional conflict but no significant improvement in decision self-efficacy
6	Dialysis Choice	Four dialysis options—home HD, hospital HD, PD, assisted PD	137 tested decision aid intervention; 16 patients completed questionnaire	Elwyn <i>et al.</i> (2012) model for shared decision-making; IPDAS guidelines; based on 'Option grid' (Pritchard and Thomas, 2012) My Kidneys, My Choice [13] and YoDDA [8]; literature review and patient interviews	Feasibility and piloting—prospective study using survey methods	The 9-item Shared Decision-Making Questionnaire (SDM Q9); 'Decision Quality Measure' (DQM)—knowledge and readiness; patient choice; treatment initiated	Increase in home dialysis, patients perceived shared decision-making occurred, patients had good knowledge and readiness scores
7	Option Grid	Four dialysis options, conservative management and transplant	65 patients at Time 1 and 39 patients at Time 2	Option Grid template (Elwyn <i>et al.</i> , 2012)	Pre- and post-test	DQM	Increased knowledge and increased readiness to make a decision
13	My Life, My Dialysis Choice	Four dialysis options—PD, Standard HD (in-centre), Daily HD, Nocturnal HD	106 comments from 'consumers' once launched online	Modification and refinement of previous research conducted at Medical Education Institute, brainstorming/pilot feedback agreement on content	Developmental article	Written feedback	Feedback incorporated in to decision aid to improve content

Table 3. Representation of the decision problem within resources (n = 17)

Decision options and treatment labels	Decision aid reference number																
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
Decision																	
Dialysis modality	X	X			X	X		X			X		X	X			
Dialysis versus conservative management			X						X	X							X
Dialysis versus conservative management versus transplantation				X			X					X			X		X
Treatment labels for conservative management																	
Conservative care	X	X		X										X	X		
Conservative management (no dialysis or transplant)							X										
Conservative kidney management									X								
Comprehensive non-dialysis care																	X
Non-dialysis management/supportive care			X														
Conservative management/supportive care					X												
Supportive care/maximum conservative care/choosing not to have any RRT												X					
Supportive management (no dialysis or transplant)																	X
Do not start dialysis										X							
Medical treatment only						X											
Not mentioned								X			X		X				
Decision map	X	X		X	X					X		X		X	X	X	

options (PtDAs 4, 7, 12, 15, 17). Different terms were used to describe dialysis and conservative management options across PtDAs (Table 3); HD and PD options were described with terms about treatment location, such as home, hospital or assisted, while conservative management used terms supporting an active (e.g. conservative care/conservative kidney management) or passive option (non-dialysis/not having kidney replacement therapy; Table 3). Some (n = 9) added a decision map to represent the decision problem and/or options in the context of managing kidney failure (PtDAs 1, 2, 4, 5, 10, 12, 14–16; Table 3).

Enabling understanding of worsening kidney disease and treatment options

Twelve PtDAs provided a description of CKD (Table 4); three (1,5,14) had information about all five schema of the illness representation framework (label, cause, consequences, timeline and control) and nine (PtDAs 1, 3, 5, 6, 9, 12–14, 17) had descriptions to help place the decision in the context of a changing health state (Table 5). The terms used to describe kidney disease were CKD (PtDAs 1, 5, 7, 10–12, 14, 17), EKD (PtDA 1), progressive kidney disease (PtDA 1), end-stage kidney disease (PtDAs 3, 8), advanced kidney disease (PtDA 5), advanced CKD (PtDA 9), kidney failure (PtDAs 1, 4–6, 10–12) established kidney failure (PtDAs 1, 2, 12, 14, 15) and established renal failure (PtDA 14) and end-stage kidney failure (PtDA 16). Five (PtDAs 1, 5, 9, 12, 14) included diagrams or photographs of kidneys in the body; some had pictures associated with dialysis, such as fistulas and catheters (PtDAs 5, 9), equipment (PtDAs 3, 5, 6, 9–12) and having dialysis (PtDAs 3, 5, 6, 8, 10–12); two included photographs of health professionals and/or patients with kidney failure (PtDAs 5, 12).

Most resources (Table 4) described positive (benefits, medical and psychosocial advantages) and negative features (harms, side effects, medical and psychosocial disadvantages) of all options; 10 resources presented the advantages and disadvantages of options in parallel, in full or in summary form (PtDAs 1, 2, 6, 7,

9, 10, 12, 14, 15, 17). Conservative management-focused PtDAs mentioned advance care planning (PtDAs 9, 12), palliative and/or hospice care (PtDAs 9, 10, 16, 17), palliative care doctor (PtDAs 9, 10) death (PtDAs 3, 9, 10, 16) and place of death (PtDAs 3, 9) options; only two dialysis-focused PtDAs (1, 14) mentioned palliative care doctors. No PtDAs talked about dialysis treatment failure and the consequences of switching or EoL.

