


# CRITICAL REVIEW OF LEAFLETS ABOUT CONSERVATIVE MANAGEMENT USED IN UK RENAL SERVICES

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## SUMMARY

**Background:** Written information supplements nurse-led education about treatment options. It is unclear if this information enhances patients' reasoning about conservative management (CM) and renal replacement therapy decisions.

**Aim:** This study describes a critical review of resources U.K. renal staff use when providing CM options to people with Established Kidney Disease (EKD) during usual pre-dialysis education.

**Design:** A survey using mixed methods identified and critically analysed leaflets about CM.

**Participants & measurements:** All 72 renal units in the United Kingdom received an 11-item questionnaire to elicit how CM education is delivered, satisfaction and/or needs with patient resources and staff training. Copies of leaflets were requested. A coding frame was utilised to produce a quality score for each leaflet.

**Results:** Fifty-four (75%) units participated. Patients discuss CM with a nephrologist (98%) or nurse (100%). Eighteen leaflets were reviewed, mean scores were 8.44 out of 12 (range 5–12, SD = 2.49) for information presentation; 3.50 out of 6 (range 0–6, SD = 1.58) for inclusion of information known to support shared decision-making and 2.28 out of 6 (range 1–4, SD = 0.96) for presenting non-biased information.

**Conclusions:** Nurses preferred communicating via face-to-face contact with patients and/or families because of the emotional consequences and complexity of planning treatment for the next stage of a person's worsening kidney disease. Conversations were supplemented with written information; 66% of which were produced locally. Staff perceived a need for using leaflets, and spend time and resources developing them to support their services. However, no leaflets included the components needed to help people reason about conservative care and renal replacement therapy options during EKD education consultations.

**KEY WORDS** Conservative management • Decision making • Patient leaflets • Pre-dialysis education • Shared decision making

## BIODATA

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## INTRODUCTION

Education is essential to support patients' involvement in their chronic kidney disease (CKD) management decisions, and enable staff to plan care based on clinical indicators and patient preferences (Farrington *et al.* 2017; Nice Guidelines 2018; Chan *et al.* 2019). Pre-dialysis education (PDE) programmes aim to facilitate shared decision making about the treatment option best-suited to people's lifestyle, goals and preferences. Renal replacement therapy (RRT) options include: haemodialysis, peritoneal dialysis or transplant; guidelines also recommend adding conservative management (CM) as an equivalent option at the same time as offering RRTs. For people with co-morbidities, increased symptom burden and significant frailty (Brown *et al.* 2010; Hussain *et al.* 2013; Coombs & Davison 2015), the benefit of having dialysis to lengthen life are less certain (Murtagh *et al.* 2007; Hussain *et al.* 2013). People on a CM pathway indicate that their quality of life is comparable with those managed on dialysis (Da Silva-Gane *et al.* 2012).

## LITERATURE REVIEW

Services report providing information about CM (Roderick *et al.* 2015) and RRTs through nurse-led education (Winterbottom *et al.* 2007; Fadem *et al.* 2011; Prieto-Velasco *et al.* 2014; van Biesen *et al.* 2014; Goovaerts *et al.* 2015; Van den Bosch *et al.* 2015). However, descriptions of CM and how it is delivered within kidney services varies widely (Roderick *et al.* 2015). Renal units supplement face-to-face education about options (van Biesen *et al.* 2014; Isnard Bagnis *et al.* 2015) often with leaflets written by their local team (Roderick *et al.* 2015). This by-service variation in information provision may explain in part why patient satisfaction with making CM decisions varies considerably; some patients feel overwhelmed by the amount of information received, yet others cannot recall being presented with more than one treatment option (Morony *et al.* 2015; Van den Bosch *et al.* 2015), they report complex decisional needs (Loiselle *et al.* 2016) and/or feel treatment decisions are not shared with them (Kidney PREM report, 2019). It is unclear if these leaflets are sufficient to enhance patients' reasoning about CM and RRT decisions. This study describes a critical review of the resources U.K. renal staff use when providing CM options to people with whose CKD is recognised as 'advanced' or 'established' during usual PDE sessions.

