



ORIGINAL ARTICLE

How do patient information documents present dialysis and conservative kidney management? A document analysis

Ryann Sowden ¹, Chloe Shaw¹, James Robb¹, Anna Winterbottom², Katherine Bristowe³, Hilary L. Bekker², James Tulsy^{4,5}, Fliss E.M. Murtagh⁶, Rebecca Barnes⁷, Fergus J. Caskey^{8,9} and Lucy E. Selman ¹

¹Palliative and End of Life Care Research Group, Bristol Medical School, University of Bristol, Bristol, UK, ²Leeds Institute of Health Sciences, University of Leeds, Leeds, UK, ³Cicely Saunders Institute, King's College London, London, UK, ⁴Department of Supportive Oncology, Dana-Farber Cancer Institute, Boston, MA, USA, ⁵Center for Palliative Care, Harvard Medical School, Boston, MA, USA, ⁶Wolfson Palliative Care Research Centre, Hull York Medical School, Hull, UK, ⁷Nuffield Department of Primary Care Health Sciences, University of Oxford, Oxford, UK, ⁸Bristol Medical School, University of Bristol, Bristol, UK and ⁹North Bristol NHS Trust, Bristol, UK

Correspondence to: Lucy E. Selman; E-mail: lucy.selman@bristol.ac.uk

ABSTRACT

Background. Most older people with advanced kidney disease face a decision between conservative kidney management (CKM) or dialysis and must weigh their potential benefits, risks and impacts on quality and length of life. Patient information documents are designed to supplement patients' understanding of their kidney disease and explain treatment options to support decision-making. We aimed to explore how patient information documents frame the treatment options of CKM and dialysis and consider implications for patients' treatment choice.

Methods. We conducted a qualitative document analysis of patient information documents collected from four UK renal outpatient departments with variation in rates of CKM for people ≥ 75 years of age. Data were analysed using critical discourse analysis.

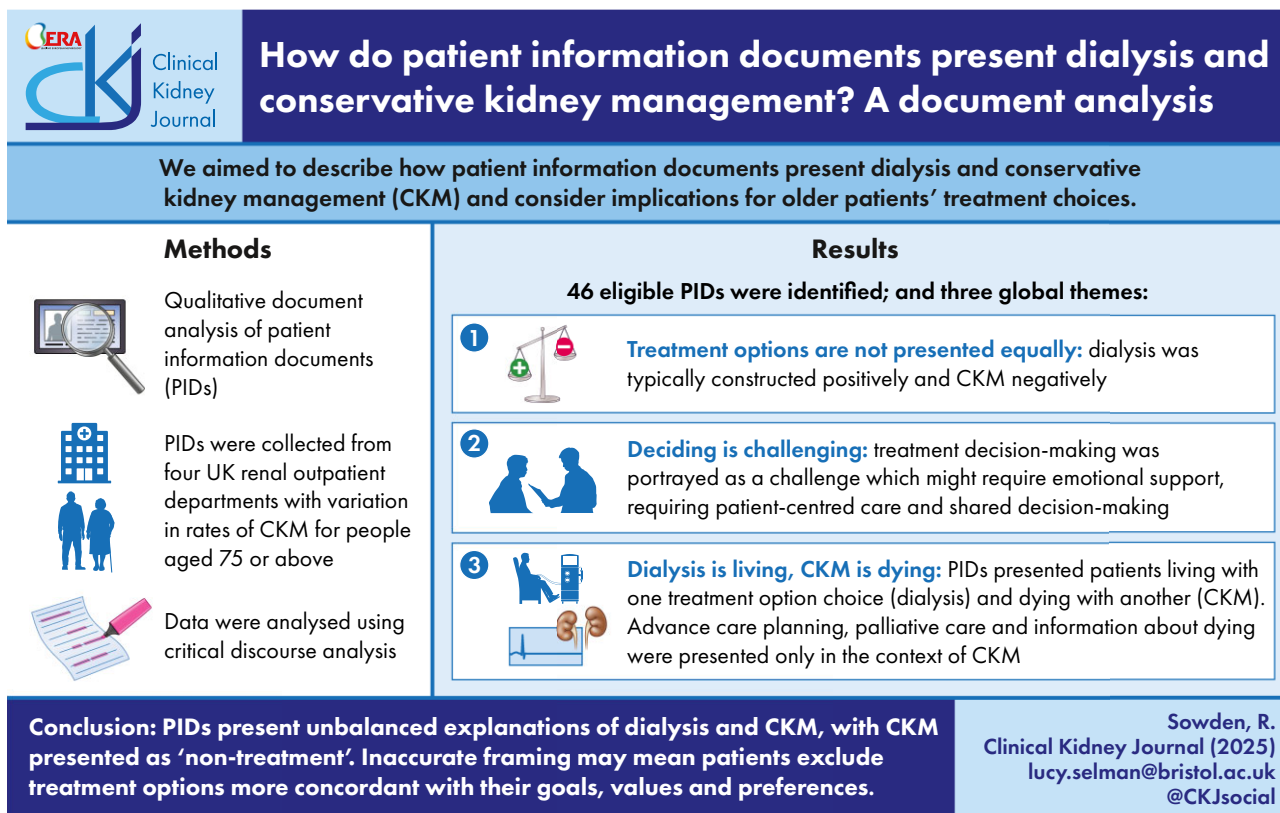
Results. Three global themes were identified: 1) Treatment options are not presented equally: Dialysis was constructed as the assumed patient choice. CKM was often omitted as an option; when included, it was always mentioned last and was typically constructed negatively. 2) Deciding is challenging: Treatment decision-making, particularly choosing CKM, was portrayed as a challenge requiring emotional support, with clinicians the ultimate decision-maker. 3) Dialysis is living, CKM is dying: Patient information documents presented patients as living with one treatment option choice (dialysis) and dying with another (CKM). Advance care planning, palliative care and information about dying were presented only in the context of CKM, implying these were irrelevant topics for people choosing dialysis.

Conclusions. Patient information documents presented unbalanced explanations of dialysis and CKM. Dialysis was framed as 'treatment' and possible complications were minimized. CKM was framed as 'non-treatment' and linked to advance care planning, palliative care and death. Inaccurate framing of both CKM and dialysis may mean patients exclude treatment options that may be more concordant with their goals, values and preferences.

Received: 4.9.2024; Editorial decision: 1.3.2025

© The Author(s) 2025. Published by Oxford University Press on behalf of the ERA. This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial License (<https://creativecommons.org/licenses/by-nc/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited. For commercial re-use, please contact journals.permissions@oup.com

GRAPHICAL ABSTRACT



Keywords: conservative kidney management, dialysis, document analysis, kidney replacement therapy, patient education

KEY LEARNING POINTS

What was known:

- Across UK renal units, there is considerable unwarranted variation in rates of CKM and dialysis among older people with kidney failure, suggesting that the guidance that people with kidney disease receive about treatment options varies.
- People with kidney failure receive patient information documents to supplement guidance provided in consultation with their clinicians.
- Previous studies have shown that patient information documents may not provide balanced or clear treatment information; however, depictions of CKM and dialysis in patient information have not been explored in detail.

This study adds:

- This study reveals how patient information documents present information relating to CKM and dialysis in unbalanced and unrealistic ways, providing recommendations for how those responsible for the production of patient information documents can rebalance information.
- Patient information documents fail to provide information regarding death, dying and end-of-life relating to dialysis and instead link death, dying and end-of-life care to CKM.
- This study shows how patient information documents, despite referencing ideals of patient-centred decision-making, may subtly undermine this goal by implicitly presenting dialysis as the first choice and CKM as second-best, without fully exploring the potential benefits and drawbacks of each decision relative to individual lifestyles and preferences.

