





EMPIRICAL RESEARCH MIXED METHODS

Shared decision making for patients with kidney failure to improve end-of-life care: Development of the DESIRE intervention

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Abstract

Aim: To describe the development of a shared decision making intervention for planning end-of-life care for patients with kidney failure, their relatives and health professionals in kidney services.

Background: End-of-life care conversations within standard disease management consultations are challenging for patients with kidney failure, their relatives and health professionals. End-of-life care planning is about making difficult decisions in advance, which is why health professionals need shared decision making skills to be able to initiate end-of-life conversations. Health professionals report needing more skills to raise the issue of end-of-life care options within consultations and patients want to be able to discuss issues important to them about future care plans.

Methods: The development design was guided by the UK Medical Research Council's framework and a user-centred approach was applied. Four workshops were conducted with end users. The Template for Intervention Description and Replication for Population Health and Policy interventions was used to shape which questions needed to be answered through the workshops and to present the intervention. The International Patient Decision Aid Standards (IPDAS) criteria set the standards to be achieved.

Results: Areas considered significant to a shared decision making intervention were training of health professionals, conversations about end-of-life care, planning and evaluation of the decisions, reporting decisions in health records and repetition of consultation. The development process went through 14 iterations.

Conclusion: An intervention named DESIRE was developed that comprises: (1) a training programme for health professionals; (2) shared decision making conversations; and (3) a patient decision aid. The intervention met 30 out of 33 IPDAS criteria.

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Implications for practice: DESIRE is intended to support shared decision making about planning end-of-life care among patients with kidney failure, their relatives and health professionals. The study provides important tools for the stakeholders engaged that can be used within different models of care.

Impact

What problem did the study address? International guidelines recommend health professionals involve patients with kidney failure in making decisions about end-of-life care, but there is variation in how this is implemented within and across kidney services. Furthermore, patients, relatives and health professionals find it challenging to initiate conversations about end-of-life care.

What were the main findings? The study resulted in the development of a complex intervention, called DESIRE, about shared decision making and planning end-of-life care for patients with kidney failure, their relatives and health professionals in kidney services, including a training programme for health professionals, shared decision making conversations and a patient decision aid.

Where and on whom will the research have an impact? The research contributes a shared decision making intervention to patients in the later stage of kidney failure, their relatives and health professionals. We believe that the DESIRE intervention could be introduced during consultations with health professionals at an earlier stage of the patient's illness trajectory, as well as being applied to other chronic diseases.

Reporting Method: This intervention development research is reported according to the GUIDance for the rEporting of intervention Development (GUIDED) checklist and the DEVELOPTOOLS Reporting Checklist.

Patient or Public Contribution: Patients, relatives and health professionals have been involved throughout the research process as part of the research team and advisory board. For this study, the advisory board has particularly contributed to the development process of the DESIRE intervention by actively participating in the four workshops, in the iterations between the workshops and in the preparation of the manuscript.

KEYWORDS

advance care planning, complex intervention, end-of-life care, intervention development, kidney failure, patient and public involvement in research, patient decision aid, shared decision making, user-centred approach, workshops

1 | INTRODUCTION

This article reports the development phase of an intervention to support patients with kidney failure, their relatives and health professionals in making decisions together about the patient's kidney disease management and end-of-life care (EoLC). Légaré et al. (Légaré et al., 2018) define shared decision making (SDM) as an interpersonal, interdependent process in which health professionals, patients and caregivers relate to and influence each other as they collaborate in making decisions about a patient's health. The purpose of this intervention is to enable an improved SDM process between patients with kidney failure, their relatives and health professionals

in order to make timely decisions about planning EoLC in the context of managing the patient's kidney failure. An additional goal is to ensure the patient's choice is based on what is important in their life as well as meeting their individual clinical and health needs.

The study is part of the Shared dEciSIon making for patients with kidney failuRE to improve end-of-life care (DESIRE) intervention development and evaluation project carried out across four Danish nephrology departments (Buur et al., 2022). The article describes the research process, findings, and analysis behind each iteration in the design of the DESIRE intervention components. The project's research design and methods are guided by the UK Medical Research Council's framework for complex intervention

development and evaluation (Skivington et al., 2021) and the Making Informed Decisions Individually and Together (MIND-IT) framework for interventions supporting multiple decision makers in healthcare (Toft et al., 2022).

2 | BACKGROUND

2.1 | EoLC planning for patients with kidney failure

Kidney failure is the last stage of five in the classification of chronic kidney disease. This classification is based on patients' estimated glomerular filtration rate (eGFR) (Levey et al., 2020). Patients diagnosed with kidney failure have an eGFR below 15 (Levey et al., 2020). Kidney failure is associated with a high symptom burden, and patients with kidney failure often suffer from comorbidities and high mortality rates (Murtagh et al., 2007). Having kidney failure increases the risk of experiencing a decline in cognitive function, referred to as cognitive impairment (Drew et al., 2019). Accelerations in multifactorial physiological patient trajectories within a few months prior to death have been reported, which correlate with increased hospitalisation rates (Chesnaye et al., 2023). Furthermore, considerable individual variation in the illness trajectory in the last year of life has been seen among patients with kidney failure (Murtagh et al., 2011). The unpredictability of the illness trajectory is an important factor, emphasising that it is meaningful to initiate decision making about the end of life for these patients at a time when they are still cognitively and physically able to make decisions on their own behalf. Good communication within health professional-patient consultations is seen as central to the exchange of thoughts, beliefs, opinions, concerns and needs by all parties (Holley, 2007).

Communication is an integral component of managing long-term health conditions (Holley, 2007). However, health professionals find it challenging to initiate topics in consultations to encourage patients to talk about EoLC preferences, especially when their health is in a stable period within their illness trajectory (Lazenby et al., 2017). The result may be that such conversations are initiated rarely, and often left until a patient experiences deterioration in their health when they may be too ill to engage in conversations about EoLC preferences (Davison, 2010; Lazenby et al., 2017; Mandel et al., 2017). There is evidence indicating that patients may want to discuss and be informed about EoLC earlier in their illness trajectory (Mandel et al., 2017). National and international guidelines recommend that health professionals involve patients in the decision making process (National Institute for health and care excellence 2014; Hemodialysis Adequacy Work Group 2006). Nevertheless, initiating discussions about EoLC preferences with patients with kidney failure is not systematically integrated into the daily care of this patient group (Davison, 2010).

