

**Feasibility and acceptability of a tablet-based, Engagement, Assessment, Support and Sign-posting (EASSi) tool used to facilitate and structure sexual wellbeing conversations in routine prostate cancer care: Mixed-methods evaluation**

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## **Abstract**

### **Background:**

Long-term side-effects associated with different prostate cancer treatment approaches are common. Sexual challenges are the most frequently occurring of these and can result in increased psychological morbidity. It is recognised that barriers to communication can make initiating discussions around sexual concerns in routine practice difficult. Healthcare professionals need to routinely initiate conversations, effectively engage with patients and assess needs in order to provide essential support. One proposed method which could support healthcare professionals to do this is use of prompts or structured frameworks to guide conversations.

### **Objective:**

To assess feasibility, acceptability and satisfaction with a tablet-based, Engagement, Assessment, Support and Sign-posting (EASSi) tool designed to facilitate and structure sexual wellbeing discussions in routine prostate cancer care.

### **Methods:**

Healthcare professionals (n=8) used the EASSi tool during 89 post-treatment appointments. Quantitative data were recorded based on programme usage and surveys completed by healthcare professionals and patients. Qualitative data exploring perceptions on use of the tool were gathered using semi-structured interviews with all healthcare professionals (n=8) and a sample of patients (n=10).

### **Results:**

Surveys were completed by healthcare professionals immediately following each appointment (n=89: 100%). Postal surveys were returned by 59 patients (66%). Healthcare professionals and patients reported that the tool helped facilitate discussions (91.1% and 82.4% respectively) and that information provided was relevant (92.1% and 84.6% respectively). Mean conversation duration was 6.01 minutes (SD: 2.91). Qualitative synthesis identified the tool's ability to initiate and structure discussions, improve 'depth' of conversations, and normalise sexual concerns.

**Conclusion:**

The EASSi tool was appropriate and acceptable for use in practice and provided a flexible approach to facilitate routine, brief conversations and deliver essential sexual wellbeing support. Further work will be conducted evaluating the effectiveness of using the tablet-based tool in prostate cancer care settings.

**Keywords**

Prostate cancer, sexual wellbeing, quality of life, communication, mHealth

## **Introduction**

Prostate cancer is the single most common cancer among men [1,2] and long-term side-effects associated with different treatment approaches are common [3]. Sexual challenges are the most frequently occurring sequela [4,5], with rates of sexual dysfunction having a moderate to severe impact on quality of life of 31 to 64% reported after radical prostatectomy and external beam radiotherapy [6,7]. In a recent, large scale survey, 81% of men reported poor sexual function post-treatment [8]. Changes to sexual function are subsequently regarded as a major issue which can result in higher levels of anxiety, depression, relational dis-satisfaction and reduced overall quality of life [9,10]. Current guidelines [11,12] support delivery of psychosexual care for prostate cancer patients and recommend a minimal level of support is provided throughout all phases of care. This includes provision of information tailored to need, advice about potential adverse effects of treatment, and ongoing access to specialist services including erectile dysfunction clinics. Despite this, sexual aspects of recovery are often not discussed [13-15] and services are not provided consistently across settings. Men frequently report that they do not receive adequate information and support to manage sexual concerns. This has been associated with increased psychological morbidity [16,17].

It is recognised that initiating discussions around sexual concerns in routine practice can be problematic [18-20]. Healthcare professionals can regard patients' sexual lives as being too personal to ask about [21,22] and may feel unequipped to deal with sexual issues, reporting a lack of resources to offer patients if they identify a problem [23]. There is evidence that attitudinal barriers and beliefs can lead healthcare professionals to actively avoid initiating discussions [24]. Fear of personal embarrassment or of causing offence, and uncertainty over whose role is it to discuss sexual issues have been identified as possible reasons for the low profile of sexual concerns [20]. Men can also feel uncertain about discussing concerns and may not be fully aware of potential side-effects of treatment on sexual function. Despite these barriers, given their frequency and substantial impact [9], sexual concerns should be discussed with all patients. To adequately address sexual wellbeing issues, healthcare professionals need to initiate conversations and effectively engage with patients and assess needs in order to provide essential support and appropriate evidence-based management [25]. One proposed method which could support healthcare professionals to do this is use of prompts or structured frameworks to guide conversations [26,27]. This approach may enhance patient-provider communication, particularly around complex or sensitive sexual issues by ensuring a more standardised provision of information [28].

## **Objectives**

The systematically developed, online Engagement, Assessment, Support and Sign-posting (EASSi) tool was designed to facilitate and structure brief sexual wellbeing discussions in routine prostate cancer care. An iterative and theory-based process modelled on the person-based approach was used to inform development, design and testing of the tool [29]. This method was primarily used to ensure development was in close collaboration with end users and to optimise acceptability, feasibility, and engagement. The EASSi tool, based on a previously published conceptual framework [30], is accessed via a tablet device and includes approximately 15 to 20 ‘pages’ with large text on screen. The text is intended to be viewed by both the healthcare professional and the patient and used as part of a shared conversation. The tools programming uses algorithms to provide information tailored to treatment type and partner status. An accompanying printed sign-posting sheet is also included to provide personalised support resources. The aim of this study was to assess feasibility, acceptability, healthcare professional and patient satisfaction with the tablet-based EASSi tool in prostate cancer care settings.