## MATERIALS AND METHODS

### DESIGN

A survey using mixed methods was carried out to identify and critically analyse leaflets about CM used by renal services to supplement their PDE.

### CONTEXT

This study is part of the "Developing the Yorkshire Dialysis and Conservative-management Decision Aid (YoDCA)" project (Kidney Research Yorkshire—reference 16-118; Winterbottom *et al.* 2018). It was carried out to elicit evidence to inform the content of a patient decision aid during its developmental process. NHS Research Ethics Committee and Health Research Authority approval granted, 19 February 2018 (17/LO/2132; 231121). YoDCA builds on our team's established interdisciplinary, multi-stakeholder research and shared decision making outputs (Winterbottom *et al.* 2007, 2008, 2014, 2016; Bekker *et al.* 2014). Our research found Conservative Care (C) and Established Kidney Disease (EKD) were acceptable terms for people with CKD and health professionals to identify the shift in stage of kidney disease, and use when planning care together as people's kidney disease worsens and progresses to CKD stages 4 and 5. It was evaluated in our YoDDA project patient decision aid research (Winterbottom *et al.* 2016), the patient decision aid is disseminated via Kidney Research UK (<https://kidneyresearchuk.org/kidney-health-information/>), the DDA is approved by NICE in 2015 and 2020 as meeting clinical guidelines, and the DDA has been used in a third of UK renal service since 2015. Feedback from renal services in Denmark and the UK show the use of CC and EKD in our YoDCA project's decision map (Figure 1) helps professionals to talk with people with CKD about the different care pathways as the disease worsens.

### SAMPLE

All 72 units in the United Kingdom and Northern Ireland (identified from Renal Association <https://renal.org/information-resources/renal-units-in-the-uk>; Renal Registry 19th Annual Report, 2016) and three renal charities (Kidney Research UK, National Kidney Federation and Kidney Care UK) were eligible for participation.

### MATERIALS

Letters of invitation, questionnaire and coding frame were developed for the study:

