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Citation for final published version:

Joseph-Williams, Natalie, Williams, Denitza, Wood, Fiona, Lloyd, Amy, Brain, Katherine, Thomas, Nerys, Prichard, Alison, Goodland, Annwen, McGarrigle, Helen, Sweetland, Helen and Edwards, Adrian 2019. A descriptive model of shared decision making derived from routine implementation in clinical practice ('Implement-SDM'): Qualitative study. *Patient Education and Counseling* 102 (10) , pp. 1774-1785. 10.1016/j.pec.2019.07.016 file

Publishers page: <http://dx.doi.org/10.1016/j.pec.2019.07.016>
<<http://dx.doi.org/10.1016/j.pec.2019.07.016>>

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A descriptive model of shared decision making derived from routine implementation in clinical practice ('Implement-SDM'): qualitative study

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Article word count: 4315

Number of Tables: 2

Abstract word count : 199

Number of Figures: 1

Keywords: Patient Centred Care, Patient Involvement, Shared Decision Making, Skills Training, Breast Cancer, Chronic Kidney Disease.

ABSTRACT

Objective

Research is needed to understand how Shared Decision-Making (SDM) is enacted in routine clinical settings. We aimed to 1) describe the process of SDM between clinicians and patients; 2) examine how well the SDM process compares to a prescriptive model of SDM, and 3) propose a descriptive model based on observed SDM in routine practice.

Methods

Patients with chronic kidney disease and early stage breast cancer were recruited consecutively via Cardiff and Vale University Health Board (UK) teams. Consultations were audio-recorded, transcribed and thematically analysed.

Results

Seventy-six consultations were observed: 26 pre-dialysis **consultations** and **two consultations each for 25** breast cancer **patients**. Key stages of the 'Three Talk Model' were observed. However, **we also observed** more elements and greater complexity: a distinct preparation phase; tailored and evolving integrative option conversation; patients and clinicians developing 'informed preferences'; distributed and multi-stage decisions; and a more open-ended planning discussion. Use of decision aids was limited.

Conclusion

A more complex picture was observed compared with previous portrayals in current theoretical models.

Practice Implications

The model can provide a basis for future training and initiatives to promote SDM, and tackle the gap between what is advocated in policy, but rarely achieved in practice.

Highlights

- We aimed to understand how SDM is *actually* enacted in routine clinical settings
- SDM is more complex than portrayed in previous **models**.
- Our descriptive model ('Implement-SDM') reflects SDM **by skilled clinicians, adapted for use** in routine settings.

1. INTRODUCTION

Shared Decision Making (SDM) **has been the subject of much research for over 30 years internationally, yielding** lessons from implementation programmes, and numerous proposed models of what SDM comprises and ‘should’ look like.[1] **However, routine enactment of SDM clinical settings is uncommon, [2-5] and more work is needed to understand how SDM is achieved,** especially by trained, committed clinicians.

Interventions to support SDM are usually based on a framework of steps that clinicians are required to undertake with their patients. Several models have been published,^[1-3] and the core features usually include highlighting choice availability, describing options, and eliciting patients’ preferences about the most suitable option for them. In practice, clinicians may then take this forward during ‘goal setting’ and ‘action planning’ stages.^[4,5] Most published models of SDM derive from theoretical analysis, often also backed up by qualitative work with patients or consensus processes among expert stakeholders.[6-9] These *prescriptive* models are representations of what ‘ought’ to happen. Perhaps the most widely known and referenced model at present is the original ‘Three Talk model’ of SDM (>900 citations, Web of Science), published in 2012.[6] This model sets out a pragmatic three-step guide on how SDM should ideally look. It rests on the process of ‘deliberation’, and involves three key steps: 1) introduction of choice; 2) describing options; 3) helping patients to explore preferences, and integrating these into a decision.

The ‘Three Talk model’[6] was the basis of the UK Making Good Decisions in Collaboration (MAGIC) SDM implementation programme, commissioned by The Health Foundation in 2010.[10,11] The focus of the programme was training for clinical teams using the ‘Three Talk

model'.[6] Other elements of the programme included working with patients to minimise barriers to involvement, developing brief decision aids, and enhancing organisational leadership and culture change to support SDM.[10] The programme's legacy was clinical teams who had received SDM skills training, who had positive attitudes towards SDM, and some who continued to routinely use SDM beyond the implementation phase (2010-2012). SDM became 'normalised'[12] particularly in those teams that had a shared understanding of the purpose of involving patients in decisions and what this 'work' involved to achieve SDM.[11] Clinicians are likely to have progressed to at least 'conscious competence', and potentially to 'unconscious competence', performing it easily and teaching others as they joined the team.[12]

This provided an ideal setting to examine what SDM *actually* looked like in routine care. We hypothesised that this pragmatic, skilled enactment of SDM may be useful for understanding how SDM may be more realistically achievable and successful than has been the case to date. As such, we sought to derive a *descriptive* model of SDM, based on observed behaviours of the clinicians and patients. **Other observational studies have assessed the extent of SDM,[2-4] or described specific aspects such as patient expectations,[5] but these findings have not been integrated as a model of practice.**

Specific objectives were to: 1) describe the process of SDM between trained, committed clinicians and their patients; 2) examine how the SDM process in routine practice compares with the prescriptive model of SDM,^[1] and 3) propose a descriptive model based on observed SDM in routine practice, which could provide an empirical basis upon which to promote SDM training and implementation.

2. METHODS

2.1 Study setting and patient recruitment

The Cardiff and Vale University Health Board (Wales, UK) Breast Centre and Pre-Dialysis Service participated; they had taken part in the earlier SDM implementation study,^[6] had received SDM skills training, used SDM interventions (e.g. patient decision aids), and were continuing to implement SDM routinely without further support. Eligible patients were recruited consecutively from the two **settings by members of the clinical teams (usually nurses; April 2014 - September 2015)**.

Patients with chronic kidney disease (CKD) stages 4-5, discussing treatment options that included dialysis and transplantation, and women diagnosed with early stage invasive breast cancer, whose treatment options included mastectomy or wide-local excision ('lumpectomy') with radiotherapy, were eligible. Patients were 18 years and older, and were excluded if they were unable to communicate in English, or the clinical team felt the study was unsuitable for them. The two clinical contexts therefore differ in terms of urgency of decision (new diagnosis requiring a **prompt** decision for breast cancer; long term for CKD, often with prior discussion / information gathered) and reversibility (irreversible surgery for breast cancer, **mainly** medical options for CKD).

Ethical approval was granted by the Wales Research Ethics Committee 1 (Ref 14/WA/0036). Clinicians received study information and provided written consent for their consultations to be audio-recorded. Patients were given information about the study between three days to one week before their consultations. Written informed consent was obtained by the research nurse (breast) or specialist nurse (renal) before the consultations.

2.2 Data collection

All consultations were audio-recorded and transcribed verbatim. Pre-dialysis home consultations with the specialist nurse were recorded for patients with CKD. Two consultations were recorded for each breast cancer patient: their initial *diagnostic* consultation, and the *follow-up visit* one-week later. Family members or friends were often present during consultations.

2.3 Analysis

All breast cancer and pre-dialysis consultations were thematically analysed [13] supported by NVivo 10 qualitative data analysis software.[14] Although we had a reference model (Three Talk), we chose thematic analysis rather than framework analysis as the latter focuses more on the ‘content of accounts’ rather than an analysis of ‘what is going on’, and it does not support theoretical development to the same extent.[15] As we were dealing with naturally occurring data (consultation data) rather than researcher generated data such as interview data, we therefore felt our data would be better suited to a thematic approach which allows for more scope in both inductive and deductive analysis.

An initial set of codes was developed, and reviewed collectively after independent analysis by two authors. The coding framework was revised and the remainder of the consultations was coded. Breast cancer and pre-dialysis consultations were analysed separately, but due to similarities in emerging themes the results were integrated, and differences noted. Themes that emerged from the data were mapped to the ‘Three Talk model’.[6] **We assessed data saturation by comparing whether any new codes emerged in the last three patients from each setting.**

3. RESULTS

3.1 Sample

Seventy-six consultations were observed; 26 pre-dialysis patients (16 males, 10 females), seen by three different clinicians (all clinical nurse specialists), and 25 female breast cancer patients (a total of 50 breast consultations, diagnostic and follow-up for each patient), seen by eight different clinicians (2 consultant surgeons, 1 consultant nurse, 1 registrar, 1 clinical nurse specialist, 3 breast care nurses). Renal consultations ranged from 50 minutes to 2 hours 25 minutes (mean 1 hour 35 minutes). Breast cancer diagnostic consultations ranged from 19 minutes to 1 hour 4 minutes (mean 33 minutes) and follow-up visits ranged from 14 minutes to 1 hour 38 minutes (mean 51 minutes).

3.2 Features of the observed SDM process

We observed six key features of the SDM process, and these are outlined below. **Example quotations from the data are presented in Table 1 for these six features.**

3.2.1 Preparation phase

All consultations were characterised by a distinct 'preparation phase', before the concept of choice was introduced, but the content differed across the two settings (e.g. support and reassurance after diagnosis for breast cancer patients; to obtain detailed medical history, social /personal understanding for CKD patients). It appeared to have an important influence on the succeeding phases of the SDM process, either as a gateway to the conversation around choice (e.g. diagnosis of new condition), to establish a patient's

suitability for choice (e.g. if they were eligible for kidney transplant), or to guide the possible options for consideration.