Potential impact:

- Our findings show that patients are exposed to unrealistic and unbalanced information about treatment options, which may lead to patients selecting treatment options that are not concordant with their goals, values and preferences.
- Specifically, findings suggest that, based on information leaflets, patients who choose dialysis may have the misconception that it is risk-free, and always life-extending, and that information regarding death, dying and end-of-life care is not relevant to them.
- Study recommendations can help inform the creation of patient information documents that are more balanced and realistic regarding treatment options, supporting patients in the choice of treatment that best suits their individual values, priorities and preferences.

INTRODUCTION

Only 1% of patients in Europe ≥ 75 years of age who receive dialysis progress to transplant [1], meaning most older people approaching kidney failure face the decision between preparing for dialysis or conservative kidney management (CKM). CKM aims to delay disease progression and treat symptoms without replacing kidney function [2]. For people ≥ 80 years of age, or ≥ 65 years with comorbidities, dialysis provides uncertain or modest survival benefits [3, 4] and has the greatest symptom burden [4] and impact on quality of life [4–6], negatively impacting daily activities and functional dependency [5–7].

Rates of CKM vary significantly between UK renal units; in 2012, the proportion of patients ≥ 75 years of age receiving CKM ranged from 5% to 95% between units [8]. This variability suggests treatment decision-making is inconsistently guided by the evidence base and that decision-making support is not consistently person-centred [9, 10], contrary to recommendations [11, 12]. How clinical staff communicate with patients and caregivers regarding treatment options is highly variable across renal units [13–16]. At units with a more established CKM pathway, patients were more aware of CKM and less often believed that dialysis guaranteed longevity [17].

Patient information documents (PIDs), available in renal care settings and online, are produced by clinicians, charities, dialysis companies and other stakeholders such as pharmaceutical companies as a supplement to clinical guidance [8, 18, 19]. PIDs inform treatment decision-making and help patients and families prepare for treatment [15, 20, 21]. PIDs may be particularly valuable for patients with cognitive impairment, common in kidney failure [22], providing the opportunity to clearly present information in an accessible way. However, PIDs are often incomplete and difficult to understand [20].

Decision aids are one type of PID, using decision science to support patients' understanding of medical problems and treatments [23]. Decision aids have been specifically developed to support patients' renal decision-making [19, 24, 25], but there are implementation barriers [26, 27] and they are not widely used [28, 29] or are provided only when treatment decision-making is imminent. However, patients are exposed to a range of PIDs from their initial referral to nephrology (e.g. in outpatient waiting rooms), long before a treatment decision might need to be made, hence understanding their framing of treatments and implications for patients' treatment decision-making is crucial. 'Framing' can be understood as the meaning conveyed about a topic from the way in which it is communicated [30]. Framing stresses certain aspects of reality and pushes others into the background through the processes of selection and salience, with consequences for how a subject is understood or interpreted.

We aimed to explore how PIDs frame the treatment options of CKM and dialysis and any variation between renal units in the information their PIDs provide and consider how this might influence patients' treatment decisions.

MATERIALS AND METHODS

Study design

We conducted a qualitative document analysis of PIDs collected as part of the Optimising Staff-Patient Communication in Advanced Renal Disease (OSCAR) study a mixed methods intervention development study to enhance how renal clini-

cians communicate with older patients (age ≥ 65 years) with advanced kidney disease [estimated glomerular filtration rate (eGFR) ≤ 20 ml/min/1.73 m²] regarding their treatment options [31]. An eGFR ≤ 20 ml/min/1.73 m² was used in OSCAR as this is when clinicians often first raise discussion of a treatment decision [8].

Data collection

Data collection occurred in four hospitals in England and Wales (June 2021–January 2023), purposively sampled to ensure diversity in kidney failure treatment rates for older people and patient ethnicity (Table 1). The Conservative Kidney Management Assessment of Practice Patterns Study (CKMAPPS) data regarding treatment rates at the sites [8] was updated prior to the study start and are presented in Table 1, as are data collected from sites on the ethnicity of their patient population. Physical and digital PIDs were collected as part of an ethnographic study involving several visits to each site (68 h of observation in total across the sites). The researchers collected physical PIDs from renal outpatient waiting areas and consultation rooms frequented by patients with advanced kidney disease and physical and digital PIDs from clinicians at each site who support treatment decision-making (consultants, registrars and specialist nurses), who were asked which PIDs they used with patients.

Inclusion and exclusion criteria

PIDs were included if they discussed CKM, dialysis (including haemodialysis (HD) and peritoneal dialysis (PD)) or both. PIDs were categorized as direct treatment option information resources (category A) when focussed on treatment options individually or in comparison, or indirect information resources (category B) when focussed on broader contextual information related to treatment options, including lifestyle information and treatment logistics.

Analysis

The analysis examined how PIDs describe and explain living and dying with kidney failure in relation to the treatment options of CKM and dialysis, considering how this might affect patients' decision-making. We considered how treatment options were contextualized, identifying themes, 'frames' and discourse [32]. Text and images were coded with a focus on identifying manifest themes (types/aims of the PIDs; framing of the content, including images), latent themes (implicit content) and differences by treatment type and renal unit.

The research team included social scientists specializing in communication, decision science, kidney disease and palliative care and clinical academics in nephrology and palliative care. Our analytic approach was consistent with critical discourse analysis [33], identifying and examining ideologies embedded in discourse [34, 35]. Our analytical process involved reading, coding and interpreting each of the PIDs, identifying recurring narrative patterns and themes and considering differences between renal units. R.S., C.S., L.E.S. and J.R. independently created draft coding frameworks by inductively coding three category A and three category B PIDs. After discussion, comparison and refinement, a hierarchical coding framework was agreed upon and applied to all PIDs, using NVivo 12 (Lumivero, Denver, CO, USA) for data management. R.S. or J.R. applied the coding framework to each PID and then met to review and check all

Table 1: Characteristics of the four sites.

Characteristics	Site 1	Site 2	Site 3	Site 4
Hospital type	Regional teaching hospital	Regional teaching hospital	Local general hospital	Regional teaching hospital
Hospital size (inpatient beds)	≥1000	≥2000	≥500	≥1500
Presence of a low-clearance clinic	Not at main hospital, but at some satellite sites	Yes	Yes	Yes
Black, Asian and minority ethnic patient ethnicity % (UK Renal Registry, 2022) [63]	12.1: South Asian 3.0 Black 6.7 Other 2.4	10.2: South Asian 6.2 Black 0.6 Other 3.4	3: South Asian 3.0 Black 0.0 Other 0.0	57.7: South Asian 21.0 Black 26.2 Other 10.5
Patients ≥75 years receiving CKM % (calculated from CKMAPPS data, 2012) [8]	16	28	1–9	45
Patients with CKD stage 5 age ≥75 years in 2016 n	350	82 ^a	120 ^a	318
CKD stage 5 patients age ≥75 years receiving CKM in 2016 n (%)	182 (52)	36 ^a (44)	15–20 ^a (13–17)	115 (36)

^aEstimated by site leads from hospital records where exact data not recorded.