Risk figures of treatment effectiveness or disease prevalence were rarely described (Tables 4 and 5). Those that did included risk as percentages (PtDAs 2, 9, 16), using positive and negative frames (PtDAs 2, 3), iconographs (PtDAs 3, 9, 16) and natural numbers with the same (PtDAs 3, 9, 15, 16) or different (PtDAs 2) denominators within a resource. Most PtDAs (n = 14) encouraged people to think about what was important to them about the treatment or their life (PtDAs 1–6, 8, 10–16), with 13 (PtDAs 1, 3–6, 8–14, 16) using prompts to help make trade-offs between options (Table 4). A few included patient stories about how to make a decision or cope with a diagnosis or treatment (PtDAs 5, 8, 10, 11).

Most PtDAs used metacognition statements to guide people's reasoning or focus their thinking on decision-relevant information (Table 5). Most (PtDAs 1–3, 5, 6, 8–11, 14–16) encouraged people to discuss the decision with friends and family and show others the PtDA. Most signposted other kidney patient resources or organizations (PtDAs 1, 4, 5, 6, 8, 9, 12, 13, 14) and provided prompts to help people discuss these issues with their kidney health professional (Table 5).

DISCUSSION

It was encouraging to identify 17 PtDAs from five countries designed explicitly to help people with EKD make treatment decisions. These PtDAs had at least a standard level of readability (an ~14-year-old readability level) [40] and included components encouraging people to think proactively about what mattered to them about their choices and share their reasoning with health professionals; perhaps explaining why using these

Table 4. Judgements of inclusion of IPDAS minimum standard components by resource (n = 17 [21, 46])

Quality assessment of DAs according to the IPDASi v4 criteria	Decision aid reference number																	Number of resources including component
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	
Judgements	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	
DA describes health condition or problem	X		X	X	X	X			X	X	X	X		X		X	X	12
DA explicitly states decision to be considered	X	X	X	X	X	X		X	X	X	X	X		X	X	X	X	15
DA describes the options	X	X	X	X	X	X	X	X	X	X	X	X		X	X	X	X	16
DA describes the positive features of each option	X	X	X	X	X	X	X		X	X	X	X		X	X	X	X	15
DA describes the negative features of each option	X	X	X	X	X	X	X		X	X	X	X		X	X	X	X	15
DA describes what it is like to experience the psychosocial consequences of the options	X	X	X	X	X				X					X			X	8
DA shows the negative and positive features of options in equal detail (similar fonts/sequence/representation of statistical information)	X	X	X	X	X	X			X	X	X	X		X	X	X	X	14
DA provides citations to the evidence selected	X	X	X		X		X		X		X	X	X	X	X		X	11
DA provides a production/publication date		X			X		X	X	X			X	X	X	X	X	X	11
DA provides information about the update policy	X	X					X					X			X			5
DA provides information about levels of uncertainty around event or outcome probabilities		X	X						X						X	X		5
DA provides information about the funding source used for development	X				X	X	X		X	X	X		X	X				9
Total IPDAS score out of 12	10	10	9	8	10	7	6	3	11	7	8	9	3	10	9	8	9	

Table 5. Judgements about components known to actively support informed and shared decision-making (IDM/SDM) by resource (n = 17)

Active IDM components	Study number of resources meeting study criteria																	Number of resources including component
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	
1. Provides accurate information about all options (IDM)	X	X	X	X	X	X	X	X	X	X	X	X		X	X	X	X	16
2. Helps people think about what matters to them about the options (IDM)	X	X	X	X	X	X		X		X	X	X	X	X		X		13
3. Supports reasoning about all options without bias (IDM)	X	X	X	X	X	X	X	X	X			X	X	X	X	X	X	15
4. Presents numerical figures in ways to support understanding (IDM)	X	X				X			X			X	X	X		X		8
5. Encourages people to trade-off their evaluations to make a choice (IDM)	X	X	X	X	X	X		X	X	X	X	X	X	X	X	X	X	15
6. Encourages people to share reasoning with their health professionals (SDM)	X		X	X	X	X	X	X				X		X		X		10
7. Focusses thinking about the decision in the context of their lifestyle (IDM)	X	X	X	X	X			X		X	X	X	X	X		X	X	13
8. Places the decision in the context of a changing illness-health state (IDM)	X		X		X	X			X			X	X	X			X	9
Total judgement score (out of eight)	8	6	7	6	7	7	3	6	5	4	4	8	6	8	3	7	4	