Previous studies on communication about EoLC with patients with kidney failure revealed that advance care planning (ACP) is a term commonly used to describe EoLC planning (Mandel et al., 2017; O'Halloran et al., 2018). ACP is a process that supports adults at

What does this paper contribute to the wider global clinical community?

- A systematic description of the development process of a complex intervention with patient and public involvement in research.
- A complex intervention supporting patients, relatives, and health professionals in shared decision making, exchanging understanding, reasoning about preferences and implementation of agreed choice(s) concerning end-of-life care.
- A patient decision aid designed to support patients, relatives and health professionals in shared decision making conversations about end-of-life care.

any age or stage of health in understanding and sharing their personal values, life goals and preferences regarding future medical care (Sudore et al., 2017). The goal is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness (Sudore et al., 2017). Detailed communication and ACP are recommended, but this approach is not often used systematically. Studies show that there are barriers to implementing ACP in kidney services, and that SDM may be a useful framework to facilitate ACP (Davison, 2011).

Recent KDIGO (Kidney Disease: Improving Global Outcomes) guidelines on supportive care in chronic kidney disease emphasise the need to endorse patient-centred care with the objective of obtaining higher quality health outcomes and better patient satisfaction, which requires the use of SDM (Davison et al., 2015). A review from 2020 (Winterbottom et al., 2020) identified 17 SDM interventions in kidney care that focus on decision making about different treatment pathways, but none are about EoLC planning. In Denmark, studies in kidney care have proven that SDM interventions are acceptable and involve patients with kidney disease in the decision making process regarding the choice of dialysis modality (Finderup et al., 2019). A study from 2021 (Finderup et al., 2021) reported that when patients with kidney disease are involved in decision making, they become more involved in their own treatment and health over time.

EoLC planning involves difficult decisions, and health professionals need SDM skills to be able to initiate end-of-life conversations with patients with kidney failure and their relatives. One way to promote SDM is the development of patient decision aids (PtDAs) to be integrated within pathways of care. PtDAs are resources that support patients to make informed decisions between healthcare options (Stacey et al., 2017). Drawing on these resources within consultations can prompt discussions about all management options available, help patients and relatives communicate what is important to them about the different options and encourage professionals to provide reasons for the clinical relevance of one option over another for the patient (Finderup et al., 2021).

3 | THE STUDY

3.1 | Aim

The aim of this study was to describe the development of an SDM intervention for planning EoLC for patients with kidney failure, their relatives and health professionals in kidney services.

3.2 | Previous research to understand end users

This article describes the steps taken to develop an EoLC SDM intervention enabling patients with kidney failure, their relatives, and health professionals to make these difficult decisions together in a timely manner, and is part of a project to develop and evaluate an SDM intervention for use in Danish kidney services (Buur et al., 2022). Our previous research to identify current practice, and the needs of multiple stakeholders, in Denmark, when making shared decisions about EoLC as part of managing kidney failure include: (1) a scoping review investigating and mapping empirical evidence of patient involvement interventions to support patients with kidney failure making EoLC decisions in kidney services (Buur, Bekker, Madsen, et al., 2023); (2)

a qualitative interview study investigating the decisional needs of people with kidney failure, their relatives, and health professionals in Denmark when planning EoLC (Buur et al., 2024); and (3) a case study investigating the experiences of people with kidney failure who received decision coaching for EoLC decisions (Buur, Bekker, Mathiesen, et al., 2023). The findings of each study were analysed individually. To identify the likely components of an intervention to support an SDM process the findings of all three studies were synthesised. Table 1 presents the identified components of each study. The synthesised findings of the three studies were presented in a workshop underpinned by examples from the findings of each study.

4 | METHODS/METHODOLOGY

The intervention development process of this research was based on a complex intervention design (Skivington et al., 2021). An iterative, user-centred approach with qualitative workshop methods was used to develop the SDM intervention. Four workshops were carried out with a multiple-stakeholder group over a four-month period to discuss, develop and refine the components within the intervention and its implementation in practice. The focus of this article is

TABLE 1 Component resources from exploration to understand end users according to targeted stakeholder.

Stakeholder	Component resources: Scoping review	Component resources: Interview study	Component resources: Case study
Patients with kidney failure	<ul style="list-style-type: none"> Information Patient decision aids 	<ul style="list-style-type: none"> Focusing on life as opposed to end of life Needing more knowledge and information 	<ul style="list-style-type: none"> Decision coaching provides an overview and more nuances to the decision Decision coaching may lead to more questions Decision coaching generates a need for further explanation about the decision Fewer decisional needs indicated Patients with kidney failure continue to have decisional needs despite decision coaching
Relatives	<ul style="list-style-type: none"> Information Patient decision aids 	<ul style="list-style-type: none"> Feeling a great responsibility regarding representing the patients' interests Needing more knowledge and information 	Not applicable
Health professionals	<ul style="list-style-type: none"> End-of-life care communication skills training Decision coaching 	<ul style="list-style-type: none"> Focusing on treatment rather than quality of life Needing more tools and training 	<ul style="list-style-type: none"> Decision coach (health professional) did not intervene with knowledge of options and potential benefits/harms of options In one of the four cases, the health professional did not intervene in relation to others' involvement in decision
Patients with kidney failure, relatives, and health professionals	<ul style="list-style-type: none"> Advance care planning Shared decision making 	<ul style="list-style-type: none"> Talking about end of life is difficult Experiencing busyness as a barrier to conversations about end of life 	<ul style="list-style-type: none"> Ottawa Personal Decision Guide

to describe the methods used and provide a document describing both the intervention and the development process (O'Cathain et al., 2019). The GUIDance for rEporting intervention Development studies in health research (GUIDED) (Duncan et al., 2020) and the DEVELOPTOOLS Reporting Checklist by Witteman et al. (Witteman et al., 2021), which can be found in the supporting information (see Appendix S1), were used to strengthen the reporting.