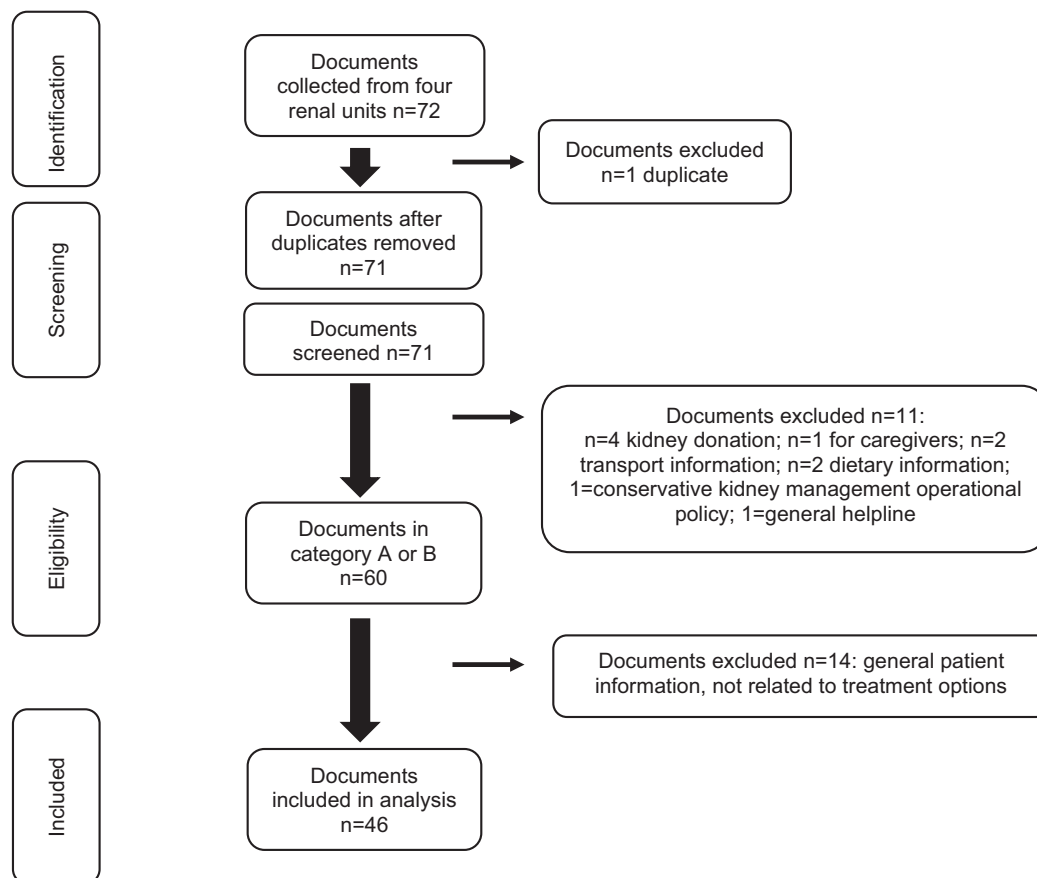


Figure 1: Flow diagram—identification of patient information documents.

coding. R.S. developed an analytic narrative, refined with the research team, drawing on Dixon-Woods' identification of two discourses in PIDs: patient education discourses, which originate from the biomedical perspective, assume patient incompetence and use a mechanistic model of communication; and

patient empowerment discourses, which value patient knowledge and focus on shared decision-making [36]. The team discussed how the distinct narratives identified were likely to influence patients' understanding of and selection of treatment options.

Table 2: Characteristics of PIDs (n = 46).

Characteristics	ID code	Treatments mentioned n	Treatments mentioned	How CKM is referred to	Locally or nationally produced
A: Treatment option information resources					
Site 1 documents (n = 9)	B10	2	HD TR	N/A	National
	B11	2	PD HD	N/A	National
	B18	2	D CKM	Not having dialysis	Local
	B19	2	TR D	N/A	Local
	B20	4	HD PD TR CKM	Conservative care	National
	B3	2	HD PD	N/A	National
	B7	2	PD HD	N/A	National
	B8	4	HD TR PD CKM	Conservative care	National
	B9	3	PD TR HD	N/A	National
Site 2 documents (n = 7)	C1	2	D CKM	Choosing not to have dialysis	National
	C10	2	D CKM	Conservative management	Local
	C2	3	TR D CKM	No dialysis	National
	C3	2	D TR	N/A	National
	C5	2	HD CKM	Conservative management	Local
	C8	1	PD	N/A	Local
	C9	2	CKM D	Conservative management/supportive care	Local
Site 3 documents (n = 8)	G10	4	TR HD PD CKM	No dialysis	National
	G11	1	HD	N/A	National
	G17	2	D TR	N/A	National
	G20	1	D	N/A	National
	G21	1	HD	N/A	National
	G6	1	D	N/A	National
	G7	3	D TR CKM	Conservative medical management	National
	G9	2	D TR	N/A	National
Site 4 documents (n = 5)	L12	2	D CKM	Not having dialysis, conservative, supportive	National
	L14	4	PD HD TR CKM	Maximum conservative management	Local
	L2	3	TR D CKM	Conservative management	National
	L4	4	PD HD TR CKM	Choosing not to have dialysis or a transplant	National
	L5	3	D PD TR	N/A	Local
B: Indirect information resources					
Site 1 documents (n = 7)	B1	1	HD	N/A	Local
	B12	1	D	N/A	National
	B14	1	HD	N/A	Local
	B15	3	HD PD TR	N/A	National
	B16	3	HD PD TR	N/A	National
	B17	2	D TR	N/A	Local
	B6	1	D	N/A	Local
Site 2 documents (n = 2)	C4	1	D	N/A	National
	C7	1	HD	N/A	National
Site 3 documents (n = 5)	G12	3	HD PD TR	N/A	National
	G22	1	D	N/A	National
	G4	2	D TR	N/A	Local
	G5	1	D	N/A	Local
	G8	1	D	N/A	National
Site 4 documents (n = 3)	L6	1	D	N/A	National
	L8	1	PD	N/A	National
	L9	1	HD	N/A	National

CKM: conservative kidney management; D: dialysis; TR: transplant; HD: haemodialysis; PD: peritoneal dialysis; N/A: Not applicable as CKM not mentioned.

Data extracts are tagged according to category (A = direct treatment option information resource, B = indirect information resource), site of collection (site 1–4) and document number (e.g. A-1-10 is a direct treatment option information resource collected from site 1 and the 10th PID collected from that site).

Ethical considerations

Ethical approval for the OSCAR study was granted by the Health Research Authority Bromley Research Ethics Committee (21/LO/0280).

RESULTS

A total of 72 PIDs were identified and 46 PIDs were included after deduplication and screening (Fig. 1): 29 direct treatment option information resources and 17 indirect information resources (Table 2). PIDs included leaflets ($n = 38$), posters or flyers ($n = 4$), magazines ($n = 2$) an app ($n = 1$) and a decision aid ($n = 1$). Across the sites, PIDs included a range of in-house ($n = 14$) and nationally produced ($n = 32$) PIDs.

Analysis identified 3 global themes, 9 themes and 41 sub-themes (Table 3). These are discussed with reference to linguistic aspects (use of language, vocabulary, grammar), layout and patient education and empowerment discourses [36]. Discussion focusses on category A PIDs, which formed most of the dataset, with category B PIDs used to supplement findings.

Treatment options are not presented equally

The treatment option of dialysis was conceptualized as an explicitly 'life-saving', death-preventing and life-prolonging treatment that patients could receive indefinitely [assuming no complications (Q1)]. Discussions of death or end-of-life care were largely absent from descriptions of dialysis.

Dialysis was constructed as the assumed patient choice. Some PIDs were labelled as published by the 'pre-dialysis service' (e.g. A-2-05/09) rather than the renal service, even when PIDs described or focused on CKM. Low kidney function was equated with a 'need' for dialysis specifically (Q2). When listing treatment options, CKM was often completely absent. When CKM was included as a treatment option, it was always the last treatment mentioned (regardless of whether dialysis was described generally or specifically as HD or PD).

Where CKM was included, it was also poorly and inconsistently defined. It was inconsistently named across PIDs and sometimes within the same PID, being referred to variously as 'conservative treatment', 'supportive care', 'choosing not to have dialysis' and 'maximum conservative management' (Table 2). CKM was often presented as the antithesis of dialysis and commonly described using negation (e.g. 'non-dialysis', 'non-treatment'). CKM was framed as opting out of the default treatment (dialysis) or erroneously equated with stopping dialysis (Q3). Even descriptions of its possible advantages framed CKM as a direct challenge to the default position of dialysis: 'Why would I choose not to have dialysis?' (A-2-01).