PtDAs within kidney services enhances people's experience of making shared decisions (ptDAs 1, 4–7). However, not all resources were designed to support the conservative management–dialysis decision problem explicitly [47], and there was variation in how conservative management was labelled and positioned within these PtDAs, how dialysis options were described and how changes to kidney disease stages were summarized. Of the 17 PtDAs identified, none included the components needed to proactively support people in making the decision between conservative management and dialysis across the trajectory from kidney failure to EoL care.

PtDAs varied in their content and structure. Conservative management was inconsistently labelled between decision aids and few resources considered EoL issues for patients on dialysis, despite withdrawal from dialysis leading to death [9] and the recognized high mortality rate among prevalent dialysis patients (~20% per annum [48]). This suggests that (i) information between options is not presented in a balanced way, (ii) patients choosing conservative management are more likely than dialysis patients to consider and/or be prepared for what happens at the end of treatment and (iii) advance care planning directives are not being discussed with all patients. These

variations in content and detail may reflect the differential focus of developers to capture by-service differences in treatment availability, a lack of clarity in guidelines to inform education programmes and/or quality improvement priorities for services around a specific treatment option or pathway.

Our analysis identified a number of components likely to support people's reasoning in this context (Tables 4 and 5): description of kidney failure and consequences for EoL care; make explicit the decision problems in the context of long-term management; labelling of conservative management as an active option and treatment failure as a consequence of kidney replacement therapies, including dialysis modalities; if risk figures are presented, ensure they are described using the same format throughout the PtDA (e.g. x in 1000; $y\%$); table summaries can help people compare across options but depend on which options and attributes are selected and described; prompts to help people think about what is important to them in their lives, after the decision is made; and make explicit people's preferences may change as their circumstances and treatment evidence changes. However, people react differentially to patient stories and/or images and including anecdotes or pictures of people receiving treatment may bias other's judgements and choices [41, 49].

Limitations of this environmental scan method are that it provides a snapshot of resources at a given time, may exclude some resources not available in the public domain or accessible in English and bases evaluations on observations of the PtDAs alone, without assessing details within other development or endorsement documents (e.g. <https://www.nice.org.uk/about/what-we-do/into-practice/endorsement>). We are confident that our findings are valid, as the survey was carried out with rigour; we followed a systematic process (the Preferred Reporting Items for Systematic Reviews and Meta-Analyses), drew on established guidelines for delivery of kidney services (NICE/KDIGO) and PtDA standards (IPDAS) and discussed, adjusted and agreed on all search, inclusion/ exclusion, analysis and synthesis decisions with our interdisciplinary, multi-stakeholder steering committee.

A challenge for developing PtDAs for people with EKD is the long-time worsening of the disease means a person's social circumstances, lifestyle, treatment preferences and services provision of treatment options may change from the point at which a care plan is agreed upon and implemented. These findings suggest a conservative care dialysis decision aid needs to be built on evidence about how people with worsening kidney disease make decisions about their health now, and in the future, and kidney professionals negotiate the different service pathways to deliver care to patients as their care needs change as their kidneys fail. These data, the kidney disease pathways, options and decision figure and IPDAS checklist may help structure a PtDA enabling people to explore what is important to them about this changing pathway of care when sharing decisions with kidney professionals [50].

FUNDING

Financial support provided entirely by Kidney Research Yorkshire (formerly Yorkshire Kidney Research Fund, KRF 16-

118. Winterbottom, Bekker, Russon and Mooney: Designing a decision aid intervention to enable renal professionals support patients making choices about conservative; 2017, 24 months). The funding agreement ensured authors' independence in study design, data interpretation, writing and publication. Study protocol presented at Sheffield Dialysis Research Day, April 2018; UK Kidney Week 2018 and Renal Supportive Care Conference, September 2018.

AUTHORS' CONTRIBUTIONS

A.E.W., H.L.B. and A.M. were the study leads. All authors contributed to the design, data interpretation, report writing and approval of the final manuscript.

