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# Navigating healthcare: a qualitative study exploring prostate cancer patients' and doctors' experience of consultations using a decision-support intervention

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## Abstract

***Background*: Men with prostate cancer face preference-sensitive decisions when choosing among treatments with similar survival outcomes but different procedures, risks and potential complications. A decision-support intervention, 'Decision Navigation' assists men with prostate cancer to prepare a question list (consultation plan) for their doctors and provides them with a consultation summary and audio recording. A randomised controlled trial of Decision Navigation showed advantages over usual care on quantitative measures including confidence in decision-making and regret.**

***Objective*: The aim of this study was to gain a qualitative understanding of patient's and doctor's perspectives on Decision Navigation.**

***Methods*: Six patients who received Decision Navigation were purposively selected for interview out of 62 randomised controlled trial participants. All four doctors who consulted Navigated patients were interviewed. Interview data was analysed using framework analysis.**

***Results*: Patients reported that planning for the consultation helped them to frame their questions, enabling them to participate in consultations and take responsibility for making decisions. They reported feeling more confident in the decisions made, having a written report of the key information and an audio recording. Patients considered routine information relating to side effects was inadequate. Doctors reported that consultation plans made them aware of patients' concerns and ensured comprehensive responses to questions posed. Doctors also endorsed implementing Decision Navigation as part of routine care.**

***Conclusion*: Results suggest that Decision Navigation facilitated patients' involvement in treatment decision-making. Prostate patients engaging in preference-sensitive decision-making welcomed this approach to personalised tailored support.**


## Introduction

Men with prostate cancer are presented the opportunity of making 'preference-sensitive decisions' about their treatment, where no one option is better than the others on outcomes valued by patients [1]. UK guidance encourages healthcare professionals to identify the extent patients wish to be involved in treatment decision-making and to support them in making such decisions in line with their personal preferences [2,3]. Sharing decisions about treatment options involves a two-way exchange of information between patient and doctor. When cancer patients are empowered to assume a more active role and make decisions consistent with their preferences, they experience less decision conflict [4], greater satisfaction with the outcome [5,6] and, in some cases, improved treatment adherence [7]. In practice, shared decision-making is inconsistently carried out [8,9]. Doctors' most cited barrier is time constraints, whilst patients often do not ask questions because of a concern about their perceived lack of knowledge or because they do not feel comfortable questioning their doctor [10–13].

The 'Decision Navigation' decision-support intervention facilitates patients' preparation for and involvement in treatment decisions. Navigation integrates three evidence-based decision-support interventions: decision coaching [11], question listing [14] and the provision of consultation summary letters and audio recordings [15].

Decision Navigation has a strong evidence base applied to cancer consultations, specifically, increasing decision self-efficacy [16] and decision quality [17], reducing barriers to communication [18,19], increasing question asking by patients during treatment consultations [20] and reducing decisional conflict [16].

Decision Navigation was trialled with newly diagnosed prostate cancer patients in Edinburgh, Scotland, in a two-arm randomised controlled trial (RCT) which had a qualitative component to triangulate the results and further understand the intervention in its 'natural context'. Quantitative analysis from patient questionnaires taken at three-time points (baseline, post-consultation and 6 month follow-up) [21] revealed that Navigated patients ($n = 62$), compared with usual care patients ($n = 52$), had significantly higher

scores in decision self-efficacy after the medical consultation, and at 6-month follow-up, significantly less decisional conflict after medical consultation and significantly less decision regret 6 months later [22].

This paper reports the results of interviews intended to explore patients' and doctors' experiences of this intervention in the real-life clinical context of making decisions for newly diagnosed prostate cancer.

## Methods

### Design

Semi-structured interviews were conducted with six prostate cancer patients who received the Decision Navigation intervention and all four doctors who participated in the intervention. Evaluation interviews were conducted 3 months post-medical consultation for patients and 4 weeks after the trial closure for doctors.

### The Decision Navigation intervention

Box 1 presents the process of the intervention.

Patients who were randomised into the navigation arm met with a Navigator to create a question list, 'consultation plan' for their first treatment consultation. During this meeting, a question prompt sheet (SCOPED) was used to help patients consider the following categories in relation to their cancer and treatment options: their *situation*; the *choices* available to them; their personal *objectives*, preferences and goals; the *people* involved in supporting them; questions that *evaluate* their choices against their objectives and how involved they wish to be in *decisions* about their care.