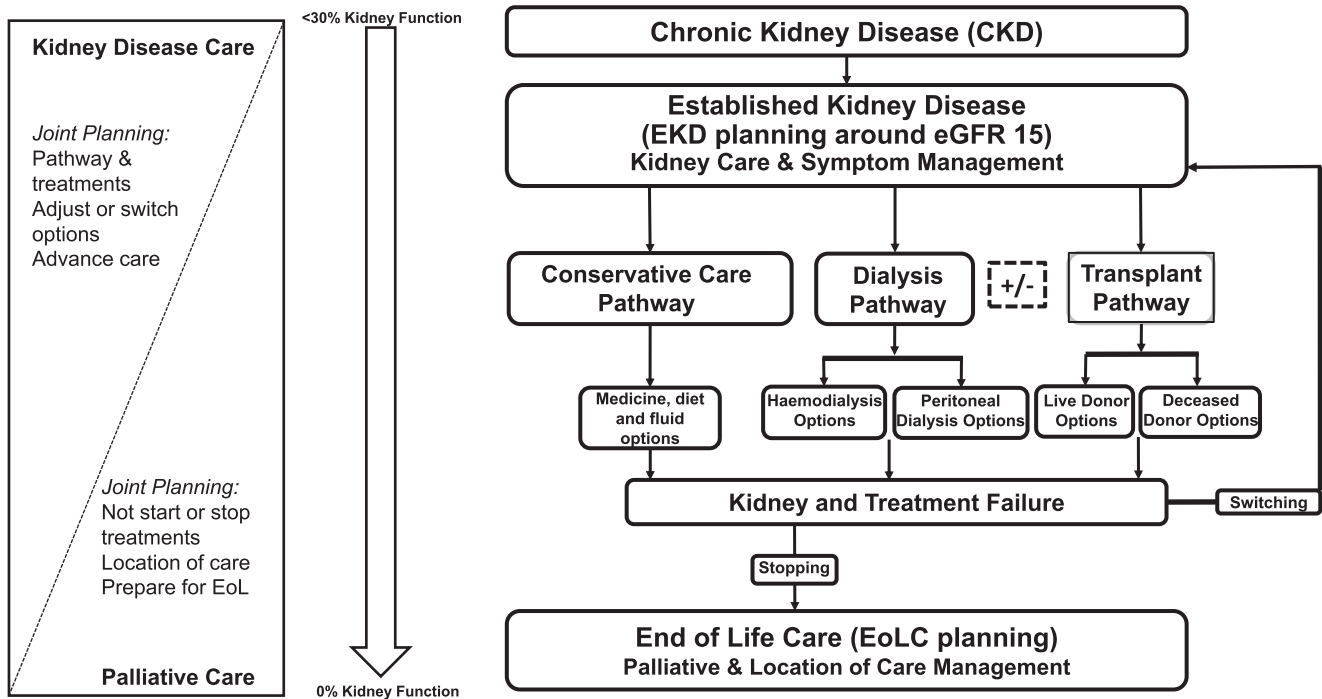


Figure 1: Decision map of the chronic kidney disease pathways, options and decisions (CKD-POD) when managing kidney failure. eGFR: epidermal growth factor receptor.

- Audit questionnaire for staff to elicit details about how CM education is delivered, leaflets provided to supplement PDE, satisfaction and/or needs with patient resources and staff training.
- Coding frame developed with reference to renal policy guidelines (Farrington *et al.* 2017; NICE 2018; Chan *et al.* 2019), previous critical analysis of dialysis modality leaflets (Winterbottom *et al.* 2007; Morony *et al.* 2015), patient-informed decision-making standards (Bekker *et al.* 1999; Charnock *et al.* 1999; Joseph-Williams *et al.* 2014; Combes *et al.* 2017) and written patient information guidance (Flesch 1946; Ley 1988; Duman 2013). The coding frame was piloted on two leaflets (AEW/HLB), and the final version applied to each of the leaflets by (AEW), eliciting: (1) leaflet purpose, description of CKD and CKD symptoms; (2) description CM, purpose of CM treatment, other treatment options; (3) CM attributes, e.g. medication, life expectancy, advanced care planning, death and CM consequences, e.g. quality of life, work, social life and family life; (4) comparison of CM, dialysis and transplant, e.g. effectiveness of treatment, co-morbidity, burden of treatment, withdrawal; (5) general format; (6) balance and biasing components and (7) shared

decision-making components. Total scores were calculated for sections 5–7 by adding up the scoring of items in each section; items scored “1” if described in the leaflet, “0” if not. All leaflets were assessed for their readability (0–100; difficult–easy to comprehend; Flesch 1946).

**PROCEDURE**

All 72 renal units were sent a questionnaire; posted to staff identified as responsible for PDE. Respondents returned the questionnaire, and copies of the CM leaflets used, in stamped addressed envelopes (SAE). Two reminder questionnaires were sent after two and four weeks. Three renal charities were emailed to request copies of their written information.

**ANALYSIS**

Data were managed using the IBM SPSS Statistics for Windows Version 20.0 (SPSS; IBM Corp., Armonk, NY, USA). Frequency and descriptive data summarised the responses from the audit questionnaire and leaflets’ content analysis. We used the figure developed as part of the YoDCA research to inform our evaluation and synthesis of the data extracted using the coding frames (Figure 1).

**RESULTS**

Fifty-four (75%) units participated (Figure 2) from England (n = 38), Wales (n = 3), Scotland (n = 7), Northern Ireland (n = 5); one was anonymous. Primarily, units provide patients with an opportunity to discuss CM with a nephrologist (98%) or nurse (100%). One-to-one consultations were supplemented by a workshop (n = 15, 28%), meetings with other patients who chose CM (n = 6, 11%) and/or a home visit from a nurse (n = 33, 61%); leaflets (n = 53, 98%) and/or DVDs (n = 14, 28%). Patient decision aids were used in 18 units: The *Dialysis Decision Aid: Making the Right Choices For You* booklet (Bekker et al. 2014; Winterbottom et al. 2016) was used in six units, the *Established Kidney Failure: Shared Decision Making* leaflet (NHS Rightcare; NHS Kidney Care 2013) used in four units, and one in-house decision aid; seven units erroneously labelled their leaflets as patient decision aids. Other leaflets described information about Advance Care Planning (n = 3), low clearance clinics (n = 1), supportive care registers (n = 1) and the Gold Standards Framework (n = 1).