Various methodological and theoretical frameworks have been used in the design of the prototype intervention and throughout the intervention development process. Table 2 provides an overview of the different frameworks used in the different parts of the process developing the intervention.

4.1 | Methodological framework

The broad methodological framework that influenced the development and evaluation process of this intervention was the UK Medical Research Council's guidance for developing and evaluating complex intervention research (Skivington et al., 2021). We focused on the intervention development and the context for its implementation in practice, to develop and refine the programme theory, engage stakeholders and refine the intervention (Skivington et al., 2021). To strengthen the development process, we combined the UK Medical Research Council's framework with the systematic development process for PtDAs from the International Patient Decision Aid Standards (IPDAS) collaboration recently updated by Witteman et al. (Witteman et al., 2021).

4.2 | Theoretical framework

The MIND-IT framework provides the theoretical guidance for developing an intervention to support the decision making of multiple stakeholders (Toft et al., 2022). The MIND-IT framework is informed by decision science approaches to design interventions proactively enabling individuals to make reasoned decisions. MIND-IT represents explicitly the roles and contexts of multiple decision makers involved in a healthcare decision. Using the MIND-IT framework helps developers consider: (1) the different goals of each stakeholder; (2) the components and active ingredients needed to support the

individual reasoning of each decision maker; (3) the interaction points within the service delivery that impact on a shared understanding of the problem and reasoning together about options; and (4) mechanisms explaining how the intervention may impact on individual decision maker actions, decision maker interactions and context infrastructure from each decision maker's perspective.

4.3 | Additional frameworks

The multiple stakeholder approach of MIND-IT was used together with the UK MRC and Consolidated Framework for Implementation Research (CFIR) (Damschroder et al., 2022) frameworks to consider the organisational context of four workshops. These frameworks guided and supported the researchers in: (1) deciding important individuals to include in the intervention development process, (2) continuously considering the implementation process of the intervention. The findings from the previous research to understand the end users was used together with the Ottawa Decision Support Framework (ODSF) (Ottawa Hospital Research Institute, 2020a) to support the workshop participants in deciding to include the generic Ottawa Personal Decision Guide (OPDG) (Ottawa Hospital Research Institute, 2020b) as an element of an intervention PtDA. The IPDAS framework (Witteman et al., 2021) has guided the process to assure that the intervention meets the IPDAS criteria.

4.4 | Context

This project was carried out within Danish kidney services at two large university hospitals and two satellite haemodialysis units. The four different nephrology departments include patients on in-centre haemodialysis, peritoneal dialysis and the conservative kidney management pathway.

4.5 | Developing and refining the programme theory

An important part of the research process for a complex intervention is building a programme theory. This involves explaining why

TABLE 2 Overview of frameworks used when developing the DESIRE intervention.

Overall frameworks	Organising workshops	Developing intervention	Achieving standards
UK MRC	UK MRC	-	-
IPDAS	-	-	IPDAS
MIND-IT	MIND-IT	MIND-IT	-
-	ODSF	ODSF	-
-	CFIR	-	-

Abbreviations: CFIR, Consolidated Framework for Implementation Research; IPDAS, International Patient Decision Aid Standards; MIND-IT, making informed decisions individually and together; ODSF, Ottawa decision support framework; UK MRC, UK Medical Research Council.

the intervention is expected to work in a specific way (O'Cathain et al., 2019; Skivington et al., 2021). To illustrate the programme theory of the DESIRE intervention, a logic model was constructed (O'Cathain et al., 2019; Skivington et al., 2021). The model has been adjusted throughout the study because it is an iterative process and changes may benefit the programme theory as evidence from the study data and from considering the core elements becomes available.

4.6 | Engaging stakeholders

To inform the development and refining of the DESIRE intervention, the data gathered from the research conducted to understand end users (Buur et al., 2024; Buur, Bekker, Madsen, et al., 2023; Buur, Bekker, Mathiesen, et al., 2023) were used during four multidisciplinary workshops hosted by the first author in September, October, November and December 2022.

Patients with kidney failure, relatives of patients with kidney failure, and health professionals were invited to and included in the workshops, together with the research team. We used purposive sampling to include participants relevant to kidney services. This co-design approach was among other things used to enable development of a user-centred intervention including considerations on how to support individuals with potential lower health literacy to ensure also supporting their needs and preferences. We recruited participants through the four nephrology hospital settings and the Danish Kidney Association. All participants were invited by email.

In an effort to encourage valuable reciprocal learning among the workshop participants, collaborative learning methods were used as inspiration for structuring the workshops (Smith & MacGregor, 1992). With a participant-centred approach, the workshops depended on discussions and active work by the various stakeholders. This article presents the data collected from the discussions and active work among participants.

4.7 | Procedure, data collection and analysis

Prior to each of the four workshops, the first author prepared a detailed script outlining the various workshop sessions. This included the aim of the workshop, presentations of data collected to support the development process (Buur et al., 2024; Buur, Bekker, Madsen, et al., 2023; Buur, Bekker, Mathiesen, et al., 2023), an introduction to different supportive methodological and theoretical frameworks to inspire the development process, an introduction to group work sessions, and plenary discussions. Subsequently, the script was discussed and approved by the research team. The Template for Intervention Description and Replication for Population Health and Policy interventions (TIDieR-PHP) (Campbell et al., 2018) was used to help determine which questions needed to be answered through the workshops. Data materials included audio recordings from the workshops together with numerous notes written by all participants.

Suggestions from all participants served as data to inform the development of a prototype of the DESIRE intervention. Analysis of data began in the workshops through a consensus-based decision making process where the entire research group participated in ensuring that all participants had a say in the process. The first author translated and adapted these decisions to develop the prototype intervention. The prototype was discussed between the research group and PPI members and adjusted accordingly. Furthermore, post-workshop prototype activities provided the participants the opportunity to provide feedback and comment on the prototype iterations between the workshops. At the following workshop, or through online feedback, this translation and adaptation process was validated and further developed through consensus-based decision making and using a multiple-stakeholder approach and collaborative learning methods. Table 3 gives an overview of the workshops.