## **Methods**

### **Study design**

A mixed-methods approach was employed. This was based on quantitative data recorded on programme usage, and surveys completed by healthcare professionals and men with prostate cancer following use of the EASSi tool. A minimum sample size of 50 appointments was selected *a priori* to ensure sufficient data was gathered. Qualitative data exploring user perceptions were gathered using semi-structured interviews with the healthcare professionals and a randomly selected sample of patients. For the qualitative component, recommendations of the consolidated criteria for reporting qualitative research (COREQ) were followed [31]. Interviews were led by a researcher with extensive experience of conducting cancer research [EMcC].

### **Study population and setting**

Participants were healthcare professionals working in prostate cancer care and men attending routine appointments as part of treatment or follow-up. No exclusions were applied to age, treatment type, stage of disease (for patients) or years of clinical experience (for healthcare professionals). Written, informed consent was obtained from all participants.

## Data collection

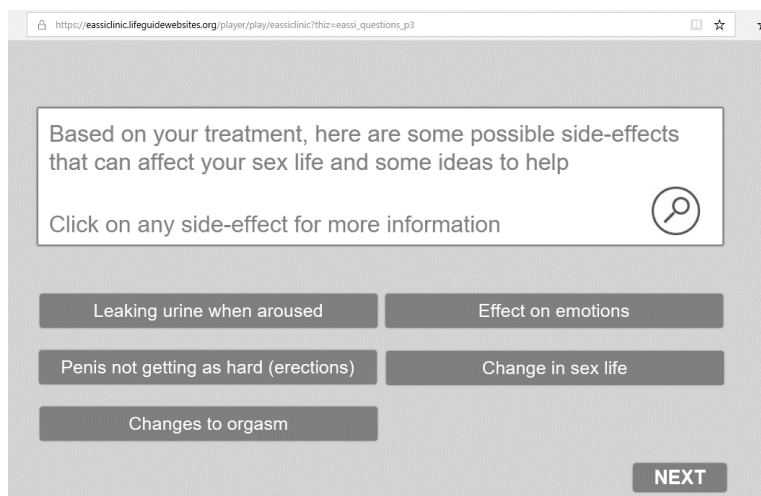
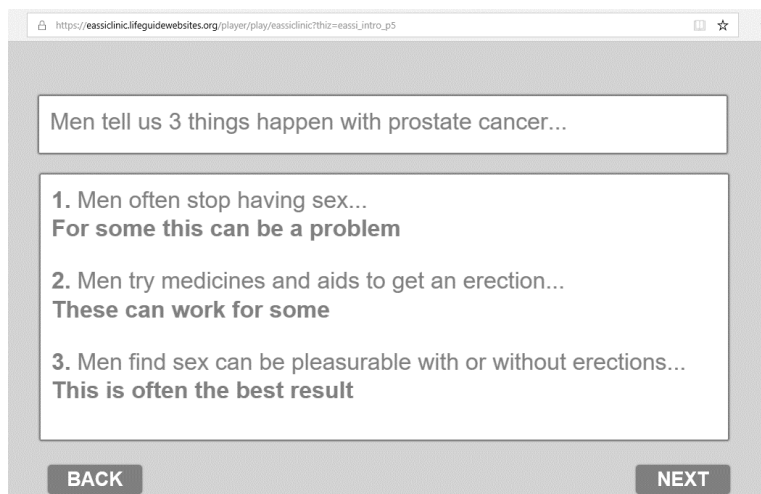
The EASSi tool was built using ‘LifeGuide’ open source software [32]. Components and design features of the tool are summarised in Figure 1. Figure 2 includes screen shots of the EASSi tool. Of the four sections included, the ‘Engagement’ section is focused on ensuring routine sexual wellbeing discussions take place, acknowledging that sexual issues are not easy to discuss and recognising that associated side-effects of treatment can have a substantial impact. The ‘Assessment’ section includes questions on treatment type and relationship status to provide tailored support based on responses to these ‘non-sensitive’ questions. The ‘Support’ section aims to provide appropriate information on common sexual challenges (relevant to treatment and relationship status). It also aims to normalise these issues and provide information on coping strategies. Lastly, the ‘Sign-posting’ section provides detail relating to other support including online self-management, erectile dysfunction clinic information and resources specific to individual needs (such as information on online support groups for gay men).