This consultation plan was sent to patients' doctor to facilitate the discussion in their consultation. The Navigator attended this consultation to take notes and audio record, subsequently posting patients a typed summary and a recording (CD) of their meeting.

Box 1: The Decision Navigation Intervention

1. Consultation planning
   - Navigator telephones patient prior to consultation.
   - Using a question prompt sheet (SCOPED), the patient's key questions, concerns and tpreferences identified and developed into a 'Consultation Plan' by Navigator, for use in consultation.
2. Medical Consultation with Decision Navigation
   - Consultation Plan used in the discussion.
   - Navigator accompanies patient to audio-record consultation and types notes.
3. Patients sent an audio-recording (CD) and typed summary of their medical consultation.

Decision Navigation was delivered by two research assistants, trained in the intervention by author J. Belkora.

### Patient sample, recruitment and interview procedure

Six 'Navigated' patients were purposively selected in chronological order by the researcher using specific selection criteria: localised prostate cancer and having received the full intervention. Patients were invited to participate via the telephone 3 months after the consultation in which a range of treatment options (surgery, radiotherapy, active monitoring) were considered, providing enough time for completion of treatment and reflection on decisions.

All participants approached agreed and were interviewed over the telephone. All interviews were audio recorded with patient permission and transcribed verbatim. An interview schedule was developed from previous research evaluating the impact of navigation [16–20]; this is available on request. Interviews explored patients' experiences of Decision Navigation in terms of participation in medical consultations, information received during the consultation, their involvement in decision-making and their experiences of the process of navigation.

### Doctor sample, recruitment and interview procedure

All four doctors who consulted Navigated patients were invited to take part in an interview to discuss their experience of Decision Navigation within the clinical context. All doctors agreed to be interviewed at 4 weeks after the trial's close.

All four doctors were interviewed face to face. Interviews were audio recorded and transcribed verbatim. The interview schedule was adapted to reflect the topics addressed with patients. Interviews explored doctors' perceptions of navigated patients' participation, involvement in decision-making and information exchange within consultations, evaluation of the impact of Decision Navigation materials and experiences regarding the overall clinical relevance and suitability of Decision Navigation.

### Analysis

All interview transcripts were anonymised and analysed using framework analysis [23], a matrix-based method for ordering and summarising data [24]. Patient and doctor interview transcripts were analysed separately, using the same method. A priori themes, defined by the study's aims and objectives, guided the study analysis with a flexible approach to integrate other themes or concepts that emerged *de novo* throughout the analysis.

Four researchers (authors S. E. Scott, S. C. Shepherd and B. Hacking and an independent researcher) independently read all of the transcripts to gain familiarity with the data and met regularly to identify and agree on themes. To develop a thematic framework, the process of constant



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comparison was applied, taking sections of interview data and comparing them to the emerging themes. As our samples were small, we concentrated on findings that clearly emerged in-depth within all the transcripts. All researchers agreed on the final thematic framework, which was applied to code the interview data into charted themes and subthemes. Coding of the data was performed independently and then agreed on. Multiple coding by the four researchers independently and collectively added to the comprehensiveness and rigour of the identified categories.

Ethical approval was granted by Coventry University and South East Scotland research ethics committee (08/F1102/45).

## Results

### Patient interviews

All patients interviewed were Caucasian, the age range was 61–75 years, four were living with a partner and two were not. Three patients were educated to 15 years, one to 18 years and two had university education. All patients had localised prostate cancer, three patients received radiotherapy, two had surgery and one was being monitored for his cancer (active monitoring). The mean time of the patient interviews was 23 min.

During the analysis, four main themes emerged: (1) preparing for and participating in consultations, (2) gathering and retaining sufficient and individualised information from consultations, (3) deliberating options and making treatment decisions, and (4) Navigator support.

1. Preparing for and participating in consultations

*Thinking ahead for the consultation*

All patients described how preparing questions before the consultation disentangled their thoughts and identify what they wanted to ask.

> '[Consultation Planning] is good for sorting out your thoughts and coming up with questions you might not have thought about.' *Patient 4*

> 'There were certain issues…that coming at it fresh I would not have been thinking about… but obviously as part of the discussion with [Navigator] did come out.' *Patient 3*

*Being part of the consultation*

The consultation plan helped all patients focus on and address their questions during the consultation,

> 'We made explicit questions that we had written down so we had this sort of check list we were able to refer to during the consultation which was useful.' *Patient 2*

> 'I did feel that the [Consultation Plan]…helped the whole experience because I did feel I knew what I was talking about.' *Patient 4*

2. Gathering and retaining sufficient and individualised information from consultations

*Information provision during consultations*

Through preparing the plan, patients felt doctors were prepared for their individual needs, ensuring a smoother exchange of information.