CONFLICT OF INTEREST STATEMENT

A.E.W., H.L.B., A.M. and J.F. developed three resources evaluated in this review. H.L.B. and A.M. were advisors to two further UK resources. None of the authors have any financial conflicts of interest. A.M. is a scientific advisor to Kidney Research Yorkshire (KRY) but played no role in the funding of this project. The application was reviewed by external committee. A.M. is not a voting member of the KRY committee.

REFERENCES

1. National Institute for Health and Care Excellence. Renal Replacement Therapy and Conservative Management. 3 October 2018. [nice.org.uk/guidance/ng107](https://www.nice.org.uk/guidance/ng107) (22 April 2020, date last accessed)
2. Levin A, Stevens P, Bilous R *et al*. KDIGO 2012 clinical practice guideline for the evaluation and management of chronic kidney disease. *Kidney Int Suppl* 2013; 3: 136–150
3. Van den Bosch J, Warren D, Rutherford P. Review of pre-dialysis education programs: a need for standardization. *Patient Prefer Adherence* 2015; 9: 1279–1291
4. Carlo B, Crepaldi C, Dean J *et al*. Quality standards for predialysis education: results from a consensus conference. *Nephrol Dial Transplant* 2015; 30: 1058–1066
5. Roderick P, Rayner H, Tonkin-Crime 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. *Health Serv Deliv Res* 2015; 3: 1–186
6. Winterbottom AE, Mooney A, Russon L *et al*. Critical review of leaflets about conservative management used in UK renal services. *J Renal Care* 2020. doi: 10.1111/jorc.12327.
7. Winterbottom A, Bekker HL, Russon L *et al*. Dialysis vs conservative management decision aid: a study protocol. *J Kidney Care* 2018; 3: 179–183
8. Winterbottom AE, Gavaruzzi T, Mooney A *et al*. Bekker HL 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: 374–381
9. Murphy E, Germain MJ, Cairns H *et al*. International variation in classification of dialysis withdrawal: a systematic review. *Nephrol Dial Transplant* 2014; 29: 625–635
10. Bristowe K, Selman LE, Higginson IJ *et al*. Invisible and intangible illness: a qualitative interview study of patients' experiences and understandings of conservatively managed end-stage kidney disease. *Ann Palliat Med* 2019; 8: 121–129
11. Van Biesen W, van der Veer SN, Murphy 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