**Figure 1. Purpose and outline content of the EASSi tool**

Section	Rationale and purpose	Outline content
Engagement	Sexual challenges are a major problem and are often not addressed <b>Section used to:</b> <ul style="list-style-type: none"> <li>- Ensure healthcare professionals take the lead in initiating conversations with all men</li> <li>- Normalise sexual concerns</li> <li>- Explain that a brief conversation about sex and prostate cancer will take place</li> <li>-</li> </ul>	<b>Includes explanation that:</b> <ul style="list-style-type: none"> <li>- Sex can be a difficult subject which is not easy to talk about, but it is an important part of life</li> <li>- At the end a sheet will be provided with more detailed information and resources</li> </ul>
Assessment	Basic assessment is needed to provide tailored support <b>Section used to:</b> <ul style="list-style-type: none"> <li>- Ask about treatment type</li> <li>- Stage of treatment</li> <li>- Relationship status</li> </ul>	<b>Section asks three questions including:</b> Have you had any of the following treatments? <ol style="list-style-type: none"> <li>1. Radiotherapy</li> <li>2. Hormone therapy</li> <li>3. Surgery</li> <li>4. Combined radio and hormone therapy</li> </ol>
Support	There are many sexual side-effects of treatment but also things that can help <b>Section used to:</b> <ul style="list-style-type: none"> <li>- Provide information on expected sexual challenges</li> <li>- Acknowledge sex life will change</li> <li>- Give brief advice on... What can be done Widening understanding of sex</li> </ul>	<b>Section provides advice (based on treatment) including:</b> List of possible side-effects and some ideas to help. <b>For example: Hormone side-effect 1:</b> Less interest in having sex <b>Advice:</b> <ul style="list-style-type: none"> <li>- The treatment affects the level of testosterone in your body</li> <li>- This has an effect on your sex drive</li> </ul>

		<ul style="list-style-type: none"> <li>- Even if you have less sex drive, you can still feel pleasure</li> </ul> <p><b>And gives other advice on:</b></p> <ul style="list-style-type: none"> <li>- need to think about sex in new ways, try new things and have patience and persistence</li> <li>-</li> </ul>
Sign-posting	<p>After providing essential support need to signpost to other services</p> <p><b>Section used to:</b></p> <ul style="list-style-type: none"> <li>- Point towards additional resources or services</li> </ul>	<p><b>Section includes provision of printed sign-posting sheet including:</b></p> <ul style="list-style-type: none"> <li>- Online self-management resource</li> <li>- Other information and support resources to address sexual challenges</li> <li>- Useful tips and exercises</li> </ul>

**Figure 2. Screen shots showing pages from the ‘Engagement’ and ‘Support’ sections of the tablet-based EASSi tool**



All healthcare professionals received standardised 30-minute familiarisation and training period in use of the tool. During the evaluation, researchers working at each clinical site [CF and JC] set up the tablet (a 9-inch screen Samsung Galaxy Tab A android tablet) prior to each patient appointment. They then entered a unique, non-identifiable study identification and gave the tablet to the healthcare professional. Consecutive patients from clinic lists at four primary and secondary care sites within three NHS Trusts in Northern Ireland and Scotland were identified. The EASSi tool was then used as part of a discussion about sexual wellbeing issues following treatment. Healthcare professional completed the brief survey at the end of the tool immediately after each use. Patient participants were provided with a pack containing an evaluation survey and a stamped addressed envelope for return and were asked to return the survey within one week of the appointment.

## **Analysis**

Quantitative data consisted of programme usage, and the survey on usability and usefulness completed by healthcare professionals. In addition, patients completed surveys which also included questions on usability and usefulness, as well as on sexual wellbeing attitudes and beliefs. Survey responses were based on four or nine-point Likert scales indicating level of agreement with each statement or question. Data were imported into SPSS Statistics for Windows version 25 [33] which was used to perform a descriptive analysis.

Qualitative data were gathered from follow-up, telephone or face-to-face interviews conducted in quiet, non-clinical rooms within a hospital setting. Semi-structured interview schedules were developed based on previous research [34]. These consisted of open-ended questions focused on exploring experience of using the EASSi tool. Interviews were audio-recorded and transcribed verbatim. Field notes were also recorded. These were summarised to support analysis and interpretation of data and were sent to participants for review on request. Reflexive thematic analysis was used to synthesise data [35]. Feasibility and acceptability were examined using programme usage data (including duration of discussions and pages viewed), as well as responses to survey questions which were reported as mean values and percentage agreement scores. Satisfaction with use of the EASSi tool was assessed using findings from qualitative interviews which explored participant experiences of use.

## **Results**

### **Participant characteristics**



Eight healthcare professionals (three urology and oncology specialist nurses, one wellbeing nurse, two oncology doctors, a general practitioner and a cancer support worker) used the EASSi tool during consecutive patient appointments. For a small number of appointments (5/94: 5.3%) the healthcare professional deemed it unsuitable to use the EASSi tool due to the patient being medically unstable or attending the appointment with a family member (other than a partner). The EASSi tool was therefore used during eighty-nine patient appointments. Of these, 53 were at clinical sites in Northern Ireland (n = 4 primary care; n = 49 secondary care) and 36 were at sites in Scotland (n = 26 secondary care; n = 10 post-treatment wellbeing clinics). Twenty-six patients (29.2%) had surgical treatment only, with the majority having had surgery within the past six months (n=22: 84.6%). Seven patients (7.8%) had or were receiving radiotherapy while nine (10.1%) were on ongoing hormone therapy only. The remainder (n=47: 52.8%) had or were receiving combined radiotherapy and hormone therapy. Most patients reported having had no previous sexual care discussions with a healthcare professional (n=52: 58.4%). The majority had a partner (n=83: 93.2%).