4.8 | Implementation

Implementation of an SDM intervention with an EoLC-focused approach could be challenging because of an existing biomedical paradigm in clinical practices, where communication typically has a low priority, and the instrumental focus on dialysis machines and equipment is given more attention. The various stakeholders involved throughout the development process played a decisive role in considering the context in which the intervention was to be implemented and which barriers to future implementation into kidney services had to be dealt with as part of the development process. Planning of the roles and responsibilities of the stakeholders engaged in the development process and the possibility of tailoring the intervention to fit different contexts of implementation presented ways to strengthen the implementation. These were part of the workshop considerations and discussions. In addition, key uncertainties that had been identified prior to the development process (Buur et al., 2024; Buur, Bekker, Madsen, et al., 2023; Buur, Bekker, Mathiesen, et al., 2023) were covered in the workshop discussions, for example, the duration of the SDM conversations and at what point in the illness trajectory a conversation should be offered to patients with kidney failure and their relatives.

4.9 | Ethical considerations

Under Danish health research legislation, conducting this kind of research does not require ethical approval. The participants in workshops I, II, III and IV had all consented to participate in the workshops and had been informed that their output would be used in the development of a prototype of the intervention and a research article. They all gave informed oral consent. The research team had some ethical considerations on the theme of the study EoLC and how this might affect the patients with kidney failure and their relatives. To ensure the well-being of the individuals who took part in the workshops and the post-workshop prototype iterations, they were followed-up before,

TABLE 3 Overview of workshops I, II, III and IV.

Workshop I—Held as a stand-alone event in September 2022, with in-person attendance

Participants:

PwKF, relatives of PwKF, PPI members, nephrology nurses, nephrologists and researchers

Group work purposes:

- To draft an invitation to PwKF and their relatives to have SDM conversations for EoLC planning
- To draft a decision diagram containing important decisions to discuss when planning EoLC
- To draft a PtDA to support PwKF, relatives, and health professionals during EoLC SDM conversations
- To structure a training programme for health professionals in kidney services

Methods:

Collaborative learning process (Smith & MacGregor, 1992)

- Following each group work session, the groups presented the results of their work, which were discussed further among all workshop participants

Supportive materials:

- MIND-IT (Toft et al., 2022)
- ODSF (Ottawa Hospital Research Institute, 2020a) and OPDG (Ottawa Hospital Research Institute, 2020b)
- Decision map of kidney disease pathways (Winterbottom et al., 2020)
- Difficult conversations booklet (Winterbottom et al., 2022)
- ALOBA (Kurtz et al., 2005)

Post-workshop prototype development—including iterations

Participants:

Researchers and PPI members

Methods:

- Results from group discussions in workshop I were used to develop a prototype of the SDM intervention entitled DESIRE

Intervention components:

- An invitation to SDM conversations
- A PtDA including a decision diagram
- A training programme for health professionals in kidney services

Iterations:

- Prototype of DESIRE was discussed between researchers and PPI members and adjusted accordingly
- Prototype of PtDA was sent to all workshop participants to comment on before workshop II

Workshop II—Held as a stand-alone event in October 2022, with online attendance

Participants:

PwKF, relatives of PwKF, PPI members, nephrology nurses, nephrologists and researchers

Group work purpose:

- To discuss and revise various elements of the prototype PtDA

Methods:

Collaborative learning process (Smith & MacGregor, 1992)

- Following each group work session, the groups presented the results of their work, which were discussed further among all workshop participants

Post-workshop prototype development—including iterations

Participants:

Researchers and PPI members

Methods:

- Results from group discussions in workshop II were used to revise the prototype of the DESIRE intervention

Iterations:

- Revised prototype of DESIRE was discussed between researchers and PPI members and adjusted accordingly
- Revised prototype of PtDA was sent to all workshop participants for final revisions before workshop III

(Continues)

TABLE 3 (Continued)

Workshop III—Held as a stand-alone event in November 2022, with online attendance

Participants:

PwKF, relatives of PwKF, PPI members, nephrology nurses, nephrologists and researchers

Group work purpose:

- To discuss and further refine the various elements of the revised PtDA

Methods:

Collaborative learning process (Smith & MacGregor, 1992)

- Following each group work session, the groups presented the results of their work, which were discussed further among all workshop participants

Post-workshop prototype development—including iterations

Participants:

Researchers and PPI members

Methods:

- Results from group discussions in workshop III were used to further revise the prototype of the DESIRE intervention

Iterations:

- Revised prototype of PtDA was sent to all workshop participants for further comments before a graphic designer prepared a visual version containing all the inputs from the workshop discussions
- The participants, including the researchers, commented on this version, which was sent back to the graphic designer for a final redesign
- The revised prototype was sent to the web editor of the Communication Department of Aarhus University Hospital, to ensure the wording of the PtDA was appropriate for the end users of the intervention

Workshop IV—Held as a stand-alone event in December 2022, with online attendance

Participants:

PwKF, relatives of PwKF, PPI members, nephrology nurses, nephrologists and researchers

Group work purposes:

- To present and discuss the iterated prototype of the PtDA among the participants, who gave their final approval for the prototype
- To discuss and refine the structure of the training programme for the health professionals

Methods:

Collaborative learning process (Smith & MacGregor, 1992)

Abbreviations: ALOBA, agenda-led outcome-based analysis; EoLC, End-of-life care; ODSF, Ottawa Decision Support Framework; OPDG, Ottawa Personal Decision Guide; PtDA, patient decision aid; PwKF, Patients with kidney failure; PPI, Patient and public involvement in research; SDM, shared decision making.

during, and after workshops. Furthermore, they were provided the opportunity to call the research team by phone at any time necessary to talk about difficult issues that may have occurred during or post attendance. There are no citations of the comments from the participants during the workshops. However, we have audio recordings of all four workshops and the participants presented their discussions from the different group work sessions during the workshops, so all were covered in the audio recordings. The audio recordings are stored in an encrypted folder in the computer system of one of the participating university hospitals. In accordance with the Danish health research legislation, data will be stored for 5 years.