12. 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
13. 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: 469–475
14. Funderup J, Jensen JKD, Lomborg K. Developing and pilot testing a shared decision-making intervention for dialysis choice. *J Renal Care* 2018; 44: 152–161
15. Subramanian L, Junhui Zhao J, Zee J *et al*. Use of a decision aid for patients considering peritoneal dialysis and in-center hemodialysis: a randomized controlled trial. *Am J Kidney Dis* 2019; 74: 351–360
16. Prichard A, Thomas N. The option grid: a shared decision making tool for renal patients. *J Renal Nurs* 2013; 5: 6–11
17. Thorsteinsdottir B, Pawar A, Pajouhi A. Effectiveness of decision aids in promoting knowledge and shared decision around treatment for end stage renal disease – a systematic review and meta-analysis. Poster presentation. *ASN Conference, Washington, DC, 2019*.
18. Davis JL, Davison SN. Hard choices, better outcomes: a review of shared decision-making and patient decision aids around dialysis initiation and conservative kidney management. *Curr Opin Nephrol Hypertens* 2017; 26: 205–213
19. Mahmoodi N, Bekker HL, King NV *et al*. Are publicly available internet resources enabling women to make informed fertility preservation decisions before starting cancer treatment: an environmental scan? *BMC Med Inform Decis Mak* 2018; 18: 104–116
20. Graham P, Evitts T, Thomas-MacLean R. Environmental scans: how useful are they for primary care research? *Can Fam Physician* 2008; 54: 1022–1023
21. Portocarrero MEL, Garvelink MM, Becerra Perez MM *et al*. Decision aids that support decisions about prenatal testing for Down syndrome: an environmental scan. *BMC Med Inform Decis Mak* 2015; 15: 76
22. Centre for Reviews Dissemination. *Systematic Reviews: CRD's Guidance for Undertaking Reviews in Healthcare*. York: Centre for Reviews & Dissemination; 2009. https://www.york.ac.uk/media/crd/Systematic_Reviews.pdf (6 February 2019, date last accessed)
23. Moher D, Liberati A, Tetzlaff J *et al*. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS Med* 2009; 6: e1000097
24. Ameling J, Priscilla Auguste P, Ephraim P *et al*. Development of a decision aid to inform patients' and families' renal replacement therapy selection decisions. *BMC Med Inform Decis Mak* 2012; 12: 140–153
25. Bekker H, Thornton JG, Airey CM *et al*. Informed decision making: an annotated bibliography and systematic review. *Health Technol Assess* 1999; 3: 1–156
26. Coulter A, Stilwell D, Kryworuchko J *et al*. A systematic development process for patient decision aids. *BMC Med Inform Decis Mak* 2013; 13(Suppl 2): S2
27. 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: 417–410
28. Sepucha KR, Abhyankar P, Hoffman AS *et al*. Standards for universal reporting of patient decision aid evaluation studies: the development of SUNDAE checklist. *BMJ Qual Saf* 2018; 27: 380–388
29. Elwyn G, O'Connor AM, Bennett C *et al*. Assessing the quality of decision support technologies using the International Patient Decision Aid Standards Instrument (IPDASI). *PLoS ONE* 2009; 4: e4705
30. Witteman H, Scherer L, Gavaruzzi T *et al*. Design features of explicit values clarification methods: a systematic review. *Med Decis Making* 2016; 36: 453–471
31. Pieterse AH, de Vries M, Kunneman M *et al*. Theory informed design of values clarification methods: a cognitive psychological perspective on patient health-related decision making. *Soc Sci Med* 2013; 77: 156–163
32. 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(Suppl 2): S9
33. Fagerlin A, Zikmund-Fisher B, Ubel P. Helping patients to decide: ten steps to better risk communication. *J Natl Cancer Inst* 2011; 103: 1436–1443
34. Trevena LJ, Zikmund-Fisher BJ, Edwards A *et al*. Presenting quantitative information about decision outcomes: a risk communication primer for patient decision aid developers. *BMC Med Inform Decis Mak* 2013; 13(Suppl 2): S7. doi.org/10.1186/1472-6947-13-S2-S7.
35. Shaffer VA, Hulseley L, Zikmund-Fisher BJ. The effects of process-focused versus experience-focused narratives in a breast cancer treatment decision task. *Patient Educ Couns* 2013; 93: 255–264.
36. Ley P. *Communicating with Patients: Improving Communication, Satisfaction and Compliance*. London, UK: Croom-Helm, 1988.
37. Leventhal A, Benyamini Y, Brownlee S *et al*. Chapter 1 – Illness representations: theoretical foundations. In: KJ Petrie, JA Weinman (eds). *Perceptions of Health and Illness. Current Research and Applications*. Amsterdam, The Netherlands: Harwood Academic, 1997
38. Horne R, Weinman J. Patients' beliefs about prescribed medicines and their role in adherence to treatment in chronic physical illness. *J Psychosom Res* 1999; 47: 555–567
39. Winterbottom A, Bekker HL, Conner M *et al*. Choosing dialysis modality: decision making in a chronic illness context. *Health Expect* 2014; 17: 710–723
40. Winterbottom A, Bekker HL, Conner M *et al*. Evaluating the quality of patient information provided by renal units across the UK. *Nephrol Dial Transplant* 2007; 22: 2291–2296
41. Winterbottom A, 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: 325–331
42. Hussain J, Mooney A, Russon L. Comparison of survival analysis and palliative care involvement in patients aged over 70 years choosing conservative management or renal replacement therapy in advanced chronic kidney disease. *Palliat Med* 2013; 27: 829–839
43. Bekker HL, Hewison J, Thornton JG. Understanding why decision aids work: linking process with outcome. *Patient Educ Couns* 2003; 50: 323–329
44. Bekker HL. The loss of reason in patient decision aid research: do checklists affect the validity of informed choice interventions? *Patient Educ Couns* 2010; 78: 357–364
45. Flesch R. A new readability yardstick. *J Appl Psychol* 1948; 32: 221–233
46. Joseph-Williams N, Newcombe R, Mary Politi M *et al*. Toward minimum standards for certifying patient decision aids: a modified Delphi consensus process. *Med Decis Making* 2014; 34: 699–710
47. Winterbottom AE, Mooney A, Russon L *et al*. Critical review of leaflets about conservative management used in UK renal services. *J Renal Care* 2020
48. UK Renal Registry. Annual Report. 2017. Bristol, UK: Renal Association.
49. Bekker HL, Winterbottom A, Fowler J *et al*. 2012 IPDAS Collaboration Background Document Chapter E: Using Personal Stories. 12 August. <http://ipdas.ohri.ca/resources.html> (22 April 2020, date last accessed)
50. 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: 1902–1908

Received: 15.11.2019; Editorial decision: 10.4.2020