**Table 1: Participant demographics [healthcare professional and patient]**

<b>Healthcare professional participant (by type and setting)</b>				
<b>Primary care</b>		<b>Secondary care</b>		
<b>General Practitioner (1)</b>		<b>Urology/Oncology specialist nurse (3)</b>	<b>Consultant oncologist (2)</b>	<b>Wellbeing/Support worker (2)</b>

<b>Patient participants (by treatment type)</b>			
<b>Prostatectomy</b>	<b>Radiotherapy</b>	<b>Hormone treatment</b>	<b>Combined therapy [Radiotherapy &amp; Hormone treatment]</b>
<b>26 (29.2%)</b>	<b>7 (7.8%)</b>	<b>9 (10.1%)</b>	<b>47 (52.8%)</b>

### Quantitative findings

Surveys completed after use (n=89 appointments) indicated that healthcare professionals viewed the EASSi tool as being valuable for helping to talk about sexual wellbeing (mean = 7.7/9: SD: 1.3; 91.1% agreement), and for providing relevant information to the patient (Mean = 7.1/9: SD: 1.5; 92.1% agreement). The tool was also viewed as simple to use (mean = 8.3/9: SD: 0.9; 97.7% agreement). Thirty patients did not return their postal surveys and evaluation data were therefore available for 59 (66%) of the 89 patients who took part in a sexual wellbeing discussion using the EASSi tool. Patient surveys also indicated that the tool was seen as helping the sexual wellbeing discussion (3.4/4: SD: 0.8; 84.6% agreement) and providing relevant information (3.3/4: SD: 0.7; 85.0%

agreement). While free text comments made by healthcare professionals and patients also indicated that the EASSi tool was seen as useful, there were differing perspectives. For example, after some appointments, healthcare professionals reported that the tool was less useful as the patient was ‘not concerned’ about sexual issues; whereas patients (commenting on the same appointment) were typically more positive, stating how valuable the conversation was (See Table 1). This was further supported by other data from the surveys which indicated that patients agreed with the statement that talking about sexual wellbeing was important to them (3.5/4: SD: 0.5; 87.5% agreement). The additional survey questions around sexual attitudes and beliefs identified that patients disagreed with the statement that they were uncomfortable discussion sexual wellbeing during appointments (1.8/4: SD: 1.4; 45.5% agreement) (See **Table 2**). The mean duration of conversations which took place using the EASSi tool was 6.01 minutes (SD: 2.91), ranging from 2.62 to 11.74 minutes. The greatest amount of time was spent in the ‘Support’ section (3.32 minutes; SD 1.12), with 1.03 minutes (SD: 0.74) spent in the ‘Engagement’; 0.59 minutes (SD: 0.33) in ‘Assessment’ and 1.23 minutes (SD: 0.74) in ‘Sign-posting’. Approximately two side-effect pages were viewed during each use, however this number ranged from 0 to 6. The most frequently viewed side-effect pages were on ‘loss of erections’ and ‘loss of interest in sex’. No technical issues with use of the tablet were identified during use.

**Table 2. Examples from individual appointments demonstrating where the perspectives of healthcare professionals and patients on ‘usefulness’ of the EASSi tool differed or agreed**

Healthcare professional views on ‘usefulness’ of discussion	Patient views on same discussion	Views differed [-] or agreed [+]
<p><i>‘... patient and his wife expressed they were not concerned about absent sexual function’</i></p> <p>[Clinical Nurse Specialist, Uro-oncology]</p>	<p><i>‘I read through the information on the tablet and found it informative’</i></p> <p>[6 months post radiotherapy, on ongoing hormone therapy, has a current partner]</p>	[-]
<p><i>‘... patient was keen to focus on fatigue and emotions rather than sexual function’</i></p>	<p><i>‘it was useful finding out about side-effects on your sex life in general, including the information on erectile dysfunction’</i></p>	[-]

[Clinical Nurse Specialist, Surgical Oncology]	[less than 6 months post radiotherapy, on ongoing hormone therapy, no current partner]
<i>'... patient was not sexually active and not really concerned about sex life at all'</i>	<i>'dealing with the nurse about sex was far more informative and helpful than dealing with the doctor. I could have done with this type of appointment when first diagnosed'</i>
[Clinical Nurse Specialist, Uro-oncology]	[more than 6 months post radiotherapy, on ongoing hormone therapy, has a current partner]
<i>'... they were not concerned. They were able to get erections, with dry orgasms'</i>	<i>'.. it made the discussion easier, especially around lack of sex drive and the problems resulting from treatment. The conversation could have actually been longer'</i>
[Clinical Nurse Specialist, Urology]	[more than 6 months post radiotherapy, on ongoing hormone therapy, has a current partner]
<i>'... it was very useful, it made discussing the topic easier and covered more depth and detail. Very easy to discuss delicate area'</i>	<i>'.. it helped with understanding the positives of aftercare after prostate cancer and with knowing there is good support after surgery. The info provided was helpful'</i>
[General practitioner]	[more than 6 months post-surgery, has a current partner]
<i>'... it prompted me to suggest getting more advice from the GP and ask about a trial of a PDE5 inhibitor'</i>	<i>'... getting the tablet explained was good, it helped a lot'</i>
[Clinical Nurse Specialist, Uro-oncology]	[less than 6 months post radiotherapy, has a current partner]
<i>'...This gentleman was very open to the discussion and use of the technology to assist the conversation.</i>	<i>'... having read all the literature given to me at the start (several times) I knew what to</i>
	[+]