In addition, CKM was routinely linked to death and dying: explicitly, in descriptions of death from kidney disease (Q4); implicitly, by presenting CKM in proximity to discussion of palliative care and advance care planning (ACP). CKM was described as appropriate for patients who had been 'advised that dialysis would not be in their best interests', akin to drawing the short straw (Q5). Occasionally, CKM was more positively presented for people with additional comorbidities (Q6), and there were attempts to legitimize and validate CKM, providing reassurance that CKM is an 'ethical choice' distinct from assisted suicide (Q7).

CKM was also portrayed as not preferred or understood by patients' family members. One PID informed patients that a 'family conference' (A-4-14) could be organized if a patient had chosen CKM and their family were not supportive (Q8).

Images used to depict dialysis and CKM supported these conceptualizations. Dialysis was typically illustrated with colourful photos of smiling, healthy, younger people enjoying life in non-medical settings or, sometimes, on dialysis machines. CKM was typically illustrated by older people, looking sad or tired.

Sometimes the vagueness of information regarding CKM was mirrored in the use of unspecific clip art. Occasionally the visual presentation of CKM was comparable to the positive depictions of dialysis, e.g. A-3-07 depicted CKM in a way that implied it allowed free time.

Deciding is challenging

PIDs presented treatment decision-making as challenging, frequently including empathic statements regarding the difficulty of choice (Q9). CKM was often singled out as requiring additional discussion with clinicians, family members or both (Q10). PIDs characterized CKM as inherently difficult to consider or discuss (Q11), potentially requiring psychological support (Q12). A choice of CKM was presented as something to be discussed and tested, with clinicians portrayed as paternalistic, ultimate decision-makers (Q13). Where PIDs made explicit reference to a patient's right to choose CKM, it was framed as relevant when dialysis was found too burdensome (Q14).

Another PID highlighted the importance of informed decision-making. Roles were constructed: clinicians as educators, patients as information receivers and deciders (Q18). The tone was suggestive of patient passivity (Q15). In line with these roles, PIDs often referred to the need for clinicians to give accurate and honest information (Q16), while patients were presented with optional roles in looking after their kidneys (Q17). Some PIDs invited patient participation directly e.g. encouraging patients to make notes within PIDs.

Discussion of patients' personal circumstances generally focussed on problems/concerns (Q31). Preferences, goals and values were only raised implicitly, in relation to patients' lifestyle. Q19 shows how consideration of treatment options (rather than a default assumption of dialysis) can help present the decision in a more neutral, patient-centred way.

Ideal patient decision-making was presented as 'involving weighing advantages and disadvantages and discussion with other people' (Q20): always clinicians (Q22), sometimes loved ones, infrequently other patients. One PID insisted on the need for external help: 'it is impossible to manage on your own' (A-2-02).

Overall, information regarding the status of the decision and the nature of the treatments was inconsistent and sometimes inaccurate. While some PIDs indicated that decisions were not static, but depended on time and circumstance (Q21), others implied that the choice of treatment was permanent until death. Trials of dialysis were infrequently described and always in the CKM section of a PID (Q23). Information on treatment complications (e.g. infection, success rate) was often absent or minimized (Q25). PIDs usually omitted information regarding prognosis and the associated risks and uncertainties of each treatment option. Where included, uncertainty and risk were typically framed in terms of potential complications related to age (Q26), frailty (Q27), comorbidity (Q28) and 'worst case scenarios', alongside reassurance (Q24). Overall, dialysis was portrayed as painless (Q30), with minimal side effects and negative aspects limited to travel and boredom.

Dialysis is living, CKM is dying

The theme 'Living with the treatment option' (typically dialysis) described how a person's life could be expected to change or stay the same. 'Dying with the treatment option' (typically CKM) described timescale and life expectancy.

Table 3: Themes, subthemes and exemplars.

Global theme	Themes	Subthemes	Exemplar	Code
1. Treatment options are not presented equally	Treatment is dialysis	Dialysis is life-saving	'Kidney failure, if left untreated, is fatal but modern medicine has provided us with a life-saving treatment—DIALYSIS'. A-3-11 (Site 3)	Q1
		Dialysis implicit choice	'Will I need dialysis for the rest of my life? As long as you have no renal function you will need dialysis'. A-1-10 (Site 1)	Q2
	CKM is non-treatment	Stopping kidney replacement therapy equated with CKM	'There are separate information leaflets about haemodialysis, kidney transplantation and stopping dialysis available on the Renal Association and Kidney Care UK websites'. A-1-09 (Site 1)	Q3
		CKM equated with death	'Some people may decide not to have dialysis and this will result in death from kidney failure'. A-1-10 (Site 1)	Q4
		Negative descriptions of CKM	'Some patients may have been advised that dialysis would not be in their best interest due to their complex medical problems or they may feel they do not want to have dialysis treatment'. A-2-5 (Site 2)	Q5
		Attempts to validate choice	'Some people with kidney failure may have lots of other serious health issues. For these people, having dialysis or a transplant may not make them feel better, or improve their quality of life'. A-3-07 (Site 3)	Q6
		Ethics of CKM	'Stopping dialysis is not suicide nor is it euthanasia or assisted dying. It is withdrawing from renal replacement treatment'. A-1-18 (Site 1)	Q7
		Family don't like choice	'It is very difficult to know how to talk to my family and friends. Can you help?' Yes. Many people find it difficult to talk about such matters to those who are close to them'. A-1-18 (Site 1)	Q8
		Empathic statements e.g. hard to choose, hard coming to terms with kidney failure	'Being diagnosed with kidney failure can be a very worrying time for patients and their families. It marks the beginning of a life-long "career" as a kidney patient and starts a journey of decision-making about treatment choices'. A-3-10 (Site 3)	Q9
		Choosing CKM requires support	'Who can I talk to if I decide not to start dialysis treatment?' 'It is important for you and your family to talk these matters through with members of the renal team. It is best if this is a decision that has been made together'. A-1-18 (Site 1)	Q10
		Difficult to discuss	'It is very difficult to know how to talk to my family and friends. Can you help?' 'Yes. Many people find it difficult to talk about such matters to those who are close to them. They are often concerned that they will upset their relatives or worried how they will react. With anything that is difficult, it is always best to talk openly and honestly'. A-1-18 (Site 1)	Q11
		Availability of emotional support	'Who should I talk to if I am considering opting for MCM (maximum conservative management)?' ... There are a number of people who can help you: - The doctors and nurses looking after you looking after you [sic] will give you every opportunity to discuss the options in clinic and ask any questions you may have. - You can also discuss your feelings and concerns with our psychologist'. A-4-14 (Site 4)	Q12