3.2.2 Introducing choice

Availability of choice and the rationale for options (i.e. equal survival rates for options, and importance of patient preferences) were confirmed in all breast cancer consultations, typically occurring immediately after diagnosis. Choice **introduction** was less prominent during pre-dialysis consultations. However, unlike breast cancer patients, CKD patients were not generally receiving a diagnosis at their consultation; they have a long-term progressive condition, and it is likely that they would have **had** this conversation before the options were presented during the pre-dialysis encounter.

3.2.3 Tailored, evolving and integrative option conversation

Option presentation was observed during all consultations. Checking patients' understanding of options was a key feature in both settings, staggered throughout option presentation.

Significantly, we observed an evolving and increasingly tailored 'option conversation' as the consultations progressed. Even when there is agreement that equipoise exists (such as breast cancer with equal survival figures for the two options) and the evidence base supports the presentation of certain options, it was not always a clear-cut choice between options. Option presentation typically evolved and was refined throughout the consultation as patients expressed their personal preferences, or as the clinician became aware of other factors (e.g. co-morbidities that contraindicated certain options).

Preference elicitation was initiated during choice **introduction**, and continued during option presentation. Typically, the presentation of pros and cons of each option began in general terms. Clinicians would then ask the patient how they felt about the outcomes; sometimes patients disclosed how they felt without explicit encouragement from the clinician. As the patient's preferences emerged, option presentation (including pros and cons) became more tailored. We observed a continuous, iterative process whereby clinicians would consider the stated preferences as they discussed further options; in some situations, options would become eliminated (e.g. if the patient had strong cultural beliefs about organ transplantation).

Overall, clinicians were very responsive to the patient's expressed preferences, and when possible, these were incorporated into the proposed treatment plan. Breast cancer nurses sometimes overtly questioned patients' preferences as a way to check the premise on which preferences had been formed, especially those stated before the options had been presented. Such checks appeared to be used supportively to ensure preferences were 'informed', rather than to influence the decision.

3.2.4 Distributed and multi-stage decisions

Patients were rarely faced with one discrete decision during their consultations. Future decisions would sometimes need to be considered during these early stages, as these future options might influence the initial treatment decision. CKD patients could, for example, consider the option of kidney transplantation, which also includes different options (e.g. live / cadaveric donor). A complex picture emerged regarding the decision-making process, with multiple and interacting decisions. These might sometimes be made in isolation (e.g. whether to have kidney transplant) or, more usually, have a bearing on

another decision (e.g. reconstructive surgery options might have influenced the decision to have a mastectomy or lumpectomy). The SDM process was frequently 'distributed' amongst family members, or significant others who were involved in the preference discussion. When thinking about 'personal preferences', patients commonly considered the preferences of their significant others. Quite often it was less a case of 'what is important to *me*', and more a case of 'what's important to *us*?', especially for the pre-dialysis patients.

3.2.5 Decision support

Brief decision aids were presented to patients during most consultations, but were rarely used as an integral part of the discussion. They were usually given after treatment options had been presented, as a 'take-home tool' that provided further information.

Use of the decision support tools was minimal in all consultations, and the *decision support* provided to patients was much more implicit, relying on the skills and empathy of the clinician. Patients received *practical* and *emotional* support especially when they were upset. Although offered in both settings, social or practical support were key features of the pre-dialysis discussion. Nurses used this 'decision' discussion to signpost patients, for example, to where they could get advice on benefit payments or financial support. These broader support tasks took up a considerable proportion of the consultations.

3.2.6 Planning discussion

Following a process of preference elicitation, which typically occurred throughout option presentation, clinicians generally attempted to elicit the option that the patient was leaning towards. Whilst there were similarities between the decision discussion for breast

and CKD patients, there were key differences (see Section 2.1). The process of discussing the decision itself was clearer, more distinct, and generally more likely to be concluded (final decision made, sometimes deferred for a short time) during the breast cancer consultations than the pre-dialysis consultations; CKD patients were more likely to be offered 'review' and 'planning' for next steps.

We observed that clinicians were also developing 'informed preferences' during the SDM process about what might be suitable for the patient. Sometimes, this was summarised during the decision-making phase, in the form of a recommended treatment plan. However, this did not seem a paternalistic act of deciding for the patient; they were making recommendations using information the patient had given them about their preferences **and checking patient understanding and agreement.**

3.3 Factors influencing the SDM process

We also identified several contributory factors that facilitated or impacted on the decision-making process. These factors are presented in Table 2. In short, these factors include: awareness (prior knowledge / experience of the condition); things that matter to patients (e.g. lifestyle considerations, hobbies, social circumstances); emotion (e.g. level of distress during consultation); and perceived urgency to make a decision (immediate or future decision). These factors **influenced** the option chosen by the patient, the depth of discussion about the options, and the patient's level of engagement with the process.

3.4 How well theoretical models capture SDM in routine practice

The observed process of SDM was mapped to the prescriptive 'Three Talk model' of SDM.[6]

Below we discuss how well elements of the model reflect observed SDM; Figure 1 presents a descriptive model that is derived from **our** routine practice observations – named 'Implement-SDM'. **Table 2 summarises the main elements and those which are comparable between both models, or new in Implement-SDM.**

'Choice Talk' (i.e. describing that options exist and providing a rationale for choice) was observed early on in all breast cancer consultations, but was much less prominent in the CKD consultations, reflecting that the CKD patients have a long-term progressive condition and they would have had many consultations before the observed consultation. A descriptive model needs to reflect that the timing and depth of the 'choice talk' phase depends on the type of condition (e.g. acute versus long-term), that the task of supporting the patient to make a decision might be completed by a different member of the healthcare team to the one presenting the options, and that it might be repeated throughout the patient's journey.

The 'option talk' phase in the 'Three Talk model' was also evident, with detailed option description and checking of patients' understanding throughout. However, the descriptive model needs to reflect an **evolving** and tailored process, in which the clinician uses emerging knowledge about the patient's clinical history and preferences to continually tailor the discussion to that individual patient. The earlier preferences were declared, the more influence they had on the 'option talk' discussion. We observed this 'suffused preference process' whereby preferences were stated or elicited throughout choice **introduction** and option presentation, rather than after the presentation **of** options **and** during the 'decision talk', as **incorporated** in the 'Three Talk model'. [6]

The depth and length of 'option talk' was also tailored for different patients, depending on various patient factors such as shock (some breast cancer patients) or prior experience of the condition (e.g. some CKD patients with family members with the condition). We observed a staged approach with, for example, less detail presented in the breast cancer diagnostic consultation, and more detail covered in the follow-up appointment. The descriptive model needs to reflect that the 'option talk' in these consultations was responsive and tailored to the needs of individual patients (e.g. emotional state, stated preferences, prior experience) and to contextual factors, such as likelihood of future appointments.

We observed that the 'decision talk' phase, outlined in the 'Three Talk model', was evident during most breast cancer consultations, but featured less during the CKD consultations. It appeared that 'decision talk' was less relevant for patients with long-term progressive conditions. The descriptive model needs to reflect that a decision may not need to be made during the discussion; this phase appears better referred to as 'planning discussion'. This indicates a much more fluid process, where at times the emphasis is on consolidating preferences and making decisions, and other times on summarising preferences and encouraging an ongoing reflective and iterative process until the point at which a decision needs to be made.

During this 'planning discussion', we observed clinicians guiding patients through preference elicitation, which is described as a core skill in the 'Three Talk model'. However, the descriptive model also needs to reflect the task of 'preference checking' by clinicians. To avoid being viewed as paternalistic and a 'challenge' to the patient's views, the descriptive model needs to reflect that this task supported the SDM process by ensuring that patients' preferences were not 'misinformed'. The descriptive model also needs to

reflect that clinicians were also developing ‘informed preferences’ about what might be suitable for their patient, based on what the patient had told them, which they sometimes summarised into a recommended treatment plan.

Data from observed consultations also revealed other SDM tasks that are not fully captured by the ‘Three Talk Model’. We observed a distinct and important phase that precedes ‘choice talk’ – i.e. a ‘preparation phase’. Although presumed in current models, our descriptive model gives this greater emphasis to stress its influence on subsequent phases. Our descriptive model also reflects the distributed decision process that characterises most SDM discussions – across time, multiple persons, and multi-stage decisions.

Decision support described in the ‘Three Talk model’ focuses on decision support tools (e.g. brief decision aid or a website). However, we observed a much broader conception of support (e.g. emotional and practical), and which are sometimes essential to progressing the SDM discussion, and possibly more important than the use of a decision support tool.

Notably, decision aid use was minimal, and when used this tended to be at the end of a consultation as ‘take-home’ material rather than a basis for discussion.