Made conversation easier. He recognised himself in the issues presented'	He expect but it is helpful to discuss where you are and to set yourself some goals'
[Nurse, Oncology]	[less than 6 months post radiotherapy, has a current partner]

**Table 3. Mean and percentage agreement scores for statements exploring patient sexual attitudes and beliefs**

Question	Mean score /4* (SD)	Mean % agreement
I understand how my treatment for prostate cancer might affect my sexual wellbeing	3.5 (1.1)	89.0
I am uncomfortable talking about sexual issues with healthcare professionals	1.8 (1.4)**	45.5
Healthcare professionals should make time to discuss sexual wellbeing with me	3.2 (1.2)	80.3
I feel confident that healthcare professionals have the ability to address my sexual concerns	3.4 (1.1)	84.7
Discussing sexual wellbeing is essential to my health outcomes	3.1 (1.3)	77.5
Some healthcare professionals are more comfortable talking about sexual issues with me than others	2.1 (1.2)	52.7
I expect healthcare professionals to ask me about my sexual concerns	3.2 (1.3)	79.7

\* [1] = Strongly Disagree; [2] = Disagree; [3] = Agree; [4] = Strongly Agree

\*\* indicates disagreement with statement

## **Qualitative findings**

Follow-up semi-structured interviews were held with all eight healthcare professionals who used the tool and with a randomly selected sample of men (n=10). Interviews lasted approximately one hour. Analysis identified three key themes around use of the EASSi tool.

### **Theme 1: Moving from optional to routine conversations**

#### **Healthcare Professionals**

Healthcare professionals acknowledged that using the EASSi tool increased the frequency with which they discussed sexual wellbeing and that it had an immediate positive impact by enabling easier initiation of discussions with a wider group of patients, including those they might not have conversations with if not using the tool. They also observed that conversations were associated with less awkwardness than they had expected. While some felt there were still men for whom it would be inappropriate to discuss sexual wellbeing, it was reflected upon by others that this represented a degree of ‘gatekeeping’ which could be used as a mechanism to avoid initiating conversations. Healthcare professionals found the purposeful design of the tool helped to ‘manage’ the conversation and provided a mechanism to direct the conversation, ensuring greater consistency and leading to a less ‘ad-hoc’ approach when discussing sexual concerns with patients.

#### **Patients**

Patients welcomed the discussion, stating how it was presented in a comfortable, professional manner. Patients recognised how the role of the partner was acknowledged using the tool. They also stated that the tablet format was straightforward, and they valued the limited words on screen.

*“actually, it was very easy to follow, just a few words on each screen... we could stop and discuss anything at any time point” (Patient)*

### **Theme 2: Improving depth of conversations and support provided**

#### **Healthcare Professionals**

Healthcare professionals found that the tool enhanced conversations and facilitated a ‘higher level’ of patient involvement. It was acknowledged that before using the EASSi tool, sexual issues were often not discussed during appointments, or were only addressed superficially by providing limited information on erectile dysfunction.

Healthcare professionals described how a greater ‘depth’ of information was provided, including simple but clear information on how patients’ sexual lives could be impacted and practical advice on how to manage these issues. Expectations around recovery were addressed and a wider understanding of intimacy was introduced, moving away from focus on erectile dysfunction only.

*“without using [it] today the value of the consultation would have been hugely inferior” (Consultant Urologist)*

Some healthcare professionals described how discussions were ‘collaborative’ and provided more than just delivery of information. The pages outlining treatment side-effects were seen as being the most interactive element, introducing an opportunity for patients to ‘take the lead’ in identifying side-effects of interest to them. Following the first use, healthcare professionals reported becoming more confident using the tool, integrating it into practice, sharing the screen with patients and adapting the content to suit their own communication style. There were practical issues reported. For example, some men did not have their glasses with them or were reluctant to read the screen. Such issues were often compensated for by the healthcare professional taking a greater lead in the discussion.

The ‘Sign-posting’ pages and accompanying printed hand-out was regarded as an important component by healthcare professionals. Its value was seen in terms of its ability to direct patients towards resources appropriate to their needs and advice to ‘get started’. It was also seen as a useful ‘prompt or reminder’, reinforcing key messages from the discussion.

## **Patients**

Patients reported that conversations were useful and straightforward. For some it was the first meaningful discussion about sexual consequences of treatment.

*“apart from before treatment when I was told that my erections would go, nobody has mentioned the sex thing. After chatting to the nurse last Friday using the computer, I was able to better understand why I was feeling so different” (Patient)*

Some reported that the tool provided a ‘sense of control’ by selecting information that was most relevant to them.