Table 3: Continued

Global theme	Themes	Subthemes	Exemplar	Code
Clinical values and principles	Empowering/paternalistic	Right to decide	'The exact timing varies from person to person and may depend on medical factors and the underlying kidney problem. Your nephrologist will ultimately decide when you need to start dialysis'. A-2-05 (Site 2)	Q13
			'Can I choose not to have dialysis treatment?'	Q14
			'Yes. You have the right to decide not to start treatment if you feel the burden of dialysis would outweigh the benefits to you and lessen your quality of life'. A-1-18 (Site 1)	Q15
		Informed decision-making	Making an informed choice	
			'If your kidneys fail, there are a number of treatment options to choose from. However certain medical and social factors will need to be discussed with you and your family/carer to help you decide what is best for you'.	
			'Your Specialist Nurse can help explore the most appropriate choice of dialysis with you. She can discuss your individual issues and worries with you and help you to plan ahead'. A-2-05 (Site 2, underlining added for emphasis)	
		Need for accuracy and honesty	'In this leaflet, we aim to give you an honest and accurate account of what might happen if you do not have dialysis. We will describe the symptoms of advanced kidney disease and how they can be managed without dialysis. We also aim to answer some of the questions that you might find difficult to ask'. A-1-18 (Site 1)	Q16
			Patient view	Q17
		Patient participation	You can sign up (via your Clinical Nurse Specialist) to access your blood test results, this puts you in more control of your condition/treatment as you become familiar regarding what is normal for you'. A-3-10 (Site 3)	
			'The team at the renal unit will work together with you'.	Q18
		Shared decision-making	'They will share their knowledge to help you make the best decision to fit with your lifestyle'. A-3-07 (Site 3)	Q19
			'Kidney failure: What choices do I have?'	
			...	
Making a choice	The best choice	Patient goals and values	'One of the best things that you can do before making any decision about your treatment is to find out as much as you can about what choices are available to you locally, what choices will suit the way you live your life and whether you want to travel for holidays'. A-3-10	Q20
			'The best way to make a choice about which dialysis treatment will suit you is to talk to the staff and to other patients about their decisions and what they like and don't like about their treatment choice. It is usually possible to change your type of dialysis if you want to after some planning'. A-2-02 (Site 2)	Q21
			'As established kidney disease is a life-long condition, people may change their treatment choice as their disease and life changes. It is likely people will make different decisions at different points in their life'. A-1-20 (Site 1)	Q22
		Decision permanency—time and circumstance relevant	'Your kidney doctors and staff should help you choose the treatment that is right for you'. A-3-10 (Site 3)	Q23
			'Sometimes it may not be clear if the benefits outweigh the burden of the dialysis. In this case you could start dialysis for a trial period. You can make you decision after that'. A-3-07 (Site 3)	
		Making choice with others		
		Trials		

Table 3: Continued

Global theme	Themes	Subthemes	Exemplar	Code
3. Dialysis is living, CKM is dying	Certainty and risk	Risk	'CKD can slowly get worse over time, although for the majority of people it remains stable and only a very small number of people will need renal replacement therapy such as dialysis. It is unusual for kidney function to improve dramatically once your kidneys have been damaged but it does depend on the cause of the problem'. A-3-6 (Site 3)	Q24
			'Dialysis itself has complications. One of the most common complications of infection as haemodialysis needs access to the blood stream. Patients on haemodialysis have a higher risk of heart attacks and strokes. It can be difficult to reduce the fluid intake as much as is required, leading to fluid on the legs and lungs'. 'Most patients experience some of these complications...but that does not mean you're bound to get all of them!' A-1-10 (Site 1)	Q25
		Older age	'[CKM] might not lengthen life for people who are older, have other long-term illnesses and have difficulty looking after themselves'. A-1-20 (Site 1)	Q26
		Frailty	'There is increasing evidence to show that if a person is older and has significant medical issues dialysis does not offer any (or little) benefit in either quality of life improvement or survival times. This will be discussed with you by your Nurse Specialist and Nephrologist'. A-2-05 (Site 2)	Q27
		Comorbidity	No dialysis 'Some patients choose a path called conservative treatment rather than treatment with dialysis. This may suit people with other medical conditions who feel dialysis is not for them'. A-3-10 (Site 3)	Q28
		Uncertainty	Approaching failure in kidney function '...Patient risk of progression to kidney failure requiring dialysis or transplant'. A-1-21 (Site 1)	Q29
	Quality of information	Accuracy of clinical information	'Is dialysis treatment painful?' 'Once you get used to the needles being placed, dialysis is not painful but can be uncomfortable'. A-1-10 (Site 1)	Q30
			'In such situations, it is important for all concerned to have a clear understanding of the likely advantages and disadvantages of undertaking dialysis treatment. This should take account of your particular problems circumstances and concerns'. A-1-18 (Site 1)	Q31
		Changes/staying the same and presentation of living	Living with kidney failure 'Becoming a dialysis patients is a turning point in your life. Modern medicine makes it possible for you to live and continue with many day-to-day activities'. 'As patients, we know that the path will not always be easy. Dialysis is now part of your life and that of your family. Do not let it dominate—the aim is to enable you to enjoy a good quality of life. Above all, at [organisation] we aim to show that living with kidney failure can be life well worth living—why not join us?' A-1-10 (Site 1)	Q32

Table 3: Continued

Global theme	Themes	Subthemes	Exemplar	Code
Dying with the treatment option	Symptoms of kidney failure and their management		'The symptoms associated with Chronic Kidney Disease may include: nausea, poor appetite, breathlessness, swollen ankles, restless legs, itching, cramps, severe tiredness, low mood, occasionally pain, or rarely seizures'. 'If your symptoms become more troublesome we will liaise with your GP to discuss medications that may be beneficial. If appropriate we may also involve the local palliative care team who are specialists in managing such symptoms. We can also contact organisations who can help you with financial matters or offer psychological support'. A-2-10 (Site 2)	Q33
			'How long can you live on dialysis?' 'We do not yet know how patients on dialysis will live. We think that some dialysis patients may live as long as people without kidney failure'. A-3-11 (Site 3)	Q35
			'What happens at the end?' 'As you get towards the end of your life, the symptoms that you already have may gradually get worse. In particular, you may find you spend more time in bed and have less energy. Those looking after you will continue to address any symptoms you have and try to relieve them. Some people become more drowsy and their thoughts less clear as they become more sleepy'. A-1-18 (Site 1)	Q36
	Description of dying		Choosing not to have dialysis or transplant Conservative and end-of-life-care 'This is not the same as end of life care. This term is used to refer to the time period and care needed when someone's life is coming to an end. It may be someone who has not decided to start dialysis at all. For others it may be that they have had dialysis for many years but become frail or disabled and have decided their time has come to stop treatment and die with dignity'. A-4-14 (Site 4)	Q37
			'When these changes to people's health happen, kidney professionals offer treatments to relieve people's symptoms and give some comfort. These types of options are sometimes known as palliative care'. A-1-20 (Site 1)	Q38
	Introduction to palliative care		What support and help will there be as my kidney function gets much worse? Your doctor or nurse may suggest talking to specialists in end of life care. 'These doctors and nurses are known as the palliative care team and they will talk to you about how you would like to be looked after as your kidney function declines. These discussions are known as Advance Care Planning. They may involve your GP, your family and staff from your local hospice'. A-2-01 (Site 2)	Q39
	Advance care planning (ACP)			

PIDs' presentation of living with treatment focused on the ability to maintain a usual lifestyle. For PIDs describing dialysis, continuation of work, holidays and hobbies were presented as common, possible and easy. Few PIDs acknowledged the potential challenges of maintaining life as usual; those that did typically minimized the challenges by outlining a need for acceptance (Q32).

The symptoms and management of kidney failure were commonly presented in a distinct section, but occasionally under CKM, implying symptoms from kidney failure were experienced only if CKM was chosen and not alongside dialysis (Q33). PIDs discussed life expectancy more commonly in relation to CKM than dialysis, with inconsistent messaging (Q27, Q35). CKM was often associated with a shorter lifespan and dialysis was presented as a treatment that could continue 'forever', providing a life expectancy comparable to someone without kidney failure. Conversely, some PIDs noted that while there was variation, life expectancy could be similar for CKM and dialysis. This information was less common in PIDs from site 3. One PID described survival on dialysis as influenced by comorbidity and lifestyle, as well as 'luck!' (A-1-11).

Descriptions of dying were typically absent, or tended to appear in relation to CKM. For patients who chose CKM, death was presented as a certainty and was generally described as 'peaceful' (Q36). Typically, end-of-life care was discussed in relation to planning lifestyle adjustments or withdrawal from dialysis (Q37). Where palliative care was introduced, it was often conflated with CKM (Q38). Several PIDs offered general suggestions regarding planning for death and, more specifically, for advance care plans (Q39), but this was only seen in CKM-focused PIDs or under the CKM section of generalized PIDs.