4. DISCUSSION AND CONCLUSION

4.1 Discussion

When SDM is enacted by skilled clinicians in settings where it has been adopted and ‘normalised’, a different picture is observed compared with what is portrayed in current theoretical models. The process appears more complex – preparation and broader support

tasks are essential, multiple and staged decisions are evident with various players contributing, and it is individually tailored and evolving. Depending on the context it may be less about 'making decisions' and more about 'support and planning next steps' in someone's health care. Decision support tools featured little in the SDM process during consultations. A descriptive model ('Implement-SDM' – see **Figure 1**) representing this complexity **appears** closer to the reality of routine SDM than current theoretical models. **As such, it** may provide a basis for future training and implementation initiatives to promote SDM, and tackle the gap between what is advocated in policy, but rarely achieved in practice.

It is possible that clinicians (and possibly patients) might have made efforts to perform SDM better or differently during recorded consultations, yet the differences between the taught model and what we observed suggests this might not be the case. However, we only observed two clinical contexts, and the descriptive model requires further testing and refinement in other patient groups (e.g. children, those with limited capacity or poor health literacy, or less serious or urgent health conditions).

The 'Three Talk model' [6] was used as the reference point for this study as it was the model the clinical teams had been trained with, and has done much to advance SDM skill training for clinicians and students. Key elements of the model were observed; 'choice talk', 'option talk', and preference elicitation were evident in nearly all consultations. Since completing our study, an updated version of the 'Three talk model' has been published, based on a consensus exercise with stakeholders.[7] The revised model is less linear, and accounts for some of the more dynamic processes of SDM, that we also observed.

However, more elements and greater complexity were noted in our observations and are represented in the descriptive model. The 'preparation phase' was highly prominent in

these consultations, and the degree of tailoring to individual needs, circumstances, and preferences was striking. This tailoring likely explains why decision support tools were rarely used during the SDM discussion, despite them being available and being given to patients as 'take-home' information. **They could potentially also be useful if given to patients before consultations, complementing the 'preparation phase'**. The support tasks observed in these consultations were much broader, focusing on emotional and practical support, rather than the 'risk communication' envisaged in current models.[16] This is consistent with other SDM training packages that recognise 'relational' competencies as core domains.[17]

Cribb and Entwistle previously identified 'narrower' and 'broader' conceptions of SDM,[18] with the narrow conception focusing on the task of decision-making and understanding a division of labour, with clinicians bringing the 'evidence' and patients bringing 'preferences'. In the narrow conception, discussion is shaped by 'meta-preferences' (e.g. how much do you want to be involved?), patient preferences are dominant and clinician 'challenge' is limited, and both leave the encounter fundamentally 'intact' in this process. Our descriptive model is more concordant with the 'broader' conception of SDM.[18] Broader conceptions focus on relationships as the context for decision-making, and there is more open-ended dialogue. The broader SDM discussion is responsive to the patient's inclination, but the clinician demonstrates respect by also challenging the patient, and in this way, they 'co-construct' their preferences. Both patient and clinician leave the consultation having been 'influenced' by the other.

The theoretical and descriptive models likely serve different purposes. The former is useful for raising awareness of the concept, building coherence around the 'principle', and

teaching core skills. The separation of the SDM consultation into three key 'talks' makes it easier for learners to understand the key skills that should be displayed during an SDM discussion with a patient, without becoming overwhelmed by the range of influences on that discussion. However, the differences between 'narrower' and 'broader' conceptions of SDM can partly be seen as reflecting tensions between principle and practice. Practice does not yet show evidence of SDM becoming a routine experience and expectation for patients.[2-4] There have been substantial problems of operationalising broader conceptions of SDM. Other conceptual thinking helps to bridge this gap from principle to practice. Rapley's 'distributed decision making' is insightful and valuable in this respect.[19] Montori [20] describes the patient's 'invisible' work behind the scenes when managing an illness, especially those with a long-term condition. In this context, SDM interventions should be 'maximally supportive and minimally disruptive', and should not transfer more 'work' to patients in the pursuit of greater patient involvement.

In the context of the challenges of trying to embed SDM as a new normal, we believe this descriptive model of SDM reflects the reality when skilled, motivated clinicians are attempting to do it routinely. It is a 'shared decision', combining two types of expertise (clinical and personal), but the emphasis is broader. It reflects developing relationships, preparation, clinicians and patients informing and influencing each other (and others), each genuinely more involved and contributing, and supporting and planning next steps using a broader range of support tasks. It reinforces the message that attitudes and skills are more important than decision support tools.[10] The tailored and evolving nature of SDM consultations is also consistent with Hawe and colleagues' discussion of **understanding** complex interventions by their 'function' or their 'form':[21] our model **presents** the

functions that need to occur in SDM (e.g. preparation, choice introduction, support tasks etc.), but the 'form' that is used to facilitate the function can be tailored to the specific consultation (e.g. depending on the patient's prior knowledge and experience).

Subject to further empirical testing and refinement, we offer this model as a basis for teaching and training SDM skills. **We believe it could support implementation strategies, partly by assisting clinical team members to reflect on SDM in more detail, to mitigate the "we do this already" barrier,[10] and to enable greater team 'coherence' of understanding what skilled and pragmatic SDM is and should like. The limited use of decision aids is potentially important for further implementation strategies, indicating greater likely acceptability and value from focusing on relational aspects, supportive aims, and the dynamic interaction of choices, options, evolving preferences and involving others.**

The Implement-SDM model could also be a basis for measurement of SDM in routine care.

There is an international drive to show that SDM is becoming embedded in healthcare settings,[22-26] and measurement is often a key part of that. We need to be careful that measurement instruments appreciate the complexity of SDM, and the differences in the process between different types of health condition. If we base measurement on theoretical rather than descriptive models, this might not result in a fair assessment of what can realistically be achieved in practice.

4.2 Conclusion

We have proposed a descriptive model of SDM based on empirical data ('Implement-SDM').

SDM models need to better emphasise that the process is distributed across time, people, and

healthcare settings, and also the multi-staged, yet sometimes parallel, and complex content and nature of many decisions. SDM implementers and educators should also acknowledge that the SDM process will look different for different clinical conditions, and that each phase of the SDM process will have lesser or greater emphasis depending on clinical and patient context. It may be less about 'decisions' and more about 'support and planning' the next steps in someone's health care. Ultimately, interventions must also address the broader range of patient, clinician, and organisational factors influencing SDM described elsewhere.[10]

4.3 Practice Implications

Existing models provide a useful starting point for teaching the core skills of SDM, but our model could further guide the development of implementation-focused training programmes, measurement, and other resources to support SDM, so that they are more reflective of what **skilled SDM looks like and the potential positive effects of SDM are maximized.**

ACKNOWLEDGEMENTS

1. Contributors

We are grateful for the input provided by the Collaborative Healthcare Group at Cardiff University. We would also like to acknowledge Cardiff and Vale University Health Board, particularly the Pre-Dialysis service and the Breast Care Centre, as this work would not have been possible without their continued support.

2. Funders

The study was funded by The Health Foundation (reference number 7212). Cardiff University acted as sponsor for the study.

CONFLICT OF INTEREST

The authors declare that they have no conflicts of interest.

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TABLES

Table 1. Summary of key themes and example quotes emerging from the thematic analysis of consultations

Theme 1: How is shared decision making occurring in real-life clinical practice?			
Descriptive themes	Brief description	Selected example quotes	
		Breast cancer consultations	Pre-dialysis consultations
Preparation Phase	Brief preparation before choice was introduced to patients. The tasks can differ (e.g. MDT meeting, diagnosis, checking emotional state after giving diagnosis, detailed medical history / checking symptoms, understanding social/personal circumstances). Influences succeeding phases of SDM.	<p>“It’s very treatable, that’s the good news, and that will involve surgery, and because it’s reasonably small...there are two ways that we can treat it surgically.” (Consultant, ID 2.14)</p> <p>“Okay, so the important thing to take from here is this is very small, but you know if anyone can be optimistic about this it's you because this is very slow, very early.” (Consultant, ID 2.15)</p> <p>“Consultant: Okay, so this is a shock for us, it has been a shock for us as well, because it wasn't what we were expecting. Patient: No, no...I think I just need to simulate The information really and yeah, I'm just shocked. Consultant: You just need, to take it in first Patient: Yeah, I'm just really surprised, I think everybody thought it was going to be...[clear]... yeah.” (Consultation ID 2.18)</p>	<p>“Clinical Nurse Specialist (CNS): Good. OK. Um, any other surgery, abdominal surgery, anything? Patient: Well, years ago, many years ago, I had a hernia operation. Wife: That’s right. Patient: Many years ago.” (Consultation ID 1.7)</p> <p>“CNS: So when I phone people, they'll say, what is it [kidney function level], and I'll say 'oh, you're 17 percent'. And they may think, 'oh, gosh, I was 22 the last time', but if you look at the creatinine level, 250 to 322, it hasn't deteriorated that much, but as a percentage, people think, oh gosh, that's a lot. Do you understand where I'm coming from? Patient: Yes, yes. CNS: So keep an eye on that, and what we do is look at the symptoms as well. So we don't start anybody on dialysis unless they're having the symptoms. So great, you haven't got any of the symptoms, which I'll go through.” (Consultation ID 1.1)</p>