*“I could press what buttons I wanted...I never would have asked out loud about dry orgasms!” (patient)*

Others indicated that they felt comfortable just listening to the healthcare professional.

*“sex is not something that bothers me at the moment but I’m glad it was mentioned, and I think it should be talked about” (patient)*

### **Theme 3: Normalising sexual wellbeing issues in routine practice**

#### **Healthcare Professionals**

Healthcare professionals described how the EASSi tool and discussing sexual wellbeing routinely had alerted them to how important sexual wellbeing care is. They described how discussions being a standard aspect of care might result in men being more comfortable with initiating future discussions. Examples of this given included patients being more able to seek out further information (from the sign-posting sheet) or discuss issues with other healthcare professionals, even after active treatment.

*“it might not be right now, but they now know that they can talk about it with you” (Specialist Oncology Nurse)*

For more experienced clinicians the EASSi tool was regarded as a way of embedding sexual wellbeing conversations into routine practice. Having used the tool with several patients, one Consultant Urologist stated:

*“providing information about sexual care simply needs to be something that everyone in the clinic just knows and that we do it as routine”*

#### **Patients**

Overall, patients felt the tool helped ‘normalise’ sexual issues, treating the topic in the same way as other symptoms. They also felt reassured that their experiences were not unique and were more common than they previously thought.

#### **Discussion**

## **Principal Findings**

This study evaluated a systematically developed tool designed to facilitate and structure sexual wellbeing discussions in prostate cancer care. The tablet-based EASSi tool was used as part of sexual wellbeing conversations in primary and secondary care settings. Overall, healthcare professionals and patients found the tool to be acceptable, appropriate and were satisfied with its use during appointments. It was found to facilitate brief but meaningful discussions which were feasible as part of routine appointments by providing a ‘standardised’ mechanism to initiate discussions, ensuring sexual wellbeing was consistently raised as a topic. It was also reported that the tool was useful for improving overall communication around sexual wellbeing through provision of fundamental information and support tailored to treatment and relationship status. Healthcare professionals and patients did have contrasting perspectives around need for use of the tool. There was evidence that some healthcare professionals may have underestimated and downplayed the value of the sexual wellbeing discussions to patients, who regarded the discussions as valuable and important. Patients also highlighted some regret that they had not had similar discussions prior to or earlier in treatment. While there are valid clinical reasons why a sexual wellbeing discussion might not take place during an appointment, for example, high levels of patient distress or medical instability; ‘gate-keeping’ or assumptions about readiness or willingness to discuss sexual issues can lead to patients not receiving appropriate information and support [36]. Ensuring that discussions occur routinely should be an important part of supporting patients to manage alterations to sexual function and expectations around recovery [37,38].

## **Strengths and limitations**

Particular strengths of the EASSi tool were that it was concise and simple to use; included an engagement section to initiate conversations in a standard manner that limited potential embarrassment; used ‘non-sensitive’ language throughout and provided support based on individual need. Onward referral to other more specialist services included within the ‘Sign-posting’ section, alongside other, readily accessible support options was also seen as valuable. Another perceived strength of the tool was its flexibility, with scope to facilitate a brief conversation or be used as part of a more involved discussion. A limitation of the study is that the perspectives of the 30 patients (33.7%) who did not return an evaluation survey after the appointment are unknown.

## **Study Implications**



This evaluation provides initial support for use of the EASSi tool in practice. Findings indicated that the tool was appropriate and acceptable for use and promoted delivery of routine sexual care for men with prostate cancer. The EASSi tool incorporates components aimed at ensuring discussions are more routine and that essential support is provided as part of prostate cancer care. These techniques include changes to the physical environment (the tablet device itself) as well as delivery of appropriate information and the use of patient prompts in the form of the printed handout used to reinforce key messages and point to effective evidence-based self-management resources. The theoretical underpinning of the EASSi tool may be similar to models such as the 5 A's approach (ask, assess, advise, agree, assist) which has been used as a framework to initiate, standardise and guide brief behaviour change interventions [39]. **The tool can be used across settings and without specific training or expertise in sexual care counselling. This could include pre-treatment consultations to better understand the impact on sexual wellbeing, aid decision making, and reduce risk of regret [9].** The tool was also identified as being useful for addressing barriers to sexual wellbeing discussions and supporting healthcare professionals to initiate discussions by facilitating brief discussions that normalised sexual issues and provided patients with essential support. However, findings suggest that healthcare professionals may under-estimate how important sexual wellbeing discussions are for patients. Additional research should be conducted to help healthcare professionals explore their views on sexual issues and overcome barriers to discussing sexual wellbeing with patients. Further work will also be conducted evaluating the effectiveness of using the tool in cancer care settings.

## **Conclusions**

The EASSi tool may provide a practical format to guide routine sexual wellbeing discussions in clinical practice. The tool also includes tangible take home messages for prostate cancer survivors in the form of a printed 'sign-posting' sheet. Use of the tool in practice may promote increased engagement around sexual wellbeing to ensure fundamental support is provided to men and their partners. This could potentially address current gaps in the lack of routine provision of sexual wellbeing support for men living with prostate cancer.