Eighteen different leaflets were used across U.K. renal services to support CM conversations; n = 15 were provided by renal units and n = 3 by charities (Table S1). The average length was 14 pages (range 2–98; SD = 22.25). Five were a standard level of readability (M = 64.5 “standard level” range 61–70, max. 100), the rest were difficult to understand (M = 49.2 “difficult to read” range 41–50, max, 100) (Flesch 1946; Winterbottom et al. 2007). CM was labelled in 11 different ways (Table 1), its stated aim being to (a) control the symptoms of kidney failure with medication (78%), (b) protect and maintain kidney function (56%) and (c) maintain quality of life, emotional and spiritual needs (50%). Most leaflets included information about life expectancy (89%) but not risk figures (6%). Two leaflets (11%) described CM and no other treatment options, 11 (61%) described CM and dialysis, and five (28%) described CM and dialysis and transplant. The leaflet purpose was stated in 16 leaflets as being either to inform and reassure patients (69%), or inform and help decision making (31%).

Information about CKD, the consequences of a worsening disease state on health and symptoms, and links with pathways of care were not mentioned explicitly in any leaflet. Some leaflets described how the kidneys worked (22%), what happens when they fail (33%), the stages of kidney function (22%), the consequences of CKD in the short/long term (27%) and/or risk factors for CKD (22%). The most common

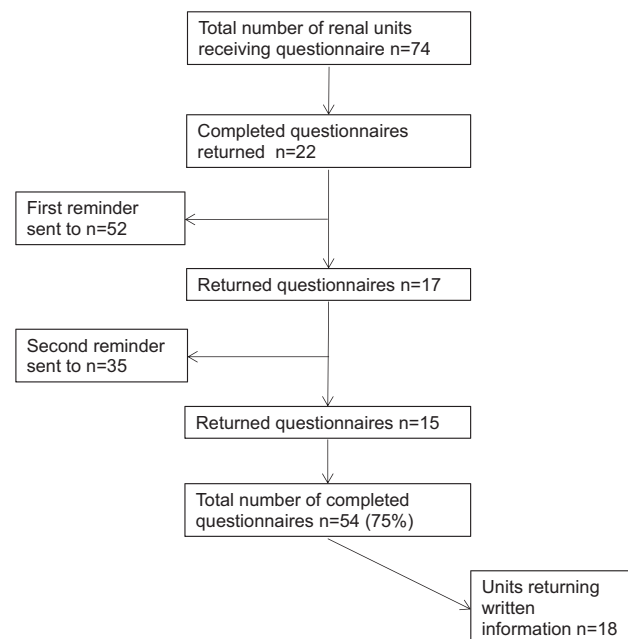


Figure 2: Flow diagram of study recruitment.

symptoms and/or side effects of kidney failure described were: itching (72%); anaemia (39%); tiredness (72%); sickness (61%); breathlessness (33%); loss of appetite (44%); oedema (56%); pain (50%); disturbed sleep (11%) and weight loss (17%).

**CONSEQUENCES OF CONSERVATIVE MANAGEMENT**

Most leaflets detailed the necessity for patients to take regular medication (72%), make changes to their diet and fluid intake (56%) and/or use renal patient view to monitor their

Treatment labels	N
Conservative management	1
Conservative kidney management	1
Conservative kidney management and choosing not to have dialysis	4
Conservative kidney management/supportive kidney management and choosing not to have dialysis	1
Conservative management and renal supportive care	2
Conservative care and choosing not to have dialysis	1
Conservative treatment and no dialysis	1
Active supportive care	1
Supportive care	1
Supportive care and choosing not to have dialysis	1
Choosing not to have dialysis	3
No dialysis	1

Table 1: Terms used to describe conservative management in each leaflet (n = 18).