<p>Introducing choice</p>	<p>Confirming the availability of choice, and providing a rationale for choice</p>	<p>“Consultant: Yes of course, I mean you take your time to think about that. What I don’t want you to do is go away with the idea that one’s better than the other. Patient: No. CNS: They’re different...they’re both very effective Consultant: That’s right; we must say to you there’s no difference in the terms of the outcome it’s how you feel about it.” (Consultation ID 2.14)</p> <p>“...both the surgical options I’ve just given you are the same in terms of survival. And what makes people decide one or the other is personal preference.” (Consultant, ID 2.15)</p> <p>“Consultant: That’s why it’s your choice you see because it’s how you feel about it, it’s not how we feel about it. Patient: It’s my chest. Consultant: That’s right; we must say to you there’s no difference in the terms of the outcome it’s how you feel about it.” (Consultation ID 2.8)</p> <p>“Because why we talk about it, different things that can be done, because it is, what you will see on the grid [decision aid] that we show you, there is really no difference between having the mastectomy or having a lumpectomy with the radiotherapy. (Consultant, ID 2.10)</p>	<p>“What we’ll do today, we’ll talk a bit about what the kidneys do, some of the symptoms you may have already, or may not have but you may develop them, and we’ll talk about the different types of treatment...” (Clinical nurse specialist, ID 1.3)</p>
<p>Tailored, evolving and integrative</p>	<p>Initial option presentation</p>	<p>“...there are two ways we can treat it surgically. One is to take the lump out with an area of normal breast around it like a safety margin and then give you radiotherapy afterwards...and the other one is to do a mastectomy...we</p>	<p>“I’ve got a picture booklet, but what I’ll do I’ll talk through it with you and just let me know if it does make some sense, okay. So there are two types of treatment. There’s one where you go</p>

<p>option presentation</p>		<p>take all of the breast tissue and you don't necessarily need the radiotherapy then." (Consultant, ID 2.14)</p>	<p>into the hospital and you have your blood cleaned through a machine, three times a week. And you're attached to the machine then for about four hours, okay. So you have your treatment and then you come home. And we'll go through that treatment in detail, now that's called haemodialysis that means cleaning of your blood. There is another treatment then that you can do here in the home, obviously with [person's name] help. Where you have a tube in your tummy and you run bags of fluid into your tummy yourself. And drain them back out again. (CNS, ID 1.11)</p>
	<p>Preference elicitation</p>	<p>"... and to know what's important for you. I know you will probably talk to lots of people, perhaps friends, relatives, whoever, about things perhaps over the next week. But the most important thing is [person's name] is that when you make...my job is not to influence you in any way, my job is to give you all the information that you need to make your decision and know that the decision that you've made is right for you. (CNS, ID P2.16)</p> <p>"CNS: Look at it this way. You can't be wrong no matter what you choose. Patient: ...you want somebody to tell you that, don't you...? CNS: Yes... Patient: ...that you're not going to make the wrong...[decision] CNS: ...you will not be wrong in choosing a decision." (Consultation ID 2.17)</p> <p>"I think, you know, I'd ask the question for you, what is important about going for the reconstruction for you? (CNS, ID 2.3)</p>	<p>"Relative: So it's, I'm quite capable of being, you know, either putting the needle in CNS: Yeah. Exactly. And what would you rather? [directed to patient] Patient: on me...I'd do it at home. Well in actual fact I'm going to train ((Husband)), because he would have made a good doctor." (Consultation ID 1.8)</p> <p>"CNS: Had you given that any thought at all or? Patient: No, I haven't. CNS: So [person's name] would you, do you want to be assessed to have a kidney transplant or do you feel it's a little bit too early yet? Patient: I feel it's a little bit too early ... CNS: Yes, that's fine." (Consultation ID 1.28)</p>
	<p>Tailoring options</p>	<p>"Consultant: And we need to sort it out. And that's the most important thing...what's the most important thing to</p>	<p>"CNS: If I was meeting you now and you had lots of health problems and you were much older, it might be that the</p>

		<p>you at the moment about this? You know, is it the not having surgery, keeping your breast, not keeping your breast, what, what do you think's the most important? Patient: I don't know. I really don't know. Consultant: I think originally you sort of said that, that the important thing perhaps was not having surgery. And that that was your fear? Patient: Yes, yes" (Consultation ID 2.23)</p> <p>"And, the other problems that you've got, other health problems and that sort of thing, I think tablets is a very, very good option. With these tablets we get very good results... tt's just a much slower way of working..." (Consultant, ID 2.18)</p> <p>"Consultant: I'll go and get you a date. I've just added a spanner to the works...erm so your mother is quite sizeable [large breasts] and you know we've always got to think these days about how we can get the cosmetic results better when we do the breast surgery, so if she chose to have a wide local incision, I can actually do it erm doing breast reduction pattern ... Daughter: Oh right. Consultant: so she'd have a very natural breast reduction but at the same time I'd be removing the breast cancer, so she seems quite interested in that as well...because otherwise, you know when I remove this lump she would be slightly lopsided, but if I did a reduction on both sides then she might have a better result." (Consultation ID 2.22)</p>	<p>burden of having dialysis would be too much...you wouldn't want to go down that route. So we do have quite a few people who choose not to have any treatment, for some people who are much older, you know, in their 80s or 90s, dialysis might not add anything to how long they're going to live, but it might mean that the last few years of their life would end up just being in and out of hospital with problems with dialysis...and actually their quality of life would be better without it. Patient: Okay. CNS: And sometimes that's just a common sense Decision that people make. But that's not something we're talking about now because you've got every reason to benefit from having dialysis or having a transplant. But the information's there for you to read if you want, just, just to balance it, really." (Consultation ID 1.30)</p>
	<p>Checking understanding</p>	<p>"So now when we know when we know what the results are, do you want to ask any questions before I go to explain possible treatments and options?" (Consultant, ID 2.10)</p> <p>"Consultant: Great. Any questions, I mean it may be off the family actually because sometimes you can't think when you've had all that information ...</p>	<p>"CNS: So have you got any questions with this? Because it's a lot to take in. Patient: No, I don't think so. No. CNS: Have you got questions? [directed to family member] Patient: I can't think of any off hand. Probably will</p>

		<p>Patient: No. Consultant: ...is there any questions that you would have? [directed to the family] Family member: Erm, no I can't think of anything err" (Consultation ID P2.15)</p>	<p>after you've gone. CNS: If you do, write them down and give me a ring because I'll leave my number. I'm more than willing to give you the answers over the phone. Okay because it does happen, because this is quite overwhelming." (Consultation ID 1.20)</p>
<p>Distributed and multi-staged decisions</p>	<p>Decisions making process characterised by multiple and multi-stage decisions, which are distributed among the patient, clinicians and sometimes significant others</p>	<p>"And in your case, because we can do the two things for the breast we can save the rest of the breast tissue, removing just the lump as I was explaining ...but with that the radiotherapies go hand in hand, or if you decide we can remove the breast completely. Then radiotherapy is not necessary, not always. One more thing to mention, that with removing the lump only there are the chances, quite small, that sometimes we need to do another surgery. And that is because what we want to be sure that when you remove the lump that we have enough clear tissue around it, that's why the procedure is called the wide local excision. And if our pathologists for example tell us that we don't have enough margin around it, sometimes we need to go back which means the second surgery for the breast, to take a bit more of a tissue, or again you may decide if you want to have a bit more of a tissue removed or you want to go to the mastectomy." (Consultant, ID 2.10)</p> <p>"Patient: Well if you say mastectomy, if you take it, can't you take the other one off as well while you're at it?...I don't want to be lob sided. [Laughs] Consultant: Okay, I'll talk about that in a second, okay?... Let me just complete, the thing about a mastectomy is that if I do, if you choose a mastectomy on one side, we have seen the other side, other side is normal so you don't need it</p>	<p>"CNS: And it's whatever really you know, whatever suits you because I often say this to people. If you're doing a home treatment, if [person's name] wasn't able to do it because she wasn't feeling well, the responsibility would then fall onto you. And what you have to ask, as a couple, is it fair that [partner's name] would be doing your treatment ... Patient: Mm. CNS:... for you everyday? There is that. Partner: Mm." (Consultation ID 1.11)</p> <p>"The only thing I'll urge you, also think about transplantation and have a read of the information. Don't have to do it obviously in the next week or two but before you come back in a month's time, have a think about transplant because I will be asking you. Ordinarily I refer patients straight away for transplant but I think you just need to have a little bit of time, because it is a new concept to you isn't it?" (CNS, ID 1.17)</p>