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### **Authors' contributions**

EMcC, KP, RM, MS, ST, SJ and MK developed the original proposal for the study. EMcC, CF, NB and SOC drafted and revised additional versions of the intervention content. EMcC, CF, RM, and JC conducted all qualitative interviews. CF and JC were responsible for recruitment and study procedures at the clinical sites. SOC was responsible for data analysis and interpretation and drafted the initial manuscript. All authors revised the manuscript for important intellectual content and approved the final version.

### **Conflict of interest**

The authors declare they have no competing interests.

### **Ethics approval and consent to participate**

Ethical approval for the study was provided via the Office for Research Ethics Committees Northern Ireland (ORECNI) (Reference number: 17/NI/014). All participants gave written, informed consent before participation.

### **References**

1. Miller KD, Nogueira L, Mariotto AB, Rowland JH, Yabroff KR, Alfano CM, et al. Cancer treatment and survivorship statistics, 2019. *CA Cancer J Clin.* 2019; Jun 11 [Epub ahead of print]
2. Pishgar P, Ebrahimi E, Saeedi Moghaddam S, Fitzmaurice C, Amini E, et al. Global, Regional and National Burden of Prostate Cancer, 1990 to 2015: Results from the Global Burden of Disease Study 2015. *J Urol.* 2018;199(2):1224-1232.
3. Donovan JL, Hamdy FL, Lane JA, Mason M, Metcalfe C, Walsh E, et al. Patient-Reported Outcomes after Monitoring, Surgery, or Radiotherapy for Prostate Cancer. *N Engl J Med.* 2016;13:1425-1437.

4. Wong MC, Goggins WB, Wang HH, Fung FD, Leung C, Wong SY, et al. Global Incidence and Mortality for Prostate Cancer: Analysis of Temporal Patterns and Trends in 36 Countries. *Eur Urol.* 2016;70(5):862-874.
5. Haahr MK, Azawi NH, Andersen LG, Carlson S, Lund L. A Retrospective Study of Erectile Function and Use of Erectile Aids in Prostate Cancer Patients After Radical Prostatectomy in Denmark. *Sex Med.* 2017;5(3):e156-e162.
6. Gaither TW, Awad MA, Osterberg EC, Murphy GP, Allen IE, Chang A, et al. The Natural History of Erectile Dysfunction After Prostatic Radiotherapy: A Systematic Review and Meta-Analysis. *J Sex Med.* 2017;14(9):1071-1078.
7. Brundage M, Sydes MR, Parulekar WR, Warde P, Cowan R, Bezzak A, et al. Impact of Radiotherapy When Added to Androgen-Deprivation Therapy for Locally Advanced Prostate Cancer: Long-Term Quality-of-Life Outcomes From the NCIC CTG PR3/MRC PR07 Randomized Trial. *J Clin Oncol.* 2015;33(19):2151-7.
8. Downing A, Wright P, Hounsome L, Selby P, Wilding S, Watson E, et al. Quality of life in men living with advanced and localised prostate cancer in the UK: a population-based study. *Lancet Oncol.* 2019;20:436-447.
9. Talvitie AM, Ojala H, Tammela T, Koivisto AM, Pietilä I. Factors related to self-rated health and life satisfaction one year after radical prostatectomy for localised prostate cancer: a cross-sectional survey. *Scand J Caring Sci.* 2019 Mar 13. Epub ahead of print].
10. Ross L, Rottmann N, Andersen KK, Hoybye MT, Johansen C, Dalton SO. Distress after a psychosocial cancer rehabilitation course. Main effects and effect modification in a randomised trial at 12 months of follow-up. *Acta Oncol.* 2015;54(5):735-742.
11. National Institute for Health and Care Excellence. Prostate cancer: diagnosis and management. Clinical guideline [NG131]. May 2019. <https://www.nice.org.uk/guidance/ng131>. Accessed: July 2019.

12. Resnick MJ, Lacchetti C, Penson DF. American Society of Clinical Oncology. Prostate cancer survivorship care guidelines: American Society of Clinical Oncology practice guideline endorsement. *J Oncol Pract*. 2015;11:e445-449.
13. Sporn NJ, Smith KB, Pirl WF, Lennes IT, Hyland KA, Park ER. Sexual health communication between cancer survivors and providers: how frequently does it occur and which providers are preferred? *Psychooncology*. 2015;24:1167-73.
14. Flynn KE, Reese JB, Jeffery DD, Abernethy AP, Lin L, Shelby RA, et al. Patient experiences with communication about sex during and after treatment for cancer. *Psychooncology*. 2012;21:594-601.
15. Ussher JM, Perz J, Gilbert E, Wong WK, Mason C, Hobbs K, et al. Talking about sex after cancer: a discourse analytic study of health care professional accounts of sexual communication with patients. *Psychol Health*. 2013;28(12):1370-90.
16. Almont T, Farsi F, Krakowski I, El Osta R, Bondil P, Huyghe É. Sexual health in cancer: the results of a survey exploring practices, attitudes, knowledge, communication, and professional interactions in oncology healthcare providers. *Support Care Cancer*. 2019;27(3):887-894.
17. Albaugh J.A., Sufrin N., Lapin B.R. Life after prostate cancer treatment: a mixed methods study of the experiences of men with sexual dysfunction and their partners. *BMC Urol*. 2017;17:45.
18. Annerstedt CF, Glasdam S. Nurses' attitudes towards support for and communication about sexual health-A qualitative study from the perspectives of oncological nurses. *J Clin Nurs*. 2019 Jun 4. [Epub ahead of print]
19. Gilbert E, Perz J, Ussher JM. Talking about sex with health professionals: the experience of people with cancer and their partners. *Eur J Cancer Care (Engl)*. 2016;25:280-293.
20. Julien JO, Thom B, Kline NE. Identification of barriers to sexual health assessment in oncology nursing practice. *Oncol Nurs Forum*. 2010;37:E186-190.