> 'The fact that he [doctor] had clearly got…a copy of those concerns/questions…that set out my range of issues that I wanted to explore and the fact that he was already aware of those meant you know, clearly he got some answers … before I had asked them, which I found very helpful…I didn't feel as though I was trying to tease information out of him.' *Patient 3*

However, patients retrospectively reported receiving insufficient detail about treatment side effects they experienced.

> 'In hindsight it might have been a little more helpful to have had you know…maybe a little bit more background as to what you might expect after surgery.' *Patient 3*

*Recalling pertinent treatment information*

The consultation materials (consultation summary and CD) were reported as beneficial to all patients in assisting their memory of treatment information provided during a difficult consultation.

> 'You never take in all that detail of a meeting like that I don't think and it's helpful having that disc [audio CD] to be able to refer back to.' *Patient 4*

> 'When I was told my preferred treatment wasn't an option, you start going blank and nodding your head and those seconds pass…you know you're not taking information in … so the [summaries] were useful.' *Patient 2*

3. Deliberating options and making treatment decisions

All patients reported that the Decision Navigation materials helped them to deliberate options.

> 'I think one of the real benefits I found …was that quite clearly I have done a 360 degree turn and ended up with surgery. It helped to play [CD] back and sit and listen… before we made the final decision.' *Patient 3*

> 'Because of [Navigation] I seem to have gotten to the root of the problem and the decision on the solution.' *Patient 5*



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Using the materials enhanced patients' confidence in the decisions reached during the consultation.

> 'Revisiting the consultation through the CD twice gave me a bit of a lift because I felt, well, yes it was positive. It didn't bring doubts into my mind; it brought a positive feeling that we had done the job at the consultation.' *Patient 4*

4. Navigator support

Having a Navigator present in the consultation made all patients feel supported.

> 'I think the consultant did sort of overawe you. It wasn't a one on one basis it was a one on two basis, and that's where I felt the benefits from [Navigator]'s involvement.' *Patient 5*

Subsequently, knowing the Navigator had observed the consultation was reassuring as patients were able to refer back to the navigator immediately following the consultation.

> 'It was helpful to have somebody else there to talk to afterwards about what had been said.' *Patient 2*

Having a Navigator to discuss issues with, in combination with the other aspects of the intervention, was supportive during a difficult time.

> 'The ability to chat to somebody else, the questions [consultation plan] and the [audio] recording, I think those are three pretty important issues for someone who, yeah, literally faces the issue of cancer and what they are going to do about it.' *Patient 3*

## Doctor interviews

The average length of the doctor interviews was 23.3 min. All four doctors interviewed were male. Two were consultant urologists and two oncology consultants.

Four main themes emerged from the data: (1) Both parties were more prepared, (2) discussing treatments with patients, (3) making treatment decisions and (4) sustainability of Navigation.

1. Both parties were more prepared

By preparing questions before the consultation, Decision Navigated patients appeared more empowered and ready to actively participate in the consultation.

> 'By virtue of the fact that they had thought about it in advance, they were more involved [than usual care patients].' *Doctor 4, Oncologist*

The consultation plans provided doctors with an insight into the patient's current understanding and treatment preferences, equipping the doctor to be able to strategize a consultation for their patient.

> 'The benefit of having the plan is knowing what the patient is thinking, what he has been told and also having prior knowledge of what a confusing picture he may have.' *Doctor 2, Urologist*

> 'The usefulness is [knowing] what treatment they are leaning towards. Is it because they are biased? Is it because they just following herd instinct? Or because they heard a friend had it and were told it worked well? That prewarning or prior information is clearly useful.' *Doctor 2, Urologist*

2. Discussing treatment with patients

Doctors reviewed the patient's consultation plan prior to the consultation. This highlighted a conflict between their own and the patient's priorities for the discussion within the treatment consultation.

> 'What is apparent is that the patient's priorities may be different…they might have right at the top 'what about my holiday in September?'…whereas right at the top for me is telling them diagnosis, staging, and treatment options…The prioritization is quite surprising.' *Doctor 3, Oncologist*

Doctors reported referring to the consultation plan at the end of the consultation to ensure all salient points had been addressed.