4.10 | Rigour and reflexivity

Thoroughness in the development process was achieved by following the methodological guidance from the UK Medical Research Council's framework (Skivington et al., 2021), ensuring that the process was based on research evidence and theory of the problem. The core

elements of the framework: consider context; develop, refine and test programme theory; engage stakeholders; identify key uncertainties; refine intervention were also considered during the four workshops and throughout the development process. To make the intervention suitable to fit into clinical practice economics were also contemplated although, we did not make an economic evaluation.

5 | RESULTS

The patient and relative participants comprised informants from the four nephrology hospital settings included in the study and members of the Danish Kidney Association. The health professional participants in the workshops comprised nurses and nephrologists with several years of experience in nephrology—both in outpatient clinics and dialysis and representing different organisational levels within the inner hospital setting. In total, three patients, two relatives, 12 nurses and four nephrologists, including the research team, agreed to participate in the workshops. However, some of the participants

were prevented from participating on the day of the workshops due to personal circumstances. An overview of participants' attendance is shown in Table 4.

5.1 | Findings from the intervention development and refining process

During the four workshops, the participants considered several areas significant for an SDM intervention. The first area was *training of health professionals* in EoLC SDM and decision coaching. The second area was *conversations about end-of-life care* including the possibility of discussing EoLC options, for example, continue as I am now, step up treatment, reduce treatment, switch treatment, stop treatment, and decide on and plan care and treatment if health deteriorates. The third area was *planning and evaluation of the decisions*. The fourth area was *reporting decisions in health records*. The fifth area was *repetition of conversation*.

Based on the workshops, the DESIRE intervention prototype was developed. During the workshop process, the prototype went

through 14 iterations before the workshop participants approved the final version.

The intervention was named DESIRE and consists of:

- A training programme for health professionals
- SDM conversations
- A PtDA called 'choosing care and treatment when your health deteriorates with kidney failure'.

Figure 1 illustrates the intervention components.

Based on guidance from the TIDieR-PHP checklist (Campbell et al., 2018), the components of the intervention are described in more detail in Table 5.

5.1.1 | The training programme for health professionals

The training of health professionals lasted one working day 7h, and was divided into three sessions:

TABLE 4 Participants' attendance at workshops and post-workshop prototype activities.

Participants	Number at work-shop I	Number post-work-shop	Number at work-shop II	Number post-work-shop	Number at work-shop III	Number post-work-shop	Number at work-shop IV
Nurses	11	10	7	7	7	7	8
Nephrologists	1	2	4	3	3	4	4
Patients	3	3	2	2	2	1	3
Relatives	2	2	2	2	2	2	2
Total number	17	17	15	14	14	14	17

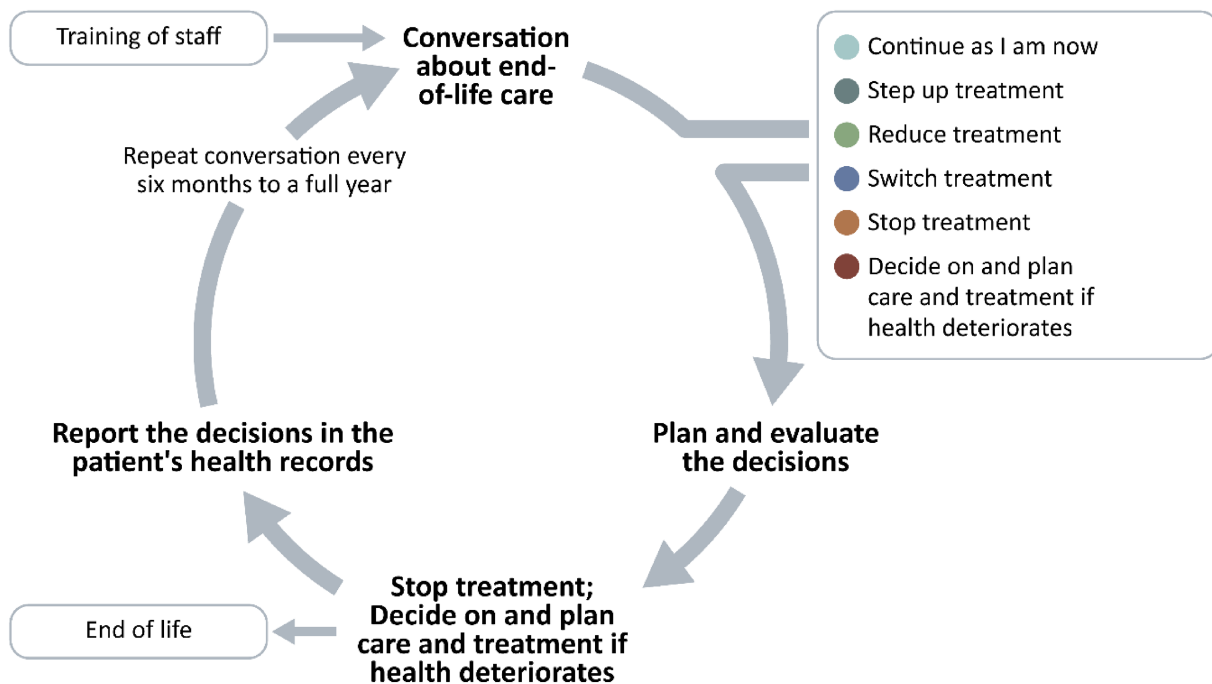


FIGURE 1 Components of the DESIRE intervention.

TABLE 5 Description of the DESIRE intervention.