Similarities and differences

Almost all PIDs focused on providing information about treatment options (rather than explaining low kidney function and why many patients might start to consider treatment options). Discussion of patients' goals and values was typically absent.

There were some differences by site. Site 1 PIDs were more likely to focus on one specific treatment option without comparison (although site 1 was also the only site to feature a decision aid comparing treatments). Site 3 had a greater number of PIDs produced by a dialysis company and more patient voice resources such as kidney charity magazines or peer support information. Site 4 PIDs generally had an increased focus on emotional well-being and psychosocial support and provided relatively more balanced information for CKM and renal replacement therapy.

DISCUSSION

This analysis of PIDs from four UK renal units identified a clear bias towards dialysis over CKM. Dialysis was constructed as the default, preferential treatment option. CKM was often omitted as an option; when included, it was inconsistently named, always mentioned last and typically framed as opting out of default treatment and constructed negatively. By omitting information on ACP, palliative care and the end of life in relation to dialysis, PIDs implied these topics are not relevant to people who choose dialysis. Simultaneously, PIDs implied that patients who choose CKM will die from kidney failure, which is why loved ones often object to the treatment and why clinicians (including psychologists) may question this choice.

Biased presentation of treatment options may lead some patients to discount CKM as a treatment option, even when closely

aligned with their goals and values, leading to unwanted, futile care [37]. Conversely, patients who choose dialysis on the basis of information from PIDs may have unrealistic expectations of life expectancy and quality of life. In the event of death from kidney disease, this lack of information may lead to poor bereavement outcomes for significant others [38].

PIDs play one part in informing patients about treatments; how clinicians discuss treatment options and communicate about the decision is another crucial element. Our findings support evidence that CKM is commonly framed as the absence of treatment, without its own standardized name, both in leaflets and in how clinicians communicate about treatment options [19, 31]. CKM was referred to variously as 'conservative treatment', 'supportive care', 'choosing not to have dialysis' and 'maximum conservative management'. This leads to confusion about what CKM is [39], undermining its status as a viable choice [2, 31]. In our analysis of video-recorded real conversations of clinicians discussing treatment options with older patients, published separately [31], we similarly found a bias towards presenting dialysis as the default option for kidney failure and CKM as a subordinate option. Findings from this analysis suggest that PIDs reinforce this message.

Similarities in PIDs between sites point to commonalities in the culture of renal care. However, we also found differences—most notably, site 4 PIDs contained relatively more balanced and holistic information regarding CKM and dialysis, which may help explain relatively high treatment rates among older people at this unit (45% CKM in 2012, 36% in 2016). But given similar rates at sites 1 and 2, at least in 2016 estimates, further research alongside accurate tracking of CKM treatment rates is needed to understand the relative contribution of PIDs (compared with, for example, information from clinicians [31]) to patients' treatment decision-making [8].

Previous studies have also found that patients receiving renal replacement therapy are unequally informed of treatment options [40, 41], leading to dissatisfaction. There is evidence that kidney disease decision aids are rarely tailored to older patients with kidney failure, and similarly lack detail about prognosis and ACP [20, 42]. Ultimately, a lack of accessible, comprehensive and accurate information means a lack of informed choice [13]. In this regard, there is a tension between PIDs' use of patient empowerment discourses, making explicit reference to the need for honest, accurate and clear information due to the uncertainties associated with each treatment option [43] and the omission of key decision-making information [44]. Dixon-Woods reports that paternalistic obfuscation of clinical uncertainty is typical of clinical information resources [36]. Building on her argument that patient education discourses view and treat patients as incompetent, omitting information can be seen as creating incompetence in the form of misconceptions about the different treatment options.

Overall, we found few explicit discussions in PIDs of prognosis, ACP and end of life. These topics are also often absent from renal consultations [45, 46], despite many patients' wishes to discuss and receive end-of-life information [47], suggesting the PIDs serve to reinforce biased messages that patients also receive from elsewhere. Kidney patients are often unaware of their prognosis [48] and discussions of palliative care occur too late [49], with evidence of high levels of unmet palliative care needs in advanced kidney disease [50]. Including these crucial topics in PIDs would support treatment decision-making, potentially reducing decisional regret [51] and improving bereavement outcomes [38].

Findings from this study support existing evidence that PIDs in medicine are not always reflective of clinical best practice and

evidence or patient need [52–55]. Reasons for the evident biases we identified are likely to be multifaceted and may include clinicians' discomfort with uncertainty and acknowledging the limits of medical care [56]. PIDs may also be written in anticipation of patients' negative preconceptions of any modality of dialysis [2], hence aiming to emphasize the ability to live a normal life on dialysis. Alternatively, PIDs may aim to reflect patient priorities such as holidays; however, descriptions of treatments and possible side effects such as pain need to be accurate. A systematic review indicated 63% of patients receiving dialysis experienced pain [57].

Given the requirement to provide integrated care for people with kidney failure which includes supportive care and expert communication [58–60], study findings have important clinical implications. Across the four sites we found a wide variety of PIDs, highlighting inconsistencies in information provision, with only one PID appearing across two sites. Renal units should carefully evaluate the PIDs they provide, considering whether they are balanced, accurate and comprehensive, including covering the implications of treatment choice for end-of-life experiences and care. Ideally, to enhance consistency and reduce variation across renal units, PIDs that have been reviewed and approved nationally should be used. However, a review and redesign of nationally available PIDs is essential, recognizing that even PIDs not explicitly focused on treatment decision-making still influence those decisions. This redesign should ensure PIDs are evidence-based, involve co-production with patients and significant others from diverse ethnic, cultural and religious backgrounds [36, 61], and draw on decision aid methodology to ensure accurate, balanced presentation of treatment options. A standardized term for the treatment pathway needs to be used; 'conservative kidney management' is recommended [59]. To align PIDs with their stated values of informed decision-making, end-of-life information should be included. As in previous studies [28, 29], we found decision aids, designed to provide more balanced information regarding treatment options [24, 25], were not readily available or used, with only one identified. Further research is required to identify implementation barriers.

Limitations

Study strengths include the range of documents analysed from four purposively sampled hospitals selected to ensure diversity in kidney failure treatment rates [8] and patient ethnicity. The inclusion of a range of document types, not just decision aids, allowed for a broader understanding of the information and framing patients are exposed to prior to the 'need' to make a treatment decision. Our qualitative findings are not generalizable to all renal units, however through descriptions of settings and samples we have provided details to enable judgement of transferability [62]. Finally, although we included PIDs concerning transplant in our analysis, our focus was on the treatment options of CKM and dialysis as these are the main treatment options for older people with kidney failure.

CONCLUSION

Once referred to a renal outpatient department, patients are routinely exposed to biased information regarding treatment options. Patient information frames dialysis as 'treatment' with minimal side effects and complications and conveys unrealistic expectations of life expectancy and quality of life. CKM is framed as 'non-treatment' and explicitly linked to death from kidney failure. Palliative care, ACP and death are discussed only in rela-

tion to CKM. Patients may therefore discount CKM, even when it aligns with their individual goals and values. PIDs collected from the renal unit with a relatively high rate of CKM among older patients were more holistic and patient-centred in content, suggesting that PIDs may reflect or reinforce local cultures of care and influence treatment choice.

ACKNOWLEDGEMENTS

This study was conducted during a time of unprecedented pressure on users and providers of healthcare services. We are hugely grateful to all the participating sites and staff. We would also like to thank members of the study patient and public involvement group who informed the development and conduct of this study (Jos Darling, Anne Parfitt, Roger Graham, Simon Miller, Max Harris) and the additional members of the expert Project Advisory Group (Barnaby Hole and Emma Murphy). Our thanks to the National Institute for Health Research (NIHR) for funding the OSCAR study.