condition (5%). Six (33%) leaflets suggested that patients could have a “trial” of dialysis before commencing CM. Although leaflets referred to patients’ quality of life, only one (5%) mentioned treatment impact on work; no leaflets described treatment impact on family life, social life, holidays, sex, hobbies or sport. Eleven (61%) leaflets talked about patients making advance care plans, although these were not always labelled explicitly (22%). Most leaflets described how care across services would be co-ordinated, e.g. kidney teams, general practitioners and community nursing teams (55%); that patients would maintain regular contact with services (55%), and/or detailed who within the healthcare team would look after patients (72%). Seven (29%) leaflets mentioned the availability of a psychologist, counsellor and/or a religious leader (22%) for patients to speak to about their concerns. Some leaflets mentioned the use of palliative care (44%) and/or hospice care services (33%), place of death (33%) and/or discussed dying (44%).

**INFORMATION PRESENTATION AND DECISION ARCHITECTURE TO PROACTIVELY SUPPORT INVOLVEMENT IN DECISION MAKING**

Leaflets scored on average, 8.44 (range 5–12; SD = 2.49) for information presentation, suggesting some components included may reduce cognitive load and increase ease of processing facts. The visual presentation of the majority of leaflets was good in terms of font size (89%), appropriateness of length (100%), inclusion of short paragraphs (72%), use of bullet points (67%), use of present/active tense (100%), clear headings (100%) and year of publication (78%). Few leaflets included diagrams (17%) or references (17%). Ten (56%) included a review date, information about local hospital services (56%) and the availability of different sources of the same information (61%).

On average leaflets scored 2.11 (max 6: range 1–4; SD = 0.96) suggesting they presented information in a way that might bias people's choices. Four leaflets (22%) provided a balanced presentation of the harms and benefits of each option; details of different aspects of treatments were dependent on which option was being described (Table 2). Most leaflets included an explicit discussion about the type of decision to make and/or gave advice about how to make the decision and/or encouraged patients to discuss the decision with health professionals. None of the leaflets provided space for people to think about what was important to them and what they liked/

disliked about treatments; two (11%) provided space for patients to write notes/questions. Leaflets scored on average 3.50 for their inclusion of information known to support shared decision making (max 9; range 1–6; SD = 1.58).

**STAFF VIEWS ON THE PROVISION OF INFORMATION ABOUT CONSERVATIVE MANAGEMENT**

All respondents were nurses; 63% (n = 33, scored 5–7, range 1–7) found the information satisfactory; 27% (n = 19, scoring 1–4, range 1–7) unsatisfactory. Thirty-seven (71%) respondents gave reasons for their ratings. Reasons for their satisfactory ratings included: leaflets were simple and easy to understand (11%); information was produced locally and included local service information (8%). Reasons for not satisfactory ratings included: not enough information available (19%); information was not detailed enough (19%); information is out of date (8%) and/or the topic area is too complicated/sensitive to be conveyed in a written format (3%). All nurses reported that their preferred method of communicating about the CM decision was via face-to-face contact with patients and/or their families.

*By a very wide margin it is face to face contact—and it's usually useful to have family present and as a nurse doing a home visit. The DVDs and decision aids are back-up. Because facing ones own life and death scenario is perhaps deepest emotional and meaningful reflection we do in life and it needs all the appropriate support we can get. That means having a human rather than a booklet or piece of software. Questions can be addressed immediately face to face and the answers can be explored until they satisfy*

	Conservative management n (%)	Dialysis n (%)
Effectiveness/prognosis/morbidity/mortality	5 (28)	7 (39)
Frailty/aging/function	1 (6)	6 (33)
Co-morbidity	7 (39)	5 (28)
Risks/side effects	4 (22)	6 (33)
Switching	5 (28)	4 (22)
Advanced care planning	5 (28)	2 (11)
Consequences to lifestyle/QoL	1 (6)	7 (39)
Treatment burden	2 (12)	10 (56)
Withdrawal	1 (6)	4 (22)

Table 2: Balance of information included in n = 18 leaflets offering an alternative option to CM.