> 'I would tend to be guided by the conversation…and then go back and use [Consultation Plan] as a checklist to make sure we've covered everything.' *Doctor 1, Urologist*

Keeping to their normal consultation style reassured doctors that all vital treatment information was covered.

> 'I've sort of stuck to my style because …it's sort of a rhythm I've followed and to change it would risk missing something out.' *Doctor 3, Oncologist*

3. Making treatment decisions together

Doctors felt that preparing for the consultation using Decision Navigation facilitated patient question asking during the consultation and enhanced decision-making.

> '[Navigation] is allowing the patient, preparing the patient, to know what questions to ask so they can make a satisfactory and better decision.' *Doctor 2, Urologist*



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One doctor reported that the active participation of patients in the treatment decision fitted with his values as a doctor.

> 'I would prefer to be challenged by a patient rather than them meekly accepting what I say…I would rather they come in and say 'tell me why I should have this, tell me why I shouldn't have that'. People [need to] come along encouraged…so that they're not coming in beholden with the person opposite.' *Doctor 1, Urologist*

4. Sustainability of Navigation

*Impact of navigation*

Doctors reported the presence of the Navigator as being no different than the patient having a family member with them.

> 'It's no different from having a sister, brother or wife.' *Doctor 1, Urologist*

All described feeling at ease with their consultations being audio recorded and recognised the benefit of giving patients audio recording of consultations.

> '…they [patients] won't remember 90% of what's said.' *Doctor 1, Urologist*

*Opinions on incorporating navigation into clinical practice*

Consultants were supportive of implementing Navigation into clinical practice.

> '[Navigation] should be up there being prioritized with other interventions… I think it's very useful.' *Doctor 3, Oncologist*

Although supportive, clinicians were concerned about the cost involved in providing the service.

> 'Given there's a salary involved, that unless you have got volunteers…well it will become too expensive.' *Doctor 1, Urologist*

To mitigate such cost clinicians suggested implementation within current roles such as the clinical nurse specialist.

> 'The cancer nurse specialists could make sure…that each patient could have a Dictaphone to take with them…. be given a CD....you could build in all the benefits [of Navigation] within the fabric of the staff we have.' *Doctor 1, Urologist*

## Discussion

This paper explores doctors' and prostate patients' experiences of Decision Navigation through interviews to gather data beyond the restrictions of the quantitative surveys. As a result, we were better able to ascertain the nature of how Decision Navigation worked in a clinical setting, how it enabled patients to feel more confident in their decisions, as shown in the main RCT [22], and the role of the Navigator in the process.

All patients reported speaking with a Navigator helped them to disentangle, identify and articulate their main concerns and questions for their medical consultation. The process of doing this before the consultation with the support of the Navigator meant patients felt prepared and confident to deliberate with the doctor about their healthcare choices. This was reflected in the doctors' interviews who explained it was useful to know the patients' concerns and understanding before meeting them. They further reported patients seemed more ready to be involved. This is substantiated by the main RCT findings [22], which show Navigated patients felt significantly more confident in making a decision than their control counterparts. Decision Navigated patients perceived their consultation as tailored to them and their individual situation.

The consultation summary and audio recording (CD) were used by patients to help them recall the clinical information provided. Patients felt reassured they could return to their decisions made during the consultation using the CD and summary. This is consistent with other 'decision coaching' interventions for prostate cancer patients [25] suggesting that such interventions should be offered as standard care, particularly in the instance of preference-sensitive decisions [11].

It is a challenge for every doctor to engage with both the biomedical and psychosocial information needs of patients simultaneously [26]. These qualitative results indicate Decision Navigation is an intervention that enables the doctors to tailor consultations to the individuals' prioritised concerns. Previous clinical evaluation of Decision Navigation [16] in the United States found equivalent results. Namely, that Navigation helped patients organise and clarify their medical questions, ensure these were attended to and was endorsed by doctors, providing them with a preview so they could plan how to conduct the consultation. Our study further found that doctors were surprised by how patients' priorities were not aligned with their own expectations of the meeting. The Consultation Plan helped bridge the distance between the patients' and doctors' views and created a shared understanding, a necessary component of shared decision-making [17].