21. Speer SA, Tucker SR, McPhillips R, Peters S. The clinical communication and information challenges associated with the psychosexual aspects of prostate cancer treatment. *Soc Sci Med.* 2017;185:17-26.
22. Krouwel EM, Nicolai MP, van Steijn-van Tol AQ, Putter H, Osanto S, Pelger RC, et al. Addressing changed sexual functioning in cancer patients: A cross-sectional survey among Dutch oncology nurses. *Eur J Oncol Nurs.* 2015;19:707-15.
23. Leonardi-Warren K, Neff I, Mancuso M, Wenger B, Galbraith M, Fink R. Sexual Health: Exploring Patient Needs and Healthcare Provider Comfort and Knowledge. *Clin J Oncol Nurs.* 2016;1:E162-E167.
24. O'Connor SR, Connaghan J, Maguire R, Kotronoulas G, Flannagan C, Jain S, et al. Healthcare professional perceived barriers and facilitators to discussing sexual wellbeing with patients after diagnosis of chronic illness: A mixed-methods evidence synthesis. *Patient Educ Couns.* 2019; 102(5):850-863.
25. Zhou ES, Bober SL, Nekhlyudov L. Physical and emotional health information needs and preferences of long-term prostate cancer survivors. *Patient Educ Couns.* 2016;99:2049–2054.
26. Lenzen SA, Daniëls R, van Bokhoven MA, Van der Weijden T, Beursjkens A. Development of a conversation approach for practice nurses aimed at making shared decisions on goals and action plans with primary care patients. *BMC Health Serv Res.* 2018;18:891.
27. Vromans RD, van Eenbergen MC, Pauws SC, Geleijnse G, van der Poel HG, van de Poll-Franse LV, et al. Communicative aspects of decision aids for localized prostate cancer treatment - A systematic review. *Urol Oncol.* 2019;37:409-429.
28. Singy P, Bourquin C, Sulstarova B, Stiefel F, et al. The impact of communication skills training in oncology: a linguistic analysis. *J Cancer Educ.* 2012;3: 404-408.

29. Yardley L, Ainsworth B, Arden-Close E, Muller I. The person-based approach to enhancing the acceptability and feasibility of interventions. *Pilot Feasibility Stud.* 2015;26;1:37
30. McCaughan E, Parahoo K, Flannagan C, Maguire R, Connaghan J, et al. Development of a conceptual framework to improve sexual wellbeing communication in routine prostate cancer care. *Patient Educ Couns.* 2020 Jan 20. pii: S0738-3991(20)30041-0. [Epub ahead of print]
31. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care.* 2007;19(6):349-357.
32. LifeGuide Software, University of Southampton. <https://www.lifeguideonline.org>. Accessed: May 2018.
33. IBM Corp. Released 2017. IBM SPSS Statistics for Windows, Version 25.0. Armonk, NY: IBM Corp.
34. McCaughan E, McKenna S, McSorley O, Parahoo K. The experience and perceptions of men with prostate cancer and their partners of the CONNECT psychosocial intervention: a qualitative exploration. *J Adv Nurs.* 2015;71:1871-1882.
35. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology,* 2006;3(2):77-101.
36. Canzona MR, Ledford CJW, Fisher CL, Garcia D, Raleigh M, Kalish VB. Clinician barriers to initiating sexual health conversations with breast cancer survivors: The influence of assumptions and situational constraints. *Fam Syst Health.* 2018;36(1):20-28
37. Almont T, Farsi F, Krakowski I, El Osta R, Bondil P, Huyghe É. Sexual health in cancer: the results of a survey exploring practices, attitudes, knowledge, communication, and professional interactions in oncology healthcare providers. *Support Care Cancer.* 2019;27(3):887-894.

38. Carrier J, Edwards D, Harden J. Men's perceptions of the impact of the physical consequences of a radical prostatectomy on their quality of life: a qualitative systematic review. *JBIC Database System Rev Implement Rep.* 2018;16(4):892-972.

39. Glasgow RE, Emont S, Miller DC. Assessing delivery of the five 'As' for patient-centered counseling. *Health Promot Int.* 2006;21(3):245-55.