

Institution: Leeds Metropolitan University
Unit of Assessment: 4a
Title of case study: Meeting the information needs of men with penile cancer
<p>1. Summary of the impact</p> <p>Men with penile cancer often feel very isolated as they are reluctant to talk to others about their condition, and as it is so rare, they do not encounter others who have experienced it. Branney and colleagues' work has produced a resource, available through the Health Talk Online website, for men and their families: http://www.healthtalkonline.org/Cancer/Penile_Cancer.</p> <p>Men with penile cancer are routinely signposted to this resource. An exhibition of the project's findings has helped to raise awareness of the condition in the general public. By increasing patient information support, clinician insight and men's awareness of the condition, this research has improved the quality of life of men with penile cancer.</p>
<p>2. Underpinning research</p> <p>Branney, working with the Centre for Men's Health at Leeds Metropolitan University, has undertaken a programme of work exploring how men engage with healthcare, how they experience threats to their health, and how to improve their experience of healthcare. Branney (Senior Research Fellow, 2009-12, Senior Lecturer in Psychology, 2012+) provides health psychology expertise to the team, and alongside Gough, focuses on innovating the use of qualitative methods in health-related research.</p> <p>The research began with Branney piloting a participatory action research methodology in which men with a health condition could themselves develop an interview topic guide to explore experiences of living with it, their choice of treatment and the extent to which their healthcare and information needs are met by existing provision. Branney obtained funding to run a feasibility study of using this approach with men with prostate cancer (a feasibility study of patient-led interviews on the experiences of choosing treatment after diagnosis of localised prostate cancer, funded by the Leeds Teaching Hospitals Charitable Foundation in 2009, £9,308). This was a collaborative study involving Branney (LMU), Sunjay (Urologist, St James' Hospital) and the Leeds Prostate Cancer Carer Group. The study demonstrated that the approach involving men themselves in the study design could be successful.</p> <p>When disseminating the results of the research to clinicians, discussions highlighted that an area that lacks research is penile cancer. Specifically, there was very little information available for men about the condition and very little information for clinicians about men's perspective about living with the condition and about their treatment options. These discussions led to a successful grant application to explore patient's experiences of this condition and its treatment and to produce an information resource for men and people who care for them (Patients' experiences of penile cancer: understanding and improving experiences of treatment for penile cancer. Research for Patient Benefit Programme, National Institute of Health Research. £172,207, 2010-2012). The prostate cancer feasibility study was used to support the proposed action research approach to producing a resource for men with penile cancer. The research was a collaborative project led by Branney (Leeds Met) and involving Eardley, (Urologist, St. James' University), Bullen (Psychologist, Aberystwyth University), Ziebland (Medical Sociologist, Oxford University), Edwards (Patient & Artist) and White (Professor of Men's Health, Leeds Metropolitan University).</p> <p>The research provided key insights into men's experiences of living with penile cancer, including their diagnosis, telling other people, deciding between treatment options, the impact on their sex</p>

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life, and life post-surgery. One of the findings was that while men do not feel confident that they can talk to others about their cancer, there are major benefits to their quality of life when they do so. It was apparent that there was a need for a resource to help men talk about penile cancer. The research also highlighted that while the treatment of penile cancer can be more conservative if it is diagnosed earlier (e.g. a local excision rather than an amputation) men often delay seeking help because they are unaware of the symptoms.

3. References to the research

Branney, P., Jain, S., Hiley, C., Flowers, P., & White, A. K. (2009). Choosing health, choosing treatment: patient choice after diagnosis of localised prostate cancer. *Urology*, 74(5), p. 968-971 - <http://dx.doi.org/10.1080/08870446.2010.502762>

Branney, P., Witty, K., & Eardley, I. (2011). Patients' experiences of penile cancer. *European Urology*, 59(6), 959-961. - <http://dx.doi.org/10.1016/j.eururo.2011.02.009>

Branney, P., (2012). What is the UK Gender Duty and why is it linked to men's health? *Critical Public Health*, 2(22), 121-126. <http://dx.doi.org/10.1080/09581596.2011.646955>

Branney, P., Witty, K., Bagnall, A.-M., South, J., & White, A. K. (2012). 'Straight to the GP; that would be where I would go': an analysis of male frequent attenders' constructions of their decisions to use or not use health-care services in the UK. *Psychology and Health*, 27(7), 865-880. <http://dx.doi.org/10.1080/08870446.2011.636443>

South, J., Meah, A., & Branney, P. (2012). 'Think differently and be prepared to demonstrate trust': findings from public hearings, England, on supporting lay people in public health roles. *Health Promotion International*, 27(2), 284-294. doi: 10.1093/heapro/dar022

South, J., Meah, A., Bagnall, A.M., Kinsella, K., Branney, P., White, J., & Gamsu, M. (2010). People in public health - a study of approaches to develop and support people in public health roles. Southampton, UK: National Co-ordinating Centre for NHS Service Delivery and Organisation R&D. http://www.netscc.ac.uk/hsdr/files/project/SDO_FR_08-1716-206_V01.pdf

4. Details of the impact

Branney's work to disseminate his research on men's use of healthcare and their treatment decisions to clinicians meant that a very specific healthcare need – information for men on penile cancer – was identified and a project team assembled to address this need. From the start of the project the aim was to produce a resource that could inform men, their families and their clinicians about this condition. While the team initially comprised of clinicians and researchers in Leeds, it was apparent that the resource produced would be of value nationally and so the team was expanded to include Bullen (Aberystwyth), who had done some earlier work on penile cancer, and Ziebland (Oxford), from the research team behind Health Talk Online. Health Talk Online is a resource used by people with the condition, their families and carers and clinicians.

The main output from the project is a resource for Health Talk Online. This includes downloadable videos of 27 men talking about their experiences of penile cancer and an information resource on the condition. The men who participated in the study identified the information they wanted to make available. This included signs and symptoms of penile cancer, the treatment options, recovering from surgery, and some of the concerns that men have such as how to tell other people about their cancer, using the toilet, the effect on sex and relationships, and the impact of surgery on men's sense of masculinity and confidence. This resource was launched in the summer of 2012 and has already received over 237,000 hits and 22,000 views. A launch event took place at the Royal Society on 23/10/12 and was attended by academics, relevant charities and the general public.

To further disseminate the results of this research and increase public awareness of penile cancer Branney and the team produced an art installation that forms a travelling exhibition. This includes quotes from the interviews illustrated by art from one of the patients and grantholders who is also an artist (Edwards). This exhibition has been installed in several venues in the UK:

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- Biannual Conference, International Society of Critical Health Psychology, Bradford University, 22nd-24th July 2013.
- St. James' Hospital, Leeds Teaching Hospitals NHS Trust, 3rd-14th June 2013.
- Aberystwyth University, 22nd-26th April 2013.
- World Cancer Day & the first week of semester 2 teaching, Leeds Metropolitan University, February 4th-8th 2013.
- Aston University, October 26th 2013.

It is typically installed for several days and open for the public to view, sometimes accompanied by a series of presentations.

Branney has also talked about the research on the Radio 4 programme Inside Health. A whole programme was dedicated to Penile Cancer and the work of Branney and his team was central to the programme. This was first broadcast on 24/10/12 and is available on the BBC iplayer. This programme led to further interest in the research, and several articles and editorials have been written that include reference to his research, e.g.

- Ally Fogg, When is it OK for a cancer campaign to be sexy? Comment is Free, The Guardian, Wednesday 24th October, 2013
<http://www.guardian.co.uk/commentisfree/2012/oct/24/cancer-campaign-sexual-hook>
- Making men think about cancer, Yorkshire Evening Post, Wed 7th Nov 2012
- Penile cancer module gives men forum to shout about it, Clinical Focus, Primary Care Today, November/December 2012, p. 31

The beneficiaries of this research are therefore:

- Men with penile cancer who can now access a resource that provides information, answers their questions, helps reduce their feelings of isolation, and helps them talk to others about their cancer. It can also help them talk to their clinicians about their treatment options;
- The families and friends of men with penile cancer who can use the resource to help them talk about the condition and its effects;
- Clinicians, who gain insight into what it is like to be diagnosed with and to live with penile cancer;
- Students (e.g. medical students, nursing students, psychology students) who can visit the website to gain insight into living with this condition.
- Men more generally who are more aware of penile cancer and its signs and symptoms and so may seek help earlier should they have this condition.

5. Sources to corroborate the impact

- Health Talk Online web resource on penile cancer:
http://www.healthtalkonline.org/Cancer/Penile_cancer
- Penile cancer nurse specialist, St James Hospital, Leeds
- Orchid Cancer Charity (the men's cancer charity) has provided the following statement:
"We routinely signpost men with penile cancer to Health Talk Online. It's made a big difference. Penile cancer is such a rare condition that men are not going to meet other men with it. It's particularly useful for men who are having treatment or who are survivors. They can identify with other men who have been diagnosed, been treated and who have got through it."

(Male Cancer Information Nurse, ORCHID)