The results of this study appear to facilitate shared decision making, in line with the model proposed by Charles *et al*. [27] 'at least two to tango'. For involvement in shared decision-making, Charles *et al*. [27] suggest complimentary roles between the doctor and the patient be established, recognising the difficultly for doctors to know how much information a patient wants and why. Patients



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taking the time with the support of the Navigator to create a question list in addition to the doctor reviewing this list beforehand and using it within the consultation ensured a conducive atmosphere for both in which to share meaningful information leading to the outcome of a mutually agreed treatment decision.

Retrospectively, the majority of patients reported not feeling prepared for the adverse effects of treatment, despite these having been discussed within consultations in general terms. This is in line with existing evidence that states that men with prostate cancer are surprised by the intensity and duration of treatment side effects [28]. This may be due to patients not processing the information about potential side effects provided because of embarrassment about incontinence or impotence and anxiety about the impact on social interactions [25] or not subsequently referring to the memory aids containing this information. The communication of side effects and how to manage them could therefore be improved.

It is interesting to note for future implementation that all doctors found the intended use of the consultation plan as an agenda was not possible. Doctors needed to abide by their own consultation script to ensure that no important safety information was omitted. The consultation plan was therefore integrated as a checklist at the end of the meeting. Nevertheless, all four doctors were unanimous in support of incorporating aspects of Decision Navigation into current practice, specifically, the consultation planning and provision of consultation audio recordings. Since the completion of this trial, the lead consultant urology surgeon obtained funding to provide consultation audio recordings to newly diagnosed prostate cancer patients in Edinburgh [26]. It is widely recognised that providing patients with consultation audio tapes is underused in oncology [29], despite the evidenced benefits of providing such a resource to patients [15,29].

The Decision Navigation model was delivered by trained researchers. Elements of Decision Navigation could be provided by usual care clinical staff or third sector organisations as practised in the United States [30,31]. The doctors interviewed suggested that clinical nurse specialists could be trained to deliver consultation planning sessions to patients and to coordinate the recording of consultations. This could address the potential governance concerns regarding introducing a third party into the healthcare system to deliver navigation. However, there are potential opportunity costs of using time from highly qualified clinical nurse specialists to deliver Decision Navigation. Systems implementing navigation in the United States [30,31] employ healthcare trainees, who gain valuable patient contact experience, along with cancer survivors, as navigators. Future studies should examine Decision Navigation across a number of different consultations and alternative models of service provision for acceptability, effectiveness, economy and sustainability.

## Limitations

The main limitation of this study is the small sample size. Our patient sample size was limited by researcher resource constraints, so sampling to saturation of themes was not attempted. Purposive sampling selected men who chose different treatment modalities, and the analysis revealed no differences in their experiences of navigation. Only Caucasian men were interviewed in this study, reflective of the local population. In future studies, it would be advisable to examine the impact of Decision Navigation in men of different ethnic groups. All four doctors were interviewed; the maximum number of doctors involved in delivering Decision Navigation to patients. The views from a larger sample of doctors would be welcomed and could be achieved by employing a multicentre trial of Decision Navigation.

The authors recognise that a larger patient sample size would allow for the saturation to reflect the diversity within the population. However, when the patient qualitative findings are considered alongside the quantitative findings of the main RCT [22], they enhance our understanding of the experiences of patients and doctors engaging with navigation in a clinical setting. Additionally, the similarity between the final themes and findings from other empirical studies [16–20] allows further confidence in our interpretation of the data.

The Decision Navigation intervention is solely patient focused. Doctors were not directly trained nor supported to change their consultation practice. This did not appar to influence the quality of the intervention. The views of the healthcare professionals, such as clinical nurse specialists, were not included in the current study as their role is more ‘on demand’ to patients, but future studies could include their perspectives.

## Conclusion

The Decision Navigation intervention was well received by this sample of men with prostate cancer and their doctors. The interviews elicited further understanding of participating in navigation, particularly in supporting treatment deliberation and facilitating patient-centred communication within consultations. Unlike many decision aids that can require time and new skills for clinicians to use confidently [32], much of the effort of Decision Navigation took place outside the consultation between the patient and the Navigator.

Decision-support interventions that optimally tailor information to the individual patient, accommodating for the variety of patient needs, are essential for patient-centred decision-making to become more widespread in clinical practice [33]. Implementation of Decision Navigation as usual practice will require exploration of affordable and effective delivery models.



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## Conflict of interest

None declared.

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