Item	Description
1 Brief name	Shared dEciSIon making for patients with kidney failuRE to improve end-of-life care (DESIRE)
2 Why	<p>The UK Medical Research Council's framework for complex intervention development and evaluation guided the research design and methods (Skivington et al., 2021), together with the IPDAS criteria (International Patient Decision Aid Standards (IPDAS) Collaboration, 2020) and its supporting chapters (Witteaman et al., 2021).</p> <p>The DESIRE intervention is an SDM intervention that includes the essential elements of SDM defined by Légaré et al. (Légaré et al., 2018).</p> <p>The intervention is based on the MIND-IT framework (Toft et al., 2022) for making informed decisions in a multiple stakeholder role setting in healthcare, but also inspired by the ODSF (Ottawa Hospital Research Institute, 2020a).</p>
3 What materials	<p>The intervention consists of a training programme for HPs, SDM conversations, and a PtDA called 'Choosing care and treatment when your health deteriorates with kidney failure'.</p> <p>Materials used in the training programme are the PtDA booklet, a video recording of an SDM conversation, detailed Power Point slides outlining the aim of the training programme and its three sessions, learning objectives, introduction to the MIND-IT theoretical framework to support SDM skills, presentation of the PtDA and its different tools, and presentation of a role-play session.</p> <p>Materials used in the SDM conversation are an invitation to the conversation in paper format and the PtDA booklet.</p> <p>Materials in the PtDA booklet are a range of tools including various pictograms and a decision map supporting a discussion of what is important in a patient's life, an overview of options and frequently asked questions to support the stakeholders in discussing various options for EoLC, and the OPDG – Danish version to support the stakeholders in making decisions and planning the patient's EoLC.</p>
4 What and how	<p>The training programme for HPs comprises three sessions: 1) training in SDM, the MIND-IT framework, and the PtDA; 2) a video recording of an SDM conversation about EoLC decision making using the PtDA; and 3) facilitation of role-play.</p> <p>The SDM conversation comprises an invitation to the conversation, the PtDA for use during the conversation for EoLC planning and decision making between the patient, the patient's relative(s), and a trained HP.</p> <p>The SDM conversation involves one or more face-to-face consultations between the patient, the patient's relative(s), and an HP to discuss and decide on future EoLC and treatment if the patient's health deteriorates.</p> <p>Before the conversation, the patient and relatives are provided with the invitation to the conversation, explaining its purpose, and the PtDA.</p> <p>At the conversation, the PtDA may support a shared discussion between the participants about the available options and the decisions that it might be relevant to take in advance, and the advantages and disadvantages of each option.</p> <p>The PtDA and the principles of SDM used may support the patient in making decisions about future EoLC based on their informed preferences.</p>
5 Who provided	<p>It is provided by HPs who have attended the DESIRE training programme.</p> <p>The preliminary training lasts one working day and will be provided to all HPs who perform the intervention.</p>
6 Where	The intervention is provided at the hospital in the outpatient clinic, in a private room at the dialysis clinic, or in the patient's home if possible.
7 When and how often	<p>Patients will be invited to the conversation when they reach the age of ≥ 75, are on an HD, PD, or CKM pathway, and are not eligible for a kidney transplant.</p> <p>The conversation is booked to last 1 h, and more conversations can be scheduled if necessary.</p>
8.1 Planned variation	<p>The number of conversations may vary for each patient.</p> <p>If the patient feels the need for another conversation, this will follow up on the discussions from the previous conversation or other decisions of interest to the patient.</p> <p>The tools will only be used if they meet the needs of the patient and/or the HP.</p> <p>Because of potential differences in participant populations in different hospital settings, the HPs performing the intervention are allowed flexibility to tailor the intervention to local circumstances.</p>
8.2 Unplanned variation	If the HPs experience variations in their provision of the intervention or challenges in following the intervention, for example, due to individual circumstances within the different treatment pathways of patients with kidney failure, they can contact the research team to discuss these issues.
9.1 How well	<p>The researchers developing the DESIRE intervention will give support to the HPs if they are unsure about any aspect of providing it.</p> <p>This is to ensure that they maintain the fidelity of the intervention.</p>

TABLE 5 (Continued)

Item	Description
9.2 How well — delivery	To determine whether the intervention is being delivered well, data from the SHARED questionnaire (Bekker, 2020) and the DSAT-10 tool (Ottawa Hospital Research Institute, 2021) will be collected. To ascertain how well the training of HPs is being delivered, data from the IcanSDM-Danish version will be collected.

Abbreviations: CKM, conservative kidney management; DSAT-10, decision support analysis tool-10; EoLC, End-of-life care; IcanSDM, I can shared decision making; HD, haemodialysis; HPs, health professionals; IPDAS, International Patient Decision Aids Standards; MIND-IT, making informed decisions individually and together; ODSF, Ottawa Decision Support Framework; PtDA, Patient decision aid; OPDG, Ottawa personal decision guide; PD, peritoneal dialysis; SDM, Shared decision making; SHARED, Patient Experience of Shared Decision Making questionnaire.