		<p>taken out for cancer purposes, but if you want it taken out for the purposes of being equal on two sides, I'd rather do it as a separate procedure ...</p> <p>Patient: Yes, okay, I can think about it.</p> <p>Consultant: ... rather than at the same time.” (Consultation ID 2.4)</p>	
Decision support tasks	<p>Broader decision, practical, and emotional support offered by the clinicians during the decision making process</p>	<p>“CNS: Ah, there's only one, one more little thing to go over here as well, just the information really. There's an option sheet [Option Grid, brief decision aid] on the front here, erm, several questions down the side here that you might ask, and the answers for if you have a mastectomy or if you have a wide excision.</p> <p>Patient: Okay</p> <p>CNS: Okay, SO that'll give you quite a few answers there, that we find most people find...</p> <p>Patient: Yes, that's helpful</p> <p>CNS: ...really helpful.” (Consultation ID 2.16)</p>	<p>“What I wanted to say as well [person's name], if you wanted to speak to anyone, if you're feeling a bit low we do have a nurse counsellor and a clinical psychologist, just let me know if you do want to speak to somebody. And we're very lucky in Wales, we've got volunteers called befrienders and I am just thinking now we've got a man who lives up in [region name] and he does the bags, and he said to me time and time again, if you want to bring anybody up to see my setup, so I'd be very happy you know to organise for you to go up there” (CNS, ID 1.17)</p> <p>“...that's a little bit more about transplantation you can keep. We do a monthly information morning, which may be a little bit too early at the moment, but we do do a support group...” (CNS, ID 1.1)</p> <p>“One thing I do want to give you and I apologise it's a little bit creased, this here is an Option Grid [brief decision aid], don't be put off by it[person's name]but what I say to my patients...so we've done a list of questions here what does it involve, how often will I need it, can I travel, erm, who will do my treatment? And just take a highlighter pen and highlight what's important to you and I like to think in your case you will be highlighting this column because that's the one that you want, transplantation.” (CNS, ID 1.17)</p>
Planning Discussion	<p>A process of consolidating or summarising preferences and moving towards a</p>	<p>“Okay. So on what I've told you so far, is there a sort of a gut feeling of where you think you will go with your decision or do you need more info from me, because [CNS] will be giving you lots of written stuff and</p>	<p>“What I do with some of my patients, in fact most of them [person's name], I come back and see them as they're approaching dialysis or needing a transplant [to discuss treatment options / decision].” (CNS, ID P1.9)</p> <p>“Okay, so just to let you know we'll see you back in</p>

	<p>decision or an ongoing reflective and iterative process until the point a decision needs to be made</p>	<p>introducing you to some online tools that can help you as well to make your decision. But most people I would say, once they have seen [CNS] they have seen me and they have asked all the questions here. Most people are able to make that decision.” (Consultant, ID 2.15)</p> <p>“Consultant: No, no. It really is personal preference really. Patient: It’s hard when you’ve got to make up your mind. Usually I’m the person makes up their mind. Friend: Usually you decide ... Patient: Usually I decide what I want to do and that’s it. Consultant: Yeah so what’s erm stopping you from making up your mind, what questions have you got that ...? Patient: I don’t have any questions really. I just can’t, just can’t say well yes... Consultant: I’ll do this... Patient: Mhm or I’ll do that, I’ve always been the person that’ll go and say well I’m going to do this I’m going to do that...but I just, for some reason or other, I mean I’ve had loads done to me so...” (Consultation ID 2.14)</p>	<p>clinic in a month's time. If there's anything untoward with your bloods I'll be on the phone. Every time you come to clinic I check your bloods the next day so now you are in my caseload, the guys here will be checking everything. Please ring me if you've got any questions, don't sit at home and think mmm, but I am quite happy at the moment to just keep an eye on you. We don't need to do anything [now]”. (CNS, ID 1.17)</p>
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Theme 2: What factors influence the SDM process?

Themes	Description	Selected example quotes
Awareness	<p>Patients’ previous knowledge about the condition or available treatment options also influenced the decision process, and sometimes the treatment choice.</p> <ul style="list-style-type: none"> Most breast cancer patients had some awareness of the disease and the treatment; for some this was based on experiences of relatives or friends, and for others it was based on personal experience of the disease. Sometimes these prior preferences were more accurately informed than others, and clinicians 	<p>Breast “My sister had, um, six weeks because, of course, it was two breasts removed at the same time. CNS: OKay Patient: So it was double [mastectomy]. My friend ((Friend 2)) at the end of the street she’s got this [breast cancer]. I was talking to her on Friday. CNS: Were you? Patient: But, um, the only thing is, she’s only got it obviously on the one side, and it was Really noticeable. CNS: Okay, Okay</p>

	<p>would address the errors, or gaps in knowledge.</p> <p>CKD patients tended to have a greater baseline knowledge of the disease and the options, in keeping with it being a long-term disease. Sometimes, patients' prior knowledge of dialysis and transplantation were based on family history of the disease, and the nurse was aware that the patient had accompanied relatives to appointments. Consequently, the nurse tailored the depth of the option presentation, whilst still checking understanding and addressing any knowledge errors or gaps.</p>	<p>Patient: That's why I thought, obviously with two am I going to match?" (Consultation ID 2.3)</p> <p>Renal "To be honest...this is the forth time, because I was there with my sister...then I was there with my deaf brother...and then I was there with my younger brother..." (Patient, ID 1.18)</p>
<p>Things that matter to patients</p>	<p>All patients were actively encouraged to think about what mattered to them.</p> <ul style="list-style-type: none"> • Lifestyle considerations were an important factor influencing both the decision process and treatment choice. • Continuity of work and minimal disruption to working life were important factors for many patients. • Hobbies and pre-planned events (e.g. upcoming holidays) were also important, and influenced the decision. <p>Social circumstances particularly influenced options presented to pre-dialysis patients e.g. whether they lived alone or had support, if they had access to transport, if they had room to store the dialysis equipment at home.</p>	<p>Breast "Patient: Alright, erm, what was I going to say. Oh no, what I was going to say is what do you think about, well how do people kind of, how does it affect them work wise? Okay. And, em, what was I going to say, oh, after then, how long do you think I'd need off work after the operation? Consultant: Right. That, that's really, really individual. Patient: Mhm. Consultant: If it's a straightforward mastectomy and, em, sentinel node biopsy ... Patient: Yeah. Consultant:... a few weeks" (Consultation ID 2.16)</p> <p>"CNS: Erm, but again, as a lady who's done a lot of swimming, you know, it'll be good and swimming would be a great an actually great activity once everything has settled down. Patient: Yeah, Yeah. CNS: Give it, er, give it a couple of months and hopefully you'll be back doing those things, gradually. Your body will tell you if you've done too much" (Consultation ID 2.3)</p> <p>Renal "Mm, that would be better for me, to have it overnight ... if I could go to work the next day or something." (Patient, ID 1.19)</p> <p>"CNS: Lovely, thank you. Do you ... I've got to ask something about your property because one of the treatments is that you can do it at home?...so I need to know if you have space</p>

		<p>for this vast amount of stock that comes with one of the treatments. So I want to know, do you own this property? Patient: No, rent it...it's housing association. CNS: And how many bedrooms have you got? Patient: One, a small bedroom and in answer to your question, no I haven't got room for anything else." (Patient, ID 1.13)</p>
<p>Emotion</p>	<ul style="list-style-type: none"> Emotional issues were evident for most breast cancer patients, and generally those who displayed higher levels of distress were less able to engage in the SDM discussion. Some CKD patients struggled with the news that they would be transitioning from living with a long-term condition to having to actively manage that condition (dialysis), and they were generally less likely to engage in the SDM discussion. <p>Clinicians always appeared sensitive to the patients' emotional states, and adapted their information and SDM discussions accordingly.</p>	<p>Breast "Consultant: Okay, so this is a shock for us, it has been a shock for us as well, because it wasn't what we were expecting... Patient: I think I just need to simulate the information really and yeah, I'm just shocked. Consultant: I know of course, of course and you know, when we do these results originally if we suspect that there's something there, we will prepare our patients beforehand and say "Look you know, we are worried about this", but it was you know just right on that cusp that you know, it could go either way sort of thing, and they weren't particularly suspicious, so this is why it's been such a shock for you [Persons name], and I'm really sorry about that. Patient: Umm. CNS: Because of course it has meant that you've come in today with nobody with you. Patient: Yeah. Consultant: It's, it's a little bit like a punch in the face isn't it when, when you have a shock like this." (Consultation ID 2.18)</p> <p>Renal "CNS: How do you feel with the information you've had? Patient: Erm shell shocked, I think is the word. Er just a ... takes time to absorb. CNS: Yes. Patient: and to even get used to the thought of having to have it, I think is the worse thing". (Patient, ID 1.13)</p>
<p>Perceived urgency to make a decision</p>	<p>Perceived urgency to make a decision appeared to have some influence on the SDM process, specifically the patient's level of engagement.</p> <ul style="list-style-type: none"> Generally, breast cancer patients were more engaged than CKD patients during the decision 	<p>Breast "Patient: How long have I got to make my mind up? Consultant: Well we can put you on an operating list in ten days' time which gives you ten days, erm or if you want longer we can leave it longer but erm ... Patient: Ten days will be enough I think.</p>

