

The Patient Experience of Penile Cancer – A Patient Led Survey



December 2024

INTRODUCTION



The aim of this study is to get a more complete understanding of the experience of patients, the services they can access and the support they are offered. This information can then be used to encourage the development of further support globally for anyone affected by penile cancer.

John Osborne

BACKGROUND

Around 36,000 men will be diagnosed globally each year with penile cancer. It will often have a huge physical and psychological impact on well-being and quality of life. In addition, awareness of the disease is low, diagnosis may be delayed, and support during and after treatment is inconsistent, with long term physical and psychological outcomes poorly understood.

In June 2024, patient advocate John Osborne created a comprehensive anonymous survey for men who had been treated for penile cancer. A survey created by a former patient, for patients and designed to obtain a global snapshot of the patient journey.

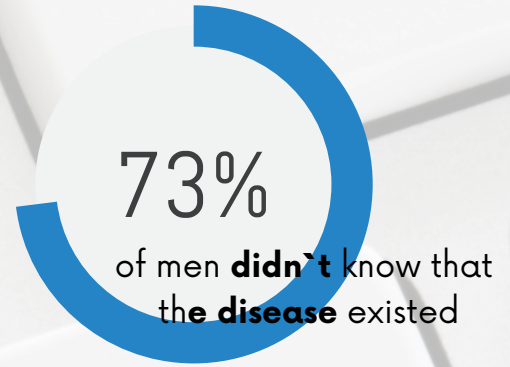
Split into four sections covering disease awareness, route to diagnosis, treatment, and long term survivorship, the survey is supported by the European Association of Urology [Patient Office](#) , [Orchid](#) and [eUROGEN](#).

It has initially been distributed in English, via UK patient networks and the world's largest (online) [penile cancer support group](#). So far 67 men have completed the survey.

This current report is based on the responses of 33 individuals diagnosed between 2022 and 2024 in the UK, and highlights key areas of the treatment journey that are recognised as problematic.

Awareness

Ninety percent of men in the survey who were diagnosed prior to 2022, didn't know that penile cancer existed. Awareness of the disease appears to have improved over the last few years in the UK, which may reflect third sector initiatives, awareness and education campaigns.



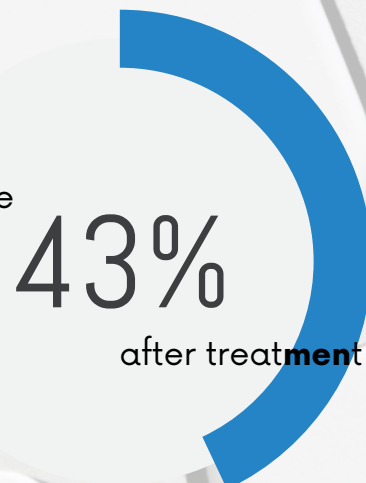
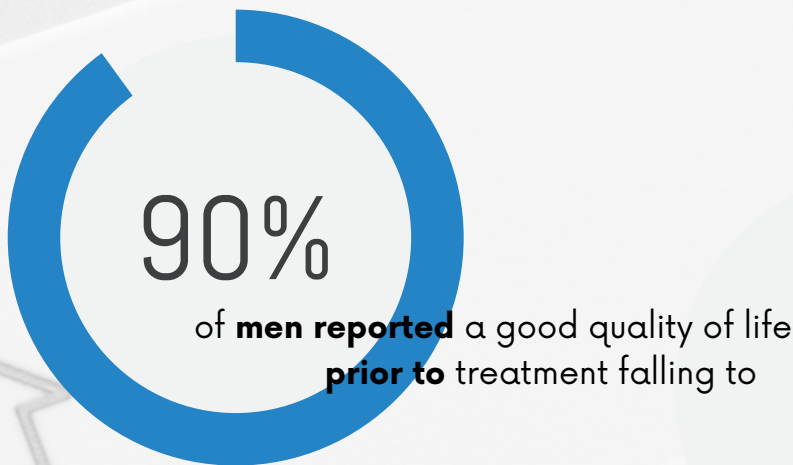
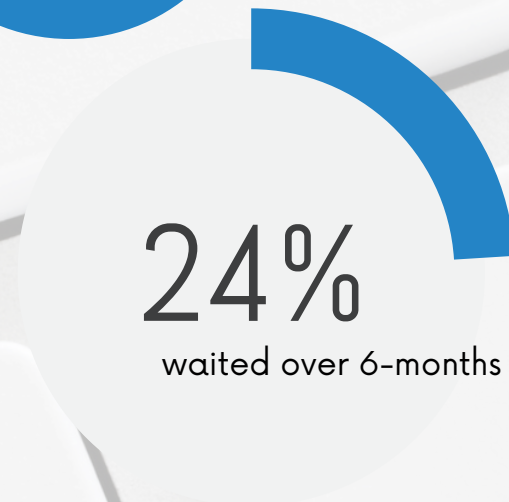
Diagnosis

In the UK, men with penile cancer are referred to regional specialist centres (supranetworks), for definitive treatment. Supranetworks enable centralisation of care by dedicated surgical teams, and support services. Prior to referral however, lack of awareness amongst the public, the rarity of its presentation to primary care, and inappropriate referral by healthcare professionals, can all lead to a delay in diagnosis.



Quality of life

Almost all curative treatment will involve surgery to the penis, therefore the longer the delay in diagnosis, the more invasive treatment may become and the greater the effect on quality of life.



Psychological impact

Following treatment for penile cancer men will often have to adjust to an altered body image and adapt to new daily routines to manage side effects of treatment, such as urinary changes or lymphoedema. These changes will inevitably affect psychological well-being.

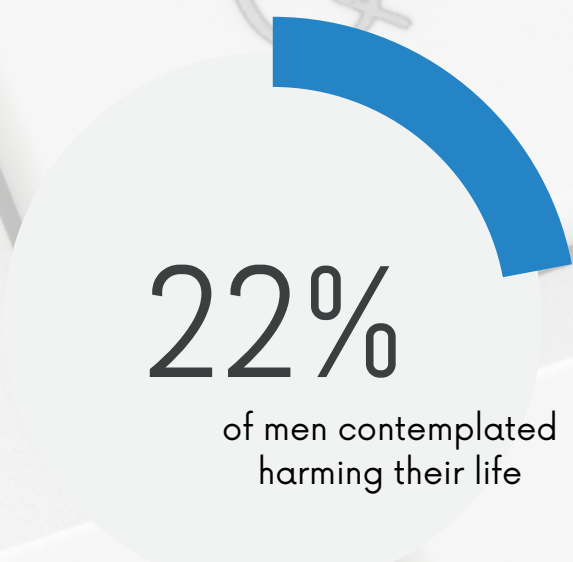
A diagnosis of penile cancer can be isolating; knowledge of its impact amongst family, friends, and healthcare professionals will be limited, and unlike more common cancers, there will be no local peer support. A combination of negative psychological and negative psychosocial factors, may therefore increase suicidal ideology.

Many men may have negative views of psychological support such as counselling, and may be unwilling to consider such an intervention. In addition in the UK, current counselling services, especially for rare cancers, are limited and may be unavailable at the point where they are needed most. In addition these services may only be accessible to patients diagnosed and treated for cancer within a specific time period.




60%

of men reported a **negative** impact on their **mental health**



22%

of men contemplated harming their life