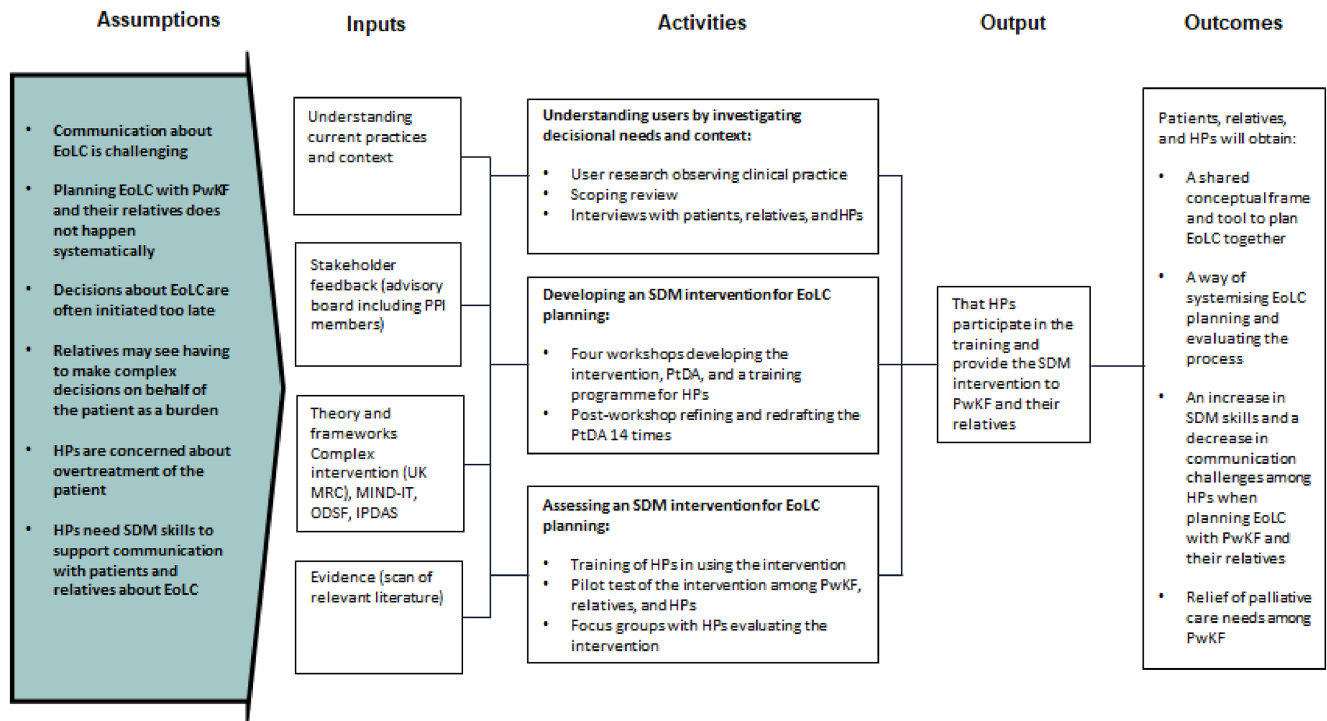


FIGURE 2 Logic model of the DESIRE intervention.

1. Training in SDM and the MIND-IT framework, and a presentation of the PtDA
2. A video recording of a patient and health professional having an SDM conversation about EoLC decision making using the PtDA, to show to the health professionals attending the training session
3. Facilitation of role-play where the participants were to take turns playing a patient with kidney failure, a health professional having SDM conversations around EoLC decision making using the PtDA, and an observer of the role-play.

All sessions were inspired by the principles of ALOBA (Kurtz et al., 2005): (1) introducing potential new theories to the participants and making time for discussion during and following the training session; (2) using a set of skills, here in an example of an SDM conversation, focusing on providing health professionals with skills in SDM conversations using the PtDA; and (3) providing the participants with the opportunity to rehearse SDM conversations using the PtDA in a supportive environment.

5.1.2 | Invitation and SDM conversations

An invitation to an SDM conversation for patients with kidney failure and their relatives was created. The original version is in Danish. An English version is provided in Appendix S2, translated by the authors to support this paper. The invitation briefly explains the purpose of the SDM conversation.

5.1.3 | The PtDA ‘choosing care and treatment when your health deteriorates with kidney failure’

The PtDA is in the form of a printed booklet, which includes a number of tools:

- An overview of examples of quality of life situations, examples of how kidney failure can affect people mentally, socially, and practically, examples of symptoms of kidney failure, and a decision diagram

- An overview of options, to help patients and relatives consider options for the various decisions
- The Ottawa Personal Decision Guide—Danish version, to help patients and relatives consider the benefits and risks of different options for the decision they may be facing
- A template for making notes about EoLC discussions and decision making during the SDM conversation.

The PtDA in English is provided in Appendix S3. The original version is in Danish. The PtDA may be provided to the patient and their relative(s) when they are invited to the SDM conversation. During the SDM conversation, the PtDA may be used to discuss the EoLC options, benefits, and risks, among other things, around EoLC planning and decision making that may be important for the patient and relative(s) to share with trained health professionals. The PtDA met 30 out of 33 IPDAS criteria. Appendix S4 presents an assessment of the PtDA according to the IPDAS criteria. A readability score was calculated for the Danish version and it was equivalent to reading magazines. Patients and relatives participating in the development of the intervention suggested not including the scientific evidence in the prototype PtDA to be tested in a clinical setting. This was instead included in a separate technical document.

5.2 | Implementation

All stakeholders discussed at what point the intervention should be integrated into kidney services. The discussions illustrated that there may not be a single identifier to initiate DESIRE consultations, as the appropriate time depends on factors known only to the service, patient and/or relatives. There was agreement that the DESIRE intervention conversation needed to be introduced near the point in the patient's illness trajectory where EoLC planning is meaningful and that this should be based on an assessment made by the health professionals responsible for the patient's care. It was agreed that decisions about when to integrate the intervention should be tailored to the needs of the individual service in which it was to be implemented. To prevent exhausting the patients, the workshop participants agreed that the conversation should last no longer than 1 h.

5.3 | Logic model

Figure 2 shows the final version of the logic model of the DESIRE intervention. The 'Assumptions' in the model present the key uncertainties identified through the programme theory for the intervention. The 'Inputs' and 'Activities' conducted to identify the key components of the intervention are described in the model. The 'Output' and 'Outcomes' describes how the intervention is expected to influence the end-users.

6 | DISCUSSION

6.1 | Strengths and limitations of the work

This study aimed to describe the development process of the DESIRE intervention. From investigating users' needs, goals, strengths, limitations, context and intuitive processes we had some idea about which components the intervention should contain (Buur et al., 2024; Buur, Bekker, Madsen, et al., 2023; Buur, Bekker, Mathiesen, et al., 2023), but the final design was not yet clear. Although the UK Medical Research Council's framework (Skivington et al., 2021) gave excellent methodological guidance and provided us with a systematic approach that supported the development phase, we chose to combine this framework with the development process of SDM interventions suggested by Witteman et al. (Witteman et al., 2021) to strengthen the methodological development process.