*Face to face communication as able to clarify any questions and pick up on body language/facial cues of patient if upset or appears to not understand*

Twenty-seven (52%) respondents said they had access to and/or had undertaken training, including: study days and/or advanced communication skills/end of life/breaking bad news courses. Most commonly reported training was available in-house, via local palliative care teams or was experiential.

## DISCUSSION

These findings provide a snapshot of how three-quarters of U.K. renal units currently support people making treatment decisions to manage their EKD. Staff emphasised the importance of talking about the CM and RRT options face-to-face with people with CKD and their families because of the emotional consequences and complexity of planning treatment for the next stage of a person's worsening kidney disease. The variation in the training opportunities for staff to deliver balanced information between these care pathways and availability of consistent information about CM (Murtagh *et al.* 2016) may account for nurses lack of confidence in talking to patients about the uncertainty of treatment outcomes (Noble *et al.* 2017), implications of a worsening disease trajectory (Winterbottom *et al.* 2016) and preparation for care at the end of life (Bristowe *et al.* 2015).

Most conversations were supplemented with written information, often written by renal-unit staff (65%). The finding suggests that staff recognise the benefit for people with EKD, and their families, having a leaflet to refer to when making a complex decision about their care during consultations. Although some units used endorsed best practice patient decision aids, these resources were designed, and evaluated, to support decisions between dialysis modalities, with signposting to information about transplant and CM options (see Figure 1; Winterbottom *et al.* under review). As with many NHS leaflets, these resources were designed to inform, reassure and/or prepare people for an option, and not facilitate informed decision making between options (Winterbottom *et al.* 2007). Further it was unclear if leaflets were handed out before, and/or used interactively within consultations, which may impact on people's experience in making decisions. There seemed to be a lack of awareness about what components are needed within a resource to

support people to reason proactively about options when making informed, values-based decisions (Elwyn *et al.* 2006; Stacey *et al.* 2017).

Enabling services to support people with EKD to make decisions between conservative care and dialysis (NICE 2018), requires facts about options being described equitably, and without judgment (NHS Kidney Care 2013). The findings illustrate the challenge for services to deliver this type of information at the start of planning care for EKD, in part because the consequences of options are disparate, and the trajectory of individuals' illness so uncertain. There was variation in the balance and type of facts when CM and dialysis options were described. Dialysis was framed within the context of treatment burden and fitting into a person's everyday life; CM in the context of symptom management and preparing for the end of life. Advance care plans and palliative care were only mentioned in the context of CM and although a few leaflets mentioned withdrawal from dialysis ( $n=5$ ), none linked the consequences of withdrawing from dialysis to advance care planning, and to preparing for end of life (typically within 7–10 days, Birmele *et al.* 2004).

## IMPLICATION FOR CLINICAL PRACTICE AND CONCLUSION

Our findings indicate that leaflets used in U.K. kidney service education may prepare people to start on CM, or dialysis pathways but do not support reasoned decision making between dialysis and CM options. U.K. kidney services recognise the value of these leaflets, and are keen to integrate them into usual practice. However, there is a need for training and guidance to support people to deliver education, and leaflets, about EKD pathways that ensures balanced and equitable information about the consequences of all options. It seems likely that early signposting to kidney disease and treatment failure as a consequence of both pathways may help to normalise advance care planning conversations routinely within EKD services. Using unbiased language to reflect accurately care pathways for people with EKD needs to start with a change to how services describe their PDE, staff and resources. For example, "EKD Education" captures both the transition to a worse state of CKD (see Figure 1) and provides a focus on managing the disease rather than focusing on choosing renal replacement therapy.



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## AUTHORS CONTRIBUTIONS

AEW, HLB and AM study leads; all authors contributed to the design, data interpretation, report writing and approval of the final manuscript.

## CONFLICT OF INTEREST

None of the authors have any financial conflicts of interest. AM is a scientific advisor to Kidney Research Yorkshire (KRY), but played no role in the funding of this project. The application was reviewed by an external committee. AM is not a voting member of the KRY committee.

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## SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.