

USER EVALUATION OF WEB-BASED INFORMATION FOR MEN WITH INCONTINENCE AFTER TREATMENT FOR PROSTATE CANCER

INTRODUCTION Long-term urinary incontinence (UI) is a common consequence of radical prostatectomy (RP) (1) that can have a serious adverse impact on men's lives leading to isolation, depression (2) and, sometimes, decision regret (3). Men may be inadequately prepared for managing their indwelling catheter and for the incontinence that is common after its removal.

Following interviews with 35 men and together with a panel of nine public patient representatives, we developed a new **Prostate Continence website** which offers multi-media resources (product selector tool, patient interviews and product use videos, PDFs and illustrations) to help men to prepare for having a catheter after surgery and for short-term, and possibly long-term, UI. We report here a study to evaluate that website.

AIMS OF THE STUDY To evaluate the value and utility to men of a novel prostate continence website and to identify areas for further improvement:

- To determine, describe and evaluate men's views about the website;
- To evaluate the comprehensiveness of the website and identify any gaps;
- To test the functionality of the website (on a PC) i.e. ease of navigation through the site and new functions e.g. suppliers' database;
- To identify further opportunities to improve the information and functionality required.

STUDY DESIGN & METHOD A mixed method study using:

- Self-completion questionnaires designed for the study and partially derived from the validated Judge questionnaire (4) about health information-seeking;
- Semi-structured interviews about the content and utility of the website, its comprehensiveness, ease of use and areas for further improvement;

We observed the men navigating the website which we recorded using Echo 360 personal capture software (5).

Sample: Up to 16 men with current or recent experience of incontinence post RP who were not involved in the development of the website. Recruitment was through prostate cancer support groups and urology outpatient clinics.

Data analysis:

Questionnaire data (quantitative): Descriptive statistics.

Interview data (qualitative): Transcripts of the audio recordings from the observations and thematic analysis from the semi-structured interviews.

RESULTS

Twelve men (3 x 40-59yrs; 8 x 60-7yrs; 1x non-responder) were recruited of whom nine had UI daily (n=3) or day and night (n=6) following either robotic (n=9) or laparoscopic (n=3) RP (mean length of time since onset 28 months). Subsequent to their RP, three men had also received an artificial urinary sphincter (AUS) to treat their UI. All those currently incontinent, including one man with an AUS, regularly used pads as their main method of containment. Although all were regular internet users for emails, shopping and information-seeking, there was a wide range of skill demonstrated when moving around the website.

Participants' views about the website

Questionnaire responses

All men found the website to be *very helpful* (11/12) or *quite helpful* (1/12) and all of them would recommend the website to others. Detailed responses in Figure 1.

Figure 1: How useful do you think the website would have been for you when:	Very helpful	Quite helpful	Neither helpful nor unhelpful	Unhelpful	Very unhelpful
When preparing for bladder leakage?	8	4	0	0	0
Looking after your catheter in hospital? (n=10)	5	4	1	0	0
Looking after your catheter at home? (n=11)	9	2	0	0	0
Having your catheter removed? (n=10)	7	3	0	0	0
Coping with incontinence in the first days/weeks after treatment?	10	2	0	0	0
Coping with incontinence long-term? (n=11)	8	3	0	0	0

Interviews

Example quotes illustrating typical views are shown in Figure 2.

Men agreed that having the website available to them prior to their surgery would have been helpful. Having the comprehensive information in one place and in a user friendly format would have helped allay fears about what to expect after surgery:

"Forewarned is forearmed and the information contained takes away some of the fear and allows you to think about relevant questions you might need to ask. It helps you to deal with your situation more easily and confidently"

"Prepares them removing the unknown and knowing the questions to ask of the professionals."

Men were asked how the website might have helped them to prepare for post-operative recovery, catheter care and post-surgical incontinence. They were also asked about specific aspects of the website.

Figure 2: Themes from qualitative analysis with selected comments:

Product information – covering what, how and where:

"I didn't know there were so many products for urinary and bowel incontinence. I hope I won't need them - I had a prostatectomy and am mainly over incontinence but I will need radiotherapy and I am better informed on the range of incontinence products I might need."

Hearing other men's experiences:

"Reassurance that I am 'typical'", "hearing other men's stories - the emotional and psychological impact)".

Catheter-related procedures, tips and practical product use all in one place:

"Detailed descriptions both verbally and visually of procedures and products"

Quantity of information:

"There may be a thought that there is too much information but it's better than having to go to different sites to gain all this information".

Need for improvement to navigation and links:

"I think it's all useful and needs to be there - just think about the navigation, the use of links and the amount of text."

INTERPRETATION OF RESULTS The evaluation has highlighted strengths and weaknesses of this website which was co-produced with men and provided data that validated the user content. The evaluation also describes some weaknesses that could be rectified. Of particular value were the 'real life' stories and videos which were perceived as indicating that they were 'not the only ones'. Interestingly some men emphasised the need for information 'at the right time' – that might not always be just before surgery when they are often focussing on their cancer diagnosis. All men felt it would have been helpful to have had access to the website before their surgery. A study limitation is our presence while the men reviewed the website which may have influenced their responses.

The *Prostate Continence website* (www.prostatecontinence.org) is part of the *Continence Product Advisor* (www.continenceproductadvisor.org) which has >4000 worldwide visitors weekly. Both websites are global resources to which health care professionals (HCP) and men have free access. Improvements to the website relate to ensuring that excess text is removed and sections link correctly. Evaluation of the website for product selection in primary care is currently taking place.

CONCLUDING MESSAGE This evaluation demonstrates that the *Prostate Continence website*, produced in partnership with men, provides comprehensive product information that, combined with media resources, helps men to feel less isolated and more prepared to manage their catheter and urinary incontinence after RP. This resource may help HCPs provide support for men before and after surgery.

BROAD CATEGORY: Continence Care Products / Devices / Technologies.

KEY WORDS: Male, incontinence, rehabilitation.