The intervention was developed in close collaboration with the end users—patients with kidney failure, relatives of patients with kidney failure, and health professionals with different roles in the organisation of clinical kidney services. A core element of developing complex interventions is engaging relevant stakeholders (Skivington et al., 2021). Following the UK Medical Research Council's framework, stakeholder involvement was considered essential to the development of the DESIRE intervention from the very beginning. During the workshops, collaborative learning methods supported valuable reciprocal learning among the participants, which was considered to be a strength of the development process. In planning the four workshops, the research team reflected on group combinations for the different group work sessions. Pros and cons of different group combinations were discussed. Next, it was decided that each group should represent all the different groups of stakeholders, with the aim of synthesising as much evidence as possible for the intervention prototype development process. However, a limitation in relation to the mixed groups could be that the participants might have felt uncomfortable and therefore might not have spoken freely because of representatives of other stakeholder groups being present in the same discussion group. During the development process, we were inspired by the approach of the US-based Patient-Centred Outcomes Research Institute for involvement of patients, relatives, and other relevant stakeholders in research which builds on six engagement principles: reciprocal relationships, co-learning, partnerships, transparency, honesty, and trust (Patient-Centered Outcomes Research Institute, 2014). To ensure the presence of these principles, we sought to inform the participants before the group work sessions that this was an environment based on honesty and trust where they could speak freely. Furthermore, looking at the participants' active participation in the workshops and their positive feedback, they did not appear to have felt any disquiet about participating; indeed, the contrary. During the workshops, they were actively providing knowledge from their lived experiences as patients with kidney failure, relatives of patients with kidney failure and health professionals

in kidney services. However, we acknowledge the power dynamics that might have been present between health professionals, patients and relatives as we do not know how they felt.

The involvement of relevant stakeholders including patients and relatives contributed to several important outcomes for the intervention development process. As well as providing knowledge from their life experiences of living with kidney failure or caring for those who do, they helped us focus our perspectives on important aspects of EoLC that we were not aware of beforehand. In general, the Danish term for EoLC may generate some discomfort in people when brought up as a discussion topic. The advisory board recommended that we used different phrasing when approaching patients with kidney failure to invite them to an SDM conversation about EoLC decision making. Throughout the workshops, they expressed their thoughts about each of the intervention components, and whenever a component's inclusion in the intervention was questioned, they gave thorough experience- and knowledge-based elaborations on whether a certain component was important to include in the intervention or irrelevant. Among other things, the patients and relatives highlighted the pictograms as important tools to implement in the PtDA. In terms of the invitation to SDM conversations, they recommended limiting the amount of text for patients to read. The text was shortened accordingly. A recent Danish/Dutch rapid review (Karlsson et al., 2023) found several enablers and outcomes from involving relevant stakeholders that were similar to our findings. They found that the researchers' perspective was changed based on the experiences of the patients and relative partners, who had provided the researchers with new knowledge from their specific stakeholder perspectives (Karlsson et al., 2023). The patient and relative participants had also expressed the view that participating was a positive experience (Karlsson et al., 2023). They found that the involvement of multiple stakeholders improved the quality of the projects and understanding of patients' and relatives' experiences.

A limitation of the project was that the DESIRE intervention was not culturally adapted to accommodate potential differences between societal groups. This may be relevant to identify how Danish clinical kidney services meet the needs of all members of Danish society, including minority groups and those with additional needs. This limitation will be addressed in future implementation of the intervention. However, it is likely the SDM conversation guided by the PtDA will help insure the information is tailored to the needs of the individual patient and their relative(s) in line with the health professional's training in patient centred communication skills and practice.

Our project was a multicentre study conducted in a Danish healthcare setting, which raises a question about transferability beyond Danish kidney services. It seems likely the research design and development of the DESIRE intervention is meaningful for other countries as it was based on findings from a scoping review of international research (Buur, Bekker, Madsen, et al., 2023), an interview study (Buur et al., 2024), a case study (Buur, Bekker, Mathiesen, et al., 2023) and the four workshops. Furthermore, internationally recognised theoretical and methodological frameworks were used to support the development and research process. It is a strength

of our study that the research and intervention were informed by end users in a co-design process. Having a multiple-stakeholder approach helps ensure the relevance of the intervention for other kidney failure care services beyond Denmark.

7 | CONCLUSION

By using a systematic approach guided by the UK Medical Research Council's framework and the MIND-IT SDM framework, we developed the DESIRE intervention with the aim of supporting and systematising EoLC planning and decision making for patients with kidney failure, their relatives, and health professionals in kidney services. Collaborative learning was shown to be a suitable method for engaging the different stakeholders participating in the four workshops and 14 prototype iterations, and to have a significant impact on the development of an SDM intervention about EoLC planning. Thus, all the stakeholders had significant input into the final design of the DESIRE intervention for patients with kidney failure, their relatives and health professionals because it was based on their culture, values, experiences, skills, knowledge and motivations, as well as the information on users we obtained by exploring decisional needs, identifying context and investigating theory. In addition, the intervention was designed to include different components in an effort to support and guide the stakeholders in conversations about EoLC planning and decision making. The process allowed patients, relatives, and health professionals to exchange understanding, reason about preferences, and implement agreed choice(s), which would be noted in the patients' health records in an effort to improve their EoLC. However, we do not know yet if the patients, relatives and health professionals will find the intervention acceptable to use in clinical practice and if the intervention is feasible; that study will be published at a later date.

8 | IMPLICATIONS FOR POLICY AND PRACTICE

The intention of the DESIRE intervention is to support and guide EoLC planning and decision making processes between the different stakeholders involved. The study provides important knowledge about the significance of supporting patients, relatives, and health professionals in sharing their values, goals, and needs relating to EoLC planning and decision making. Even though the DESIRE intervention was developed for patients with kidney failure, their relatives and health professionals in kidney services, we believe that the intervention could be implemented earlier in the disease trajectory of chronic kidney disease, as well as other chronic diseases.

AUTHOR CONTRIBUTIONS

Louise Engelbrecht Buur: Principal project leader, design of the study, data collection, data analysis, draft, revision and final approval of the manuscript. Jeanette Finderup, Hilary Louise Bekker, Dinah

Sherzad Khatir, and Jens Kristian Madsen: Design of the study, data collection, data analysis, critical revision, and final approval of the manuscript. PPI members Michell Kannegaard and Henning Søndergaard: Design of the study, data analysis, critical revision, and final approval of the manuscript.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

The authors confirm that any data utilised in the submitted manuscript have been lawfully acquired and the relevant fieldwork permission was obtained. Permit number: 1-16-02-243-21.

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SUPPORTING INFORMATION

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

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