FUNDING

This report represents independent research sponsored by the University of Bristol, conducted as part of an NIHR Career Development Fellowship to L.E.S. (CDF-2018-11-ST2-009) <https://fundingawards.nihr.ac.uk/award/CDF-2018-11-ST2-009>. F.E.M.M. is an NIHR Senior Investigator. The views expressed in this article are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.

AUTHORS' CONTRIBUTIONS

R.S. was responsible for data collection, formal analysis, writing the original draft and review and editing. C.S. and J.R. were responsible for formal analysis, and review and editing. A.W., K.B. and H.L.B. were responsible for review and editing. J.T., F.E.M.M., R.B. and F.J.C. were responsible for funding acquisition, methodology and review and editing. L.E.S. was responsible for conceptualization, funding acquisition, methodology, supervision, formal analysis and review and editing.

DATA AVAILABILITY STATEMENT

The datasets used and analysed during the current study are available from the corresponding author upon reasonable request.

CONFLICT OF INTEREST STATEMENT

F.C. is chief investigator for the Prepare for Kidney Care Study, a randomized controlled trial comparing outcomes for older people preparing for kidney dialysis versus CKM (<https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/prepare-for-kidney-care/>).

REFERENCES

1. Pippias M, Stel VS, Kramer A et al. Access to kidney transplantation in European adults aged 75–84 years and related outcomes: an analysis of the European Renal Association–European Dialysis and Transplant Association Registry. *Transpl Int* 2018;31:540–53. <https://doi.org/10.1111/tri.13125>

2. Jongejan M, de Lange S, Bos WJW et al. Choosing conservative care in advanced chronic kidney disease: A scoping review of patients' perspectives. *Nephrol Dial Transplant* 2023;39:659–68.
3. Voorend CG, van Oevelen M, Verberne WR et al. Survival of patients who opt for dialysis versus conservative care: a systematic review and meta-analysis. *Nephrol Dial Transplant* 2022;37:1529–44. <https://doi.org/10.1093/ndt/gfac010>
4. Engelbrecht BL, Kristian MJ, Inge E et al. Does conservative kidney management offer a quantity or quality of life benefit compared to dialysis? A systematic review. *BMC Nephrol* 2021;22:1.
5. Pereira M, Tocino MLS, Mas-Fontao S et al. Dependency and frailty in the older haemodialysis patient. *BMC Geriatr* 2024;24:416. <https://doi.org/10.1186/s12877-024-04973-8>
6. Ishiwatari A, Yamamoto S, Fukuma S et al. Changes in quality of life in older hemodialysis patients: a cohort study on dialysis outcomes and practice patterns. *Am J Nephrol* 2020;51:650–8. <https://doi.org/10.1159/000509309>
7. Moreels T, Van de Velde D, Van Duyse S et al. The impact of in-centre haemodialysis treatment on the everyday life of older adults with end-stage kidney disease: a qualitative study. *Clin Kidney J* 2023;16:1674–83. <https://doi.org/10.1093/ckj/sfad104>
8. 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. *Health Soc Care Deliv Res* 2015;3. <https://doi.org/10.3310/hsdr03120>
9. RightCare. *NHS Atlas of Variation in Healthcare for People with Kidney Disease: Reducing unwarranted variation to increase value and improve quality*. London: National Health Service, 2012.
10. 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>
11. Moss AH. Revised dialysis clinical practice guideline promotes more informed decision-making. *Clin J Am Soc Nephrol* 2010;5:2380–3. <https://doi.org/10.2215/CJN.07170810>
12. National Institute for Health and Care Excellence. *Renal replacement therapy and conservative management*. NG107. London: National Institute for Health and Care Excellence, 2018.
13. 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.
14. Hussain JA, Flemming K, Murtagh FE 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>
15. Selman LE, Bristowe K, Higginson IJ et al. The views and experiences of older people with conservatively managed renal failure: A qualitative study of communication, information and decision-making. *BMC Nephrol* 2019;20:38. <https://doi.org/10.1186/s12882-019-1230-4>
16. 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>
17. Tonkin-Crine S, Okamoto I, Leydon GM et al. Understanding by older patients of dialysis and conservative management for chronic kidney failure. *Am J Kidney Dis* 2015;65:443–50. <https://doi.org/10.1053/j.ajkd.2014.08.011>
18. Winterbottom A, Conner M, Mooney A 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>
19. 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>
20. Winterbottom A, Conner M, Mooney A 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>
21. Moerenhout T, Borgermans L, Schol S et al. Patient health information materials in waiting rooms of family physicians: do patients care? *Patient Prefer Adherence* 2013;7:489–97.
22. Davey A, Elias MF, Robbins MA et al. Decline in renal functioning is associated with longitudinal decline in global cognitive functioning, abstract reasoning and verbal memory. *Nephrol Dial Transplant* 2013;28:1810–9. <https://doi.org/10.1093/ndt/gfs470>
23. 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>
24. Bekker HL, Winterbottom AE, Gavaruzzi T et al. Decision aids to assist patients and professionals in choosing the right treatment for kidney failure. *Clin Kidney J* 2023;16:20–38. <https://doi.org/10.1093/ckj/sfad172>
25. Ladin K, Tighiouart H, Bronzi O et al. Effectiveness of an intervention to improve decision making for older patients with advanced chronic kidney disease: a randomized controlled trial. *Ann Intern Med* 2023;176:29–38. <https://doi.org/10.7326/M22-1543>
26. van Eck van der Sluijs A, Vonk S, Bonenkamp AA et al. Value of patient decision aids for shared decision-making in kidney failure. *J Ren Care* 2024;50:15–23. <https://doi.org/10.1111/jorc.12468>
27. Scalia P, Durand M-A, 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>
28. Dahm MR, Raine SE, Slade D et al. Shared decision making in chronic kidney disease: a qualitative study of the impact of communication practices on treatment decisions for older patients. *BMC Nephrol* 2023;24:383. <https://doi.org/10.1186/s12882-023-03406-9>
29. Engels N, de Graaf 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>
30. Entman RM. Framing: toward clarification of a fractured paradigm. *J Commun* 1993;43:51–8. <https://doi.org/10.1111/j.1460-2466.1993.tb01304.x>
31. Selman LE, Shaw CB, Sowden R et al. Communicating treatment options to older patients with advanced kidney disease: a conversation analysis study. *BMC Nephrol* 2024;25:417. <https://doi.org/10.1186/s12882-024-03855-w>
32. Altheide DL. Tracking discourse and qualitative document analysis. *Poetics* 2000;27:287–99. [https://doi.org/10.1016/S0304-422X\(00\)00005-X](https://doi.org/10.1016/S0304-422X(00)00005-X)
33. Wodak R, Meyer M (eds). *Critical discourse analysis: history, agenda, theory*. 2nd edn. Los Angeles: Sage, 2015.
34. Wodak R. Critical discourse analysis and the study of doctor-patient interaction. In: Gunnarsson BL, Linell P, Nordberg B

