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**Title:**

Patients' Experiences of Penile Cancer

**Authors:**

Peter Branney<sup>1</sup>, Karl Witty<sup>1</sup>, Ian Eardley<sup>2</sup>,

1. Centre for Men's Health, Leeds Metropolitan University, Queen Square House, 80 Woodhouse Lane, Leeds, LS20 9DT, UK
2. Pyrah Department of Urology, St James University Hospital, Beckett Street, Leeds, LS9 7TF

**Corresponding Author:** Peter Branney; email [p.branney@leedsmet.ac.uk](mailto:p.branney@leedsmet.ac.uk); tel +44(0)1138127679

## **Title: Patients' Experiences of Penile Cancer**

Penile cancer is a rare but destructive disease in western populations. In the UK, penile cancer accounts for less than 1% of all new cases of cancer and less than 1% of deaths due to cancer every year (See Table 1).

INSERT TABLE 1 AROUND HERE

Surgical removal of the cancer is the primary form of treatment. This involves surgical excision of the primary tumour and of involved inguinal lymph nodes. Chemotherapy and radiotherapy are rarely helpful, with their use restricted either to adjuvant use or for palliative treatment of extensive disease. In treating the primary tumour, the standard of care is to provide a surgical cure (ie excising the tumour and a margin of normal penile tissue) while maintaining the function of the penis. The traditional view was that at least a 2cm margin of normal tissue should be removed, but there are recent publications that suggest that more conservative surgery may be safe (1, 2). The advantage of such organ preserving surgery is intuitively advantageous to the patient, in that penile function can be better preserved, but the evidence to support this view is, at present, limited.

## **Quality of Life**

The surgery for penile cancer is technically uncomplicated; hospital stays are short and most patients quickly recover good physical health. Indeed the chances of cure are high, particularly for early stage disease with over 80% of men typically surviving (3). Nevertheless, treatments have long-term and often distressing functional effects. However, to date studies of function in men who have undergone penectomy have typically been small and retrospective. A Norwegian study of 30 men who had been treated for penile cancer assessed sexual function by using a semi-structured interview together with a number of self administered questionnaires (4). Unsurprisingly those patients who had undergone the most radical surgery had the worst sexual function, as evidenced by a reduced interest, severely limited sexual ability, markedly reduced sexual enjoyment and sexual frequency. Those who had undergone radiotherapy or local excision or laser therapy had the best sexual function whilst those patients who had undergone partial penectomy were in an intermediate position. A subsequent Brazilian study explored sexual function in 18 men who had undergone partial penectomy by means of a structured interview and completion of the International Index of Erectile Function (5). Significant reductions in erectile function, orgasmic function, sexual desire and intercourse satisfaction were identified. These two studies, taken together have led to a view that

the more radical the penile surgery, the greater the effect on sexual function, with even partial penectomy having significant adverse effects. A more conservative approach using treatment modalities such as laser therapy, brachytherapy or conservative surgery such as glans resurfacing or glansectomy has recently been advocated (1, 2). While the potential benefits of using a more conservative surgical approach has not been fully evaluated the effects of laser therapy for early stage tumours has been investigated in some detail (6). A third of patients failed to resume sexual activities three years after treatment. Of those who did resume sexual activities, there is a reduction in fellatio and manual genital stimulation with a partner. Nevertheless, when compared to an ad hoc comparison group, these patients are equally satisfied with their overall life, including their sexual life. The literature regarding the effects of penile surgery on voiding function is even more limited. Many men will need to sit down to void. Indeed even those with a penile stump often have difficulty in finding “something to hold on to” (7), while those who have undergone conservative penile surgery may have problems with spraying of the urinary stream. Some men use a funnel in order to minimise spraying of urine at the time of micturition but the extent of the urinary problems, the need for treatment and the effect upon the psyche of the patient are poorly documented in the literature and need further research.

The research on quality of life still leaves many questions, not least of which is the effect of treatments other than laser therapy and partial amputation. Other areas for exploration are the maintenance of sexual satisfaction when sexually inactive, why some sexual activities are maintained whereas other are reduced, and the effects on urinary functioning. If we are to better treat penile cancer, then we need to improve our understanding of patients’ experiences. We are helping to achieve this through a study funded by the UK NHS Research for Patient Benefit programme utilising narrative interviews to explore in depth Patients’ Experiences of Penile Cancer (PEPC; Figure 1).

INSERT FIGURE ONE AROUND HERE

### **Service Changes**

Health service changes, such as those introduced recently in the UK, offer the potential to improve our understanding of both the treatment and the impact of penile cancer. Published in 2002, UK guidelines from the National Institute for Clinical Excellence and Health recommend that penile cancer is managed by specialist supranetwork multidisciplinary teams (Sn-MDTs) that should see at least 25 new patients annually. A ‘supranetwork’ covers a population of at least 3 million people

with surgical procedures and post-operative care restricted to named hospitals. A team includes urological surgeons, clinical oncologists, histopathologists, palliative care representatives, plastic surgeons, radiologists, and nurse specialists.

The implementation of Sn-MDTs in the UK raises questions about if and how service changes impact patients. The creation of specialised and geographically centralised services for a rare disease should create a network of centres that have a critical mass of experience and resources. At the very least, penile cancer Sn-MDTs should be able to standardise the care pathway and provide a consistent protocol-driven level of service and indeed the evidence is that this has been achieved (8). Over the longer-term, Sn-MDTs should contribute to the development of evidence about how to treat penile cancer so that we improve survival.

Given the potential impact of the treatments for penile cancer, Sn-MDTs should be using their critical mass and experience to improve the maintenance of urological function and patients' quality of life. For example, patients' managed under the UK Guidelines want support with urinary function (7). Unfortunately, there is a dearth of research on post-treatment urinary function that could help us decide how best to offer such support. The narrative interview methodology being used in PEPC will allow us to identify such needs.

### **Information sharing**

Carer groups, charities, or friends with experience of similar issues can provide the emotional and practical support throughout the patient journey. As with all who are diagnosed with a rare illness, patients with penile cancer will find a lack of formal and informal support networks that draw upon direct or indirect experience with their cancer, its treatment and long term effects. Even those lucky enough to have a specialist penile cancer team will find a lack of experience in associated health professionals and services, such as with a community continence nurse or primary care practice. The only source of health information about penile cancer that is widely available is a book detailing an individual's experiences through his art (9).

One way of dealing with the lack of support outside specialist teams is to provide good quality information that is accessible via mass media, such as the internet. [Healthtalkonline.org](http://Healthtalkonline.org) (previously [DIPEX.org](http://DIPEX.org), which stood for 'database of patients experiences') is one such website that is built up of over 2,000 interviews on conditions from pregnancy to cancer (10). For each condition, patients are interviewed to form a 'module' on the site that has audio and video clips on the topics that emerged

from the interviews. There are, for example, modules on prostate and testicular cancer and a user can search for themes that cut across different clinical areas, such as incontinence. PEPC will create a penile cancer module. Nevertheless, we must avoid limiting ourselves to the internet. We can, for example, develop training resources for health professionals, involve journalists, and produce leaflets for patients.

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Table 1: new registrations and mortality in England and Wales for penile cancer

	2002*	2003	2004	2005	2006
New registrations for malignant neoplasm of the penis (C60)	337 (.25%)	319 (.28%)	331 (.28%)	389 (.33%)	415 (.34%)
All new (male) cancer registrations: (C00-C97 exclud. C44 – non-melanoma skin cancer)	136,931 (100.00%)	112,732 (100.00%)	117,805 (100.00%)	119,625 (100.00%)	121,564 (100.00%)
Mortality for malignant neoplasm of the penis (C60)	95 (.13%)	104 (.15%)	69 (.10%)	89 (.13%)	
All (male) malignant neoplasms mortality (C00-C97)	71,030 (100.00%)	70,814 (100.00%)	70,573 (100.00%)	70,394 (100.00%)	

\* Data are presented from 2002 when the UK National Institute for Clinical Excellence recommended that cancer should be managed by specialist supranetwork multi-disciplinary teams



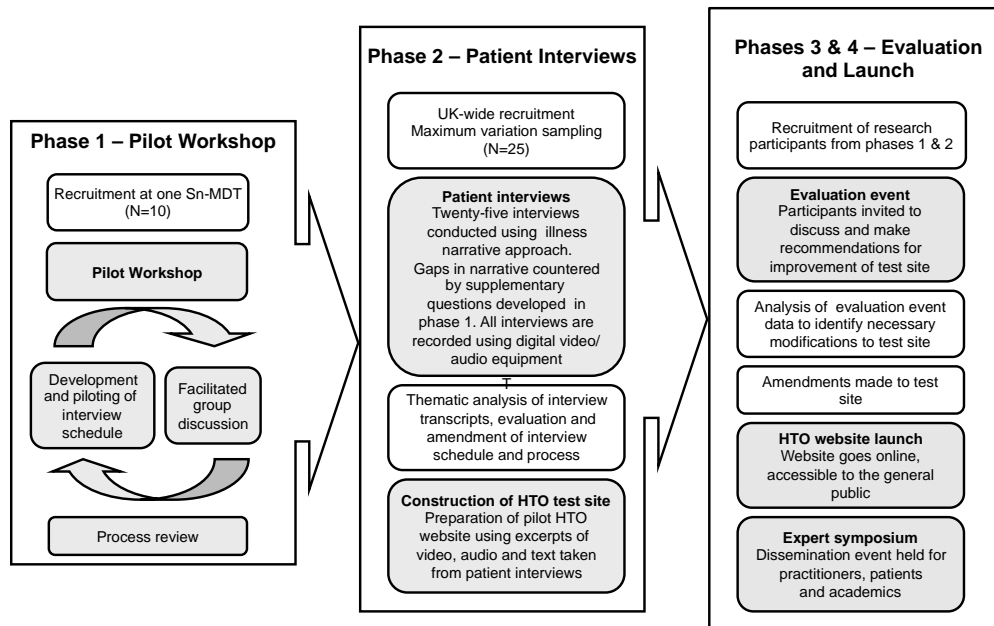


Figure 1