	<p>phase of the consultation, reflecting that it is a time-bound irreversible surgical decision.</p> <ul style="list-style-type: none"> • Most CKD patients are not required to make their decision for several months, or even years, and so discussing the 'decision' appeared less relevant to them, and it appeared more difficult to engage the patient. 	<p>Consultant: Yeah because we don't delay it. Unless it's... Patient: I don't want to leave it any longer because I'd start to dither then so I'd rather have it done..." (Consultation ID 2.14)</p> <p>Renal "Okay, so just to let you know we'll see you back in clinic in a month's time. If there's anything Untoward with your bloods I'll be on the phone. Every time you come to clinic I check your bloods the next day so now you are in my caseload, the guys here will be checking everything. Please ring me if you've got any questions, don't sit at home and think mmm, but I am quite Happy at the moment to just keep an eye on you. We don't need to do anything [now]". (CNS, ID 1.17)</p>
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Table 2. Comparison of elements of “Implement-SDM” model observed, compared to the Three-Talk Model[6]

Three Talk Model[6]	Comparison between models	Implement-SDM Model
Patient’s prior preferences	Partly comparable + new elements	Prior preferences of <i>clinician, patient and family</i>
	New	Preparation phase
Choice Talk	Comparable	Choice Introduction
Option Talk	New	Evolving Option Presentation
Decision support - Inside consultation: ‘brief decision aids’ - Outside consultation: more comprehensive decision aids	Partly comparable + new elements	Decision support tasks - Decision support - Emotional support - Practical support
Decision Talk	New	Planning Discussion
Patient’s informed preferences	Partly comparable + new elements	Informed preferences of <i>clinician, patient and family</i> “Distributed decision”

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		Breast cancer consultations	Pre-dialysis consultations
Preparation Phase	Brief preparation before choice was introduced to patients. The tasks can differ (e.g. MDT meeting, diagnosis, checking emotional state after giving diagnosis, detailed medical history / checking symptoms, understanding social/personal circumstances). Influences succeeding phases of SDM.	<p>“It’s very treatable, that’s the good news, and that will involve surgery, and because it’s reasonably small...there are two ways that we can treat it surgically.” (Consultant, ID 2.14)</p> <p>“Okay, so the important thing to take from here is this is very small, but you know if anyone can be optimistic about this it's you because this is very slow, very early.” (Consultant, ID 2.15)</p> <p>“Consultant: Okay, so this is a shock for us, it has been a shock for us as well, because it wasn’t what we were expecting. Patient: No, no...I think I just need to simulate The information really and yeah, I’m just shocked. Consultant: You just need, to take it in first Patient: Yeah, I’m just really surprised, I think everybody thought it was going to be...[clear]... yeah.” (Consultation ID 2.18)</p>	<p>“Clinical Nurse Specialist (CNS): Good. OK. Um, any other surgery, abdominal surgery, anything? Patient: Well, years ago, many years ago, I had a hernia operation. Wife: That’s right. Patient: Many years ago.” (Consultation ID 1.7)</p> <p>“CNS: So when I phone people, they’ll say, what is it [kidney function level], and I’ll say ‘oh, you’re 17 percent’. And they may think, ‘oh, gosh, I was 22 the last time’, but if you look at the creatinine level, 250 to 322, it hasn’t deteriorated that much, but as a percentage, people think, oh gosh, that’s a lot. Do you understand where I’m coming from? Patient: Yes, yes. CNS: So keep an eye on that, and what we do is look at the symptoms as well. So we don’t start anybody on dialysis unless they’re having the symptoms. So great, you haven’t got any of the symptoms, which I’ll go through.” (Consultation ID 1.1)</p>

<p>Introducing choice</p>	<p>Confirming the availability of choice, and providing a rationale for choice</p>	<p>“Consultant: Yes of course, I mean you take your time to think about that. What I don’t want you to do is go away with the idea that one’s better than the other. Patient: No. CNS: They’re different...they’re both very effective Consultant: That’s right; we must say to you there’s no difference in the terms of the outcome it’s how you feel about it.” (Consultation ID 2.14)</p> <p>“...both the surgical options I’ve just given you are the same in terms of survival. And what makes people decide one or the other is personal preference.” (Consultant, ID 2.15)</p> <p>“Consultant: That’s why it’s your choice you see because it’s how you feel about it, it’s not how we feel about it. Patient: It’s my chest. Consultant: That’s right; we must say to you there’s no difference in the terms of the outcome it’s how you feel about it.” (Consultation ID 2.8)</p> <p>“Because why we talk about it, different things that can be done, because it is, what you will see on the grid [decision aid] that we show you, there is really no difference between having the mastectomy or having a lumpectomy with the radiotherapy. (Consultant, ID 2.10)</p>	<p>“What we’ll do today, we’ll talk a bit about what the kidneys do, some of the symptoms you may have already, or may not have but you may develop them, and we’ll talk about the different types of treatment...” (Clinical nurse specialist, ID 1.3)</p>
<p>Tailored, evolving and integrative option presentation</p>	<p>Initial option presentation</p>	<p>“...there are two ways we can treat it surgically. One is to take the lump out with an area of normal breast around it like a safety margin and then give you radiotherapy afterwards...and the other one is to do a mastectomy...we take all of the breast tissue and you don’t necessarily need the radiotherapy then.” (Consultant, ID 2.14)</p>	<p>“I’ve got a picture booklet, but what I’ll do I’ll talk through it with you and just let me know if it does make some sense, okay. So there are two types of treatment. There’s one where you go into the hospital and you have your blood cleaned through a machine, three times a week.</p>

			<p>And you're attached to the machine then for about four hours, okay. So you have your treatment and then you come home. And we'll go through that treatment in detail, now that's called haemodialysis that means cleaning of your blood. There is another treatment then that you can do here in the home, obviously with [person's name] help. Where you have a tube in your tummy and you run bags of fluid into your tummy yourself. And drain them back out again. (CNS, ID 1.11)</p>
	Preference elicitation	<p>"... and to know what's important for you. I know you will probably talk to lots of people, perhaps friends, relatives, whoever, about things perhaps over the next week. But the most important thing is [person's name] is that when you make...my job is not to influence you in any way, my job is to give you all the information that you need to make your decision and know that the decision that you've made is right for you. (CNS, ID P2.16)</p> <p>"CNS: Look at it this way. You can't be wrong no matter what you choose. Patient: ...you want somebody to tell you that, don't you...? CNS: Yes... Patient: ...that you're not going to make the wrong...[decision] CNS: ...you will not be wrong in choosing a decision." (Consultation ID 2.17)</p> <p>"I think, you know, I'd ask the question for you, what is important about going for the reconstruction for you? (CNS, ID 2.3)</p>	<p>"Relative: So it's, I'm quite capable of being, you know, either putting the needle in CNS: Yeah. Exactly. And what would you rather? [directed to patient] Patient: on me...I'd do it at home. Well in actual fact I'm going to train ((Husband)), because he would have made a good doctor." (Consultation ID 1.8)</p> <p>"CNS: Had you given that any thought at all or? Patient: No, I haven't. CNS: So [person's name] would you, do you want to be assessed to have a kidney transplant or do you feel it's a little bit too early yet? Patient: I feel it's a little bit too early ... CNS: Yes, that's fine." (Consultation ID 1.28)</p>
	Tailoring options	<p>"Consultant: And we need to sort it out. And that's the most important thing...what's the most important thing to you at the moment about this? You know, is it the not</p>	<p>"CNS: If I was meeting you now and you had lots of health problems and you were much older, it might be that the burden of having dialysis would be too much...you wouldn't</p>

		<p>having surgery, keeping your breast, not keeping your breast, what, what do you think's the most important? Patient: I don't know. I really don't know. Consultant: I think originally you sort of said that, that the important thing perhaps was not having surgery. And that that was your fear? Patient: Yes, yes" (Consultation ID 2.23)</p> <p>"And, the other problems that you've got, other health problems and that sort of thing, I think tablets is a very, very good option. With these tablets we get very good results... tt's just a much slower way of working..." (Consultant, ID 2.18)</p> <p>"Consultant: I'll go and get you a date. I've just added a spanner to the works...erm so your mother is quite sizeable [large breasts] and you know we've always got to think these days about how we can get the cosmetic results better when we do the breast surgery, so if she chose to have a wide local incision, I can actually do it erm doing breast reduction pattern ... Daughter: Oh right. Consultant: so she'd have a very natural breast reduction but at the same time I'd be removing the breast cancer, so she seems quite interested in that as well...because otherwise, you know when I remove this lump she would be slightly lopsided, but if I did a reduction on both sides then she might have a better result." (Consultation ID 2.22)</p>	<p>want to go down that route. So we do have quite a few people who choose not to have any treatment, for some people who are much older, you know, in their 80s or 90s, dialysis might not add anything to how long they're going to live, but it might mean that the last few years of their life would end up just being in and out of hospital with problems with dialysis...and actually their quality of life would be better without it. Patient: Okay. CNS: And sometimes that's just a common sense Decision that people make. But that's not something we're talking about now because you've got every reason to benefit from having dialysis or having a transplant. But the information's there for you to read if you want, just, just to balance it, really." (Consultation ID 1.30)</p>
	<p>Checking understanding</p>	<p>"So now when we know when we know what the results are, do you want to ask any questions before I go to explain possible treatments and options?" (Consultant, ID 2.10)</p> <p>"Consultant: Great. Any questions, I mean it may be off the family actually because sometimes you can't think when you've had all that information ...</p>	<p>"CNS: So have you got any questions with this? Because it's a lot to take in. Patient: No, I don't think so. No. CNS: Have you got questions? [directed to family member] Patient: I can't think of any off hand. Probably will</p>

		<p>Patient: No. Consultant: ...is there any questions that you would have? [directed to the family] Family member: Erm, no I can't think of anything err" (Consultation ID P2.15)</p>	<p>after you've gone. CNS: If you do, write them down and give me a ring because I'll leave my number. I'm more than willing to give you the answers over the phone. Okay because it does happen, because this is quite overwhelming." (Consultation ID 1.20)</p>
<p>Distributed and multi-staged decisions</p>	<p>Decisions making process characterised by multiple and multi-stage decisions, which are distributed among the patient, clinicians and sometimes significant others</p>	<p>"And in your case, because we can do the two things for the breast we can save the rest of the breast tissue, removing just the lump as I was explaining ...but with that the radiotherapies go hand in hand, or if you decide we can remove the breast completely. Then radiotherapy is not necessary, not always. One more thing to mention, that with removing the lump only there are the chances, quite small, that sometimes we need to do another surgery. And that is because what we want to be sure that when you remove the lump that we have enough clear tissue around it, that's why the procedure is called the wide local excision. And if our pathologists for example tell us that we don't have enough margin around it, sometimes we need to go back which means the second surgery for the breast, to take a bit more of a tissue, or again you may decide if you want to have a bit more of a tissue removed or you want to go to the mastectomy." (Consultant, ID 2.10)</p> <p>"Patient: Well if you say mastectomy, if you take it, can't you take the other one off as well while you're at it?...I don't want to be lob sided. [Laughs] Consultant: Okay, I'll talk about that in a second, okay?... Let me just complete, the thing about a mastectomy is that if I do, if you choose a mastectomy on one side, we have seen</p>	<p>"CNS: And it's whatever really you know, whatever suits you because I often say this to people. If you're doing a home treatment, if [person's name] wasn't able to do it because she wasn't feeling well, the responsibility would then fall onto you. And what you have to ask, as a couple, is it fair that [partner's name] would be doing your treatment ... Patient: Mm. CNS:... for you everyday? There is that. Partner: Mm." (Consultation ID 1.11)</p> <p>"The only thing I'll urge you, also think about transplantation and have a read of the information. Don't have to do it obviously in the next week or two but before you come back in a month's time, have a think about transplant because I will be asking you. Ordinarily I refer patients straight away for transplant but I think you just need to have a little bit of time, because it is a new concept to you isn't it?" (CNS, ID 1.17)</p>

		<p>the other side, other side is normal so you don't need it taken out for cancer purposes, but if you want it taken out for the purposes of being equal on two sides, I'd rather do it as a separate procedure ...</p> <p>Patient: Yes, okay, I can think about it.</p> <p>Consultant: ... rather than at the same time." (Consultation ID 2.4)</p>	
Decision support tasks	<p>Broader decision, practical, and emotional support offered by the clinicians during the decision making process</p>	<p>"CNS: Ah, there's only one, one more little thing to go over here as well, just the information really. There's an option sheet [Option Grid, brief decision aid] on the front here, erm, several questions down the side here that you might ask, and the answers for if you have a mastectomy or if you have a wide excision.</p> <p>Patient: Okay</p> <p>CNS: Okay, SO that'll give you quite a few answers there, that we find most people find...</p> <p>Patient: Yes, that's helpful</p> <p>CNS: ...really helpful." (Consultation ID 2.16)</p>	<p>"What I wanted to say as well [person's name], if you wanted to speak to anyone, if you're feeling a bit low we do have a nurse counsellor and a clinical psychologist, just let me know if you do want to speak to somebody. And we're very lucky in Wales, we've got volunteers called befrienders and I am just thinking now we've got a man who lives up in [region name] and he does the bags, and he said to me time and time again, if you want to bring anybody up to see my setup, so I'd be very happy you know to organise for you to go up there" (CNS, ID 1.17)</p> <p>"...that's a little bit more about transplantation you can keep. We do a monthly information morning, which may be a little bit too early at the moment, but we do do a support group..." (CNS, ID 1.1)</p> <p>"One thing I do want to give you and I apologise it's a little bit creased, this here is an Option Grid [brief decision aid], don't be put off by it[person's name]but what I say to my patients...so we've done a list of questions here what does it involve, how often will I need it, can I travel, erm, who will do my treatment? And just take a highlighter pen and highlight what's important to you and I like to think in your case you will be highlighting this column because that's the one that you want, transplantation." (CNS, ID 1.17)</p>
Planning Discussion	<p>A process of consolidating or summarising</p>	<p>"Okay. So on what I've told you so far, is there a sort of a gut feeling of where you think you will go with your</p>	<p>"What I do with some of my patients, in fact most of them [person's name], I come back and see them as they're approaching dialysis or needing a transplant [to discuss</p>

	<p>preferences and moving towards a decision or an ongoing reflective and iterative process until the point a decision needs to be made</p>	<p>decision or do you need more info from me, because [CNS] will be giving you lots of written stuff and introducing you to some online tools that can help you as well to make your decision. But most people I would say, once they have seen [CNS] they have seen me and they have asked all the questions here. Most people are able to make that decision.” (Consultant, ID 2.15)</p> <p>“Consultant: No, no. It really is personal preference really. Patient: It’s hard when you’ve got to make up your mind. Usually I’m the person makes up their mind. Friend: Usually you decide ... Patient: Usually I decide what I want to do and that’s it. Consultant: Yeah so what’s erm stopping you from making up your mind, what questions have you got that ...? Patient: I don’t have any questions really. I just can’t, just can’t say well yes... Consultant: I’ll do this... Patient: Mhm or I’ll do that, I’ve always been the person that’ll go and say well I’m going to do this I’m going to do that...but I just, for some reason or other, I mean I’ve had loads done to me so...” (Consultation ID 2.14)</p>	<p>treatment options / decision].” (CNS, ID P1.9)</p> <p>“Okay, so just to let you know we'll see you back in clinic in a month's time. If there's anything untoward with your bloods I'll be on the phone. Every time you come to clinic I check your bloods the next day so now you are in my caseload, the guys here will be checking everything. Please ring me if you've got any questions, don't sit at home and think mmm, but I am quite happy at the moment to just keep an eye on you. We don't need to do anything [now]”. (CNS, ID 1.17)</p>
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Theme 2: What factors influence the SDM process?

Themes	Description	Selected example quotes
<p>Awareness</p>	<p>Patients’ previous knowledge about the condition or available treatment options also influenced the decision process, and sometimes the treatment choice.</p> <ul style="list-style-type: none"> • Most breast cancer patients had some awareness of the disease and the treatment; for some this was based on 	<p>Breast “My sister had, um, six weeks because, of course, it was two breasts removed at the same time. CNS: OKay Patient: So it was double [mastectomy]. My friend ((Friend 2)) at the end of the street she’s got this [breast</p>

	<p>experiences of relatives or friends, and for others it was based on personal experience of the disease. Sometimes these prior preferences were more accurately informed than others, and clinicians would address the errors, or gaps in knowledge.</p> <p>CKD patients tended to have a greater baseline knowledge of the disease and the options, in keeping with it being a long-term disease. Sometimes, patients' prior knowledge of dialysis and transplantation were based on family history of the disease, and the nurse was aware that the patient had accompanied relatives to appointments. Consequently, the nurse tailored the depth of the option presentation, whilst still checking understanding and addressing any knowledge errors or gaps.</p>	<p>cancer]. I was talking to her on Friday. CNS: Were you? Patient: But, um, the only thing is, she's only got it obviously on the one side, and it was really noticeable. CNS: Okay, Okay Patient: That's why I thought, obviously with two am I going to match?" (P2.3)</p> <p>Renal "To be honest...this is the forth time, because I was there with my sister...then I was there with my deaf brother...and then I was there with my younger brother..." (Patient, ID 1.18)</p>
<p>Things that matter to patients</p>	<p>All patients were actively encouraged to think about what mattered to them.</p> <ul style="list-style-type: none"> • Lifestyle considerations were an important factor influencing both the decision process and treatment choice. • Continuity of work and minimal disruption to working life were important factors for many patients. • Hobbies and pre-planned events (e.g. upcoming holidays) were also important, and influenced the decision. <p>Social circumstances particularly influenced options presented to pre-dialysis patients e.g. whether they lived alone or had support, if they had access to transport, if they had room to store the dialysis equipment at home.</p>	<p>Breast "Patient: Alright, erm, what was I going to say. Oh no, what I was going to say is what do you think about, well how do people kind of, how does it affect them work wise? Okay. And, em, what was I going to say, oh, after then, how long do you think I'd need off work after the operation? Consultant: Right. That, that's really, really individual. Patient: Mhm. Consultant: If it's a straightforward mastectomy and, em, sentinel node biopsy ... Patient: Yeah. Consultant:... a few weeks" (Consultation ID 2.16)</p> <p>"CNS: Erm, but again, as a lady who's done a lot of swimming, you know, it'll be good and swimming would be a great an actually great activity once everything has settled down. Patient: Yeah, Yeah. CNS: Give it, er, give it a couple of months and hopefully you'll be back doing those things, gradually. Your body will tell you if you've done too much" (Consultation ID 2.3)</p>

		<p>Renal “Mm, that would be better for me, to have it overnight ... if I could go to work the next day or something.” (Patient, ID 1.19)</p> <p>“CNS: Lovely, thank you. Do you ... I’ve got to ask something about your property because one of the treatments is that you can do it at home?...so I need to know if you have space for this vast amount of stock that comes with one of the treatments. So I want to know, do you own this property? Patient: No, rent it...it’s housing association. CNS: And how many bedrooms have you got? Patient: One, a small bedroom and in answer to your question, no I haven’t got room for anything else.” (Patient, ID 1.13)</p>
<p>Emotion</p>	<ul style="list-style-type: none"> Emotional issues were evident for most breast cancer patients, and generally those who displayed higher levels of distress were less able to engage in the SDM discussion. Some CKD patients struggled with the news that they would be transitioning from living with a long-term condition to having to actively manage that condition (dialysis), and they were generally less likely to engage in the SDM discussion. <p>Clinicians always appeared sensitive to the patients’ emotional states, and adapted their information and SDM discussions accordingly.</p>	<p>Breast “Consultant: Okay, so this is a shock for us, it has been a shock for us as well, because it wasn’t what we were expecting... Patient: I think I just need to simulate the information really and yeah, I’m just shocked. Consultant: I know of course, of course and you know, when we do these results originally if we suspect that there’s something there, we will prepare our patients beforehand and say “Look you know, we are worried about this”, but it was you know just right on that cusp that you know, it could go either way sort of thing, and they weren’t particularly suspicious, so this is why it’s been such a shock for you [Persons name], and I’m really sorry about that. Patient: Umm. CNS: Because of course it has meant that you’ve come in today with nobody with you. Patient: Yeah. Consultant: It’s, it’s a little bit like a punch in the face isn’t it when, when you have a shock like this.” (Consultation ID 2.18)</p> <p>Renal “CNS: How do you feel with the information you’ve had?”</p>

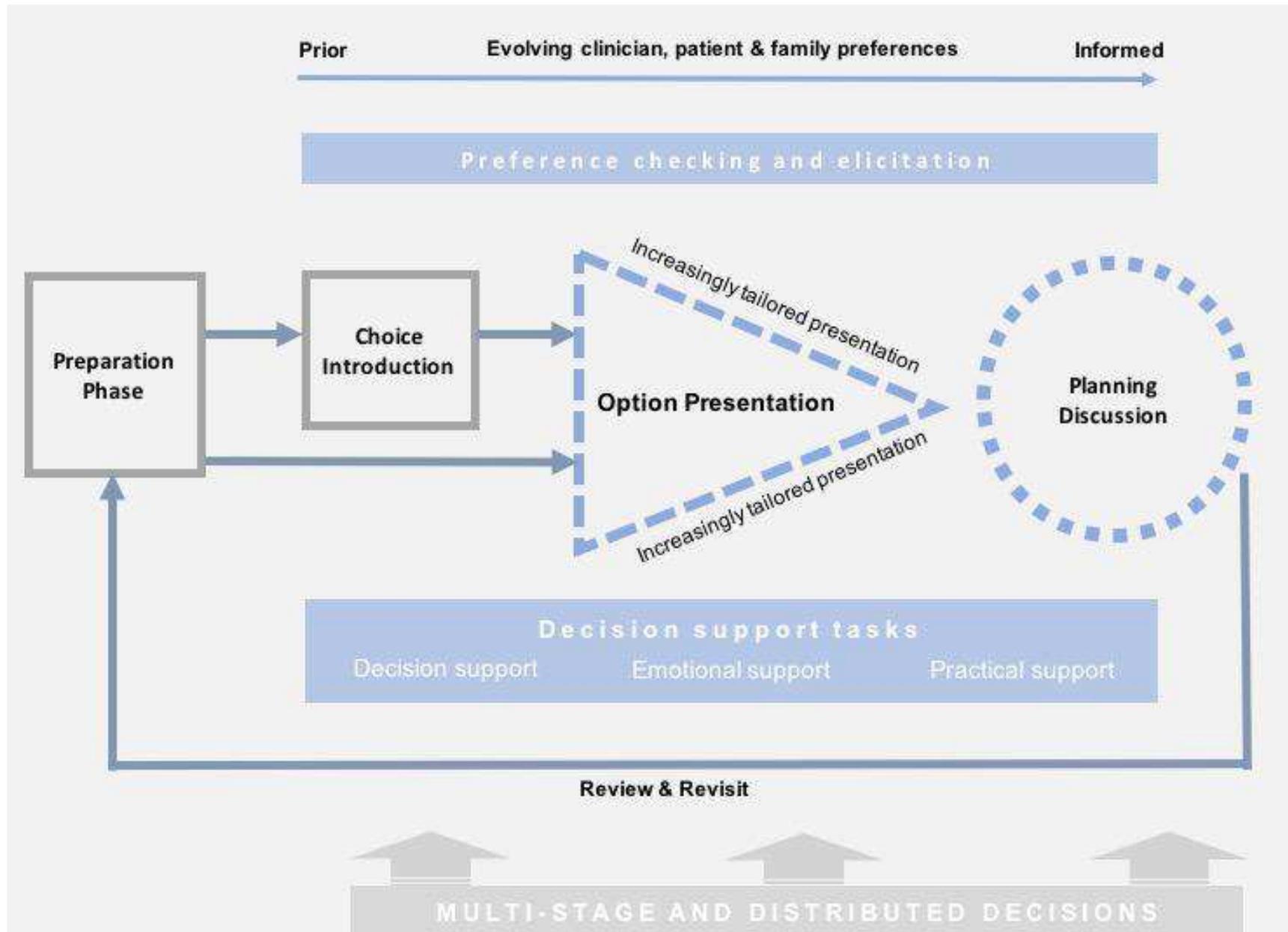
		<p>Patient: Erm shell shocked, I think is the word. Er just a ... takes time to absorb. CNS: Yes. Patient: and to even get used to the thought of having to have it, I think is the worse thing". (Patient, ID 1.13)</p>
<p>Perceived urgency to make a decision</p>	<p>Perceived urgency to make a decision appeared to have some influence on the SDM process, specifically the patient's level of engagement.</p> <ul style="list-style-type: none"> • Generally, breast cancer patients were more engaged than CKD patients during the decision phase of the consultation, reflecting that it is a time-bound irreversible surgical decision. • Most CKD patients are not required to make their decision for several months, or even years, and so discussing the 'decision' appeared less relevant to them, and it appeared more difficult to engage the patient. 	<p>Breast "Patient: How long have I got to make my mind up? Consultant: Well we can put you on an operating list in ten days' time which gives you ten days, erm or if you want longer we can leave it longer but erm ... Patient: Ten days will be enough I think. Consultant: Yeah because we don't delay it Unless it's... Patient: I don't want to leave it any longer because I'd start to dither then so I'd rather have it done..." (Consultation ID 2.14)</p> <p>Renal "Okay, so just to let you know we'll see you back in clinic in a month's time. If there's anything untoward with your bloods I'll be on the phone. Every time you come to clinic I check your bloods the next day so now you are in my caseload, the guys here will be checking everything. Please ring me if you've got any questions, don't sit at home and think mmm, but I am quite happy at the moment to just keep an eye on you. We don't need to do anything [now]". (CNS, ID 1.17)</p>

Table 2. Comparison of elements of “Implement-SDM” model observed, compared to Three-Talk Model [6]

Three Talk Model	Comparison between models	Implement-SDM Model
Patient’s prior preferences	Partly comparable + new elements	Prior preferences of <i>clinician, patient and family</i>
	New	Preparation phase
Choice Talk	Comparable	Choice Introduction
Option Talk	New	Evolving Option Presentation
Decision support - Inside consultation: ‘brief decision aids’ - Outside consultation: more comprehensive decision aids	Partly comparable + new elements	Decision support tasks - Decision support - Emotional support - Practical support
Decision Talk	New	Planning Discussion
Patient’s informed preferences	Partly comparable + new elements	Informed preferences of <i>clinician, patient and family</i> “Distributed decision”

Figure 1

Figure 1: 'Implement-SDM' - Descriptive model of shared decision making based on observations of routine



CRedit Roles

A descriptive model of shared decision making derived from routine implementation in clinical practice ('Implement-SDM'): qualitative study

Natalie Joseph-Williams: Conceptualization, Formal analysis, investigation, methodology, supervision, writing original draft

Denitza Williams: Data curation, formal analysis, methodology, validation, writing – review and editing

Fiona Wood: Formal analysis, methodology, supervision, validation, writing – review and editing

Amy Lloyd: Data curation, writing – review and editing

Katherine Brain: Conceptualization, funding acquisition, project administration, supervision, writing – review and editing

Nerys Thomas: investigation, writing – review and editing

Annwen Goodland: investigation, writing – review and editing

Helen McGarrigle: investigation, writing – review and editing

Helen Sweetland: investigation, writing – review and editing

Adrian Edwards: Conceptualization, Funding acquisition, methodology, supervision, writing-review and editing.