- (eds). *The construction of professional discourse*. London: Routledge, 2014:173–200.
35. Pattison N. A critical discourse analysis of provision of end-of-life care in key UK critical care documents. *Nurs Crit Care* 2006;11:198–208. <https://doi.org/10.1111/j.1362-1017.2006.00172.x>
 36. Dixon-Woods M. Writing wrongs? An analysis of published discourses about the use of patient information leaflets. *Soc Sci Med* 2001;52:1417–32.
 37. Houben CH, Spruit MA, Groenen MT et al. Efficacy of advance care planning: a systematic review and meta-analysis. *J Am Med Dir Assoc* 2014;15:477–89. <https://doi.org/10.1016/j.jamda.2014.01.008>
 38. Song M-K, Ward SE, Fine JP et al. Advance care planning and end-of-life decision making in dialysis: a randomized controlled trial targeting patients and their surrogates. *Am J Kidney Dis* 2015;66:813–22. <https://doi.org/10.1053/j.ajkd.2015.05.018>
 39. Low J, Myers J, Smith G et al. The experiences of close persons caring for people with chronic kidney disease stage 5 on conservative kidney management: contested discourses of ageing. *Health (London)* 2014;18:613–30. <https://doi.org/10.1177/1363459314524805>
 40. Fadem SZ, Walker DR, Abbott G et al. Satisfaction with renal replacement therapy and education: the American Association of Kidney Patients survey. *Clin J Am Soc Nephrol* 2011;6:605–12. <https://doi.org/10.2215/CJN.06970810>
 41. 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>
 42. Ladin K, Pandya R, Kannam A et al. Discussing conservative management with older patients with CKD: an interview study of nephrologists. *Am J Kidney Dis* 2018;71:627–35. <https://doi.org/10.1053/j.ajkd.2017.11.011>
 43. Kanbay M, Basile C, Battaglia Y et al. Shared decision making in elderly patients with kidney failure. *Nephrol Dial Transplant* 2024;39:742–51.
 44. Murphy E, Burns A, Murtagh FE 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>
 45. Cortez D, Maynard DW, Campbell TC. Creating space to discuss end-of-life issues in cancer care. *Patient Educ Couns* 2019;102:216–22. <https://doi.org/10.1016/j.pec.2018.07.002>
 46. Ladin K, Neckermann I, D'Arcangelo N et al. Advance care planning in older adults with CKD: patient, care partner, and clinician perspectives. *J Am Soc Nephrol* 2021;32:1527–35. <https://doi.org/10.1681/ASN.2020091298>
 47. Eneanya ND, Labbe AK, Stallings TL et al. Caring for older patients with advanced chronic kidney disease and considering their needs: a qualitative study. *BMC Nephrol* 2020;21:213. <https://doi.org/10.1186/s12882-020-01870-1>
 48. Davison SN. End-of-life care preferences and needs: perceptions of patients with chronic kidney disease. *Clin J Am Soc Nephrol* 2010;5:195–204. <https://doi.org/10.2215/CJN.05960809>
 49. Axelsson L, Benzein E, Lindberg J et al. End-of-life and palliative care of patients on maintenance hemodialysis treatment: a focus group study. *BMC Palliat Care* 2019;18:89. <https://doi.org/10.1186/s12904-019-0481-y>
 50. Axelsson L, Alvariza A, Lindberg J et al. Unmet palliative care needs among patients with end-stage kidney disease: a national registry study about the last week of life. *J Pain Symptom Manage* 2018;55:236–44. <https://doi.org/10.1016/j.jpainsymman.2017.09.015>
 51. Saeed F, Ladwig SA, Epstein RM et al. Dialysis regret: prevalence and correlates. *Clin J Am Soc Nephrol* 2020;15:957–63. <https://doi.org/10.2215/CJN.13781119>
 52. Low M, Burgess LC, Wainwright TW. A critical analysis of the exercise prescription and return to activity advice that is provided in patient information leaflets following lumbar spine surgery. *Medicina (Kaunas)* 2019;55:347.
 53. Protheroe J, Estacio EV, Saidy-Khan S. Patient information materials in general practices and promotion of health literacy: an observational study of their effectiveness. *Br J Gen Pract* 2015;65:e192–7. <https://doi.org/10.3399/bjgp15X684013>
 54. Wolverson E, Harrison Denning K, Gower Z et al. What are the information needs of people with dementia and their family caregivers when they are admitted to a mental health ward and do current ward patient information leaflets meet their needs? *Health Expect* 2023;26:1227–35. <https://doi.org/10.1111/hex.13738>
 55. Umeria R, Mowforth O, Grodzinski B et al. A scoping review of information provided within degenerative cervical myelopathy education resources: towards enhancing shared decision making. *PLoS One* 2022;17:e0268220. <https://doi.org/10.1371/journal.pone.0268220>
 56. Noble H, Brazil K, Burns A et al. Clinician views of patient decisional conflict when deciding between dialysis and conservative management: qualitative findings from the Palliative Care in chronic Kidney diSease (PACKS) study. *Palliat Med* 2017;31:921–31. <https://doi.org/10.1177/0269216317704625>
 57. Lambourg E, Colvin L, Guthrie G et al. The prevalence of pain among patients with chronic kidney disease using systematic review and meta-analysis. *Kidney Int* 2021;100:636–49. <https://doi.org/10.1016/j.kint.2021.03.041>
 58. 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>
 59. Davison SN, Pommer W, Brown MA et al. Conservative kidney management and kidney supportive care: core components of integrated care for people with kidney failure. *Kidney Int* 2024;105:35–45. <https://doi.org/10.1016/j.kint.2023.10.001>
 60. Gelfand SL, Scherer JS, Koncicki HM. Kidney Supportive Care: Core Curriculum 2020. *Am J Kidney Dis* 2020;75:793–806. <https://doi.org/10.1053/j.ajkd.2019.10.016>
 61. Bennett SE, Gooberman-Hill R, Clark EM et al. Improving patients' experiences of diagnosis and treatment of vertebral fracture: co-production of knowledge sharing resources. *BMC Musculoskelet Disord* 2024;25:165. <https://doi.org/10.1186/s12891-024-07281-9>
 62. Drisko JW. Transferability and generalization in qualitative research. *Res Soc Work Pract* 2025;35:102–10. <https://doi.org/10.1177/10497315241256560>
 63. UK Renal Registry. UK Renal Registry 24th Annual Report - data to 31/12/2020, Bristol, UK; 2022.

Received: 4.9.2024; Editorial decision: 1.3.2025

© The Author(s) 2025. Published by Oxford University Press on behalf of the ERA. This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial License (<https://creativecommons.org/licenses/by-nc/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited. For commercial re-use, please contact journals.permissions@oup.com

[Click here for Prescribing Information](#)




This is a promotional advertisement intended for UK HCPs only, produced and funded by MEDICE UK

Vafseo® is indicated for the treatment of symptomatic anaemia associated with chronic kidney disease (CKD) in adults on chronic maintenance dialysis¹

A once-daily oral treatment for anaemia associated with CKD in patients receiving dialysis¹

Vafseo® is now recommended by NICE, within its marketing authorisation, as an option for treating symptomatic anaemia caused by CKD in adults having maintenance dialysis²



Contact MEDICE UK now to be put in touch with your regional Vafseo® Key Account Manager

Contact Us

▼ **This medicinal product is subject to additional monitoring. This will allow quick identification of new safety information. Adverse events should be reported. Reporting forms and information can be found at <https://yellowcard.mhra.gov.uk/> or search for MHRA Yellow Card in Google Play or Apple App Store. Adverse events should also be reported to Medice UK Ltd, 0204 582 2845, medicalinformation@medice.co.uk**

MEDICE UK makes no warranties or representations of any kind as to the accuracy, completeness, reliability or usefulness of any information contained in third party sites and shall have no liability for any loss or damage of any kind that may arise from your use of such content or information. Inclusion of any third-party link does not imply an endorsement or recommendation by MEDICE UK.

Abbreviations: CKD, chronic kidney disease; HCP, healthcare professional; NICE, National Institute of Health and Care Excellence. **References:** 1. Vafseo 300 mg film-coated tablets Summary of Product Characteristics (SmPC). Available at: <https://www.medicines.org.uk/emc/product/15656/smpc> (Accessed March 2025). 2. NICE Guidance TA1035. Vadadustat for treating symptomatic anaemia in adults having dialysis for chronic kidney disease. Available at: <https://www.nice.org.uk/guidance/ta1035> (Accessed March 2025).



UK-VAF-2024-1963-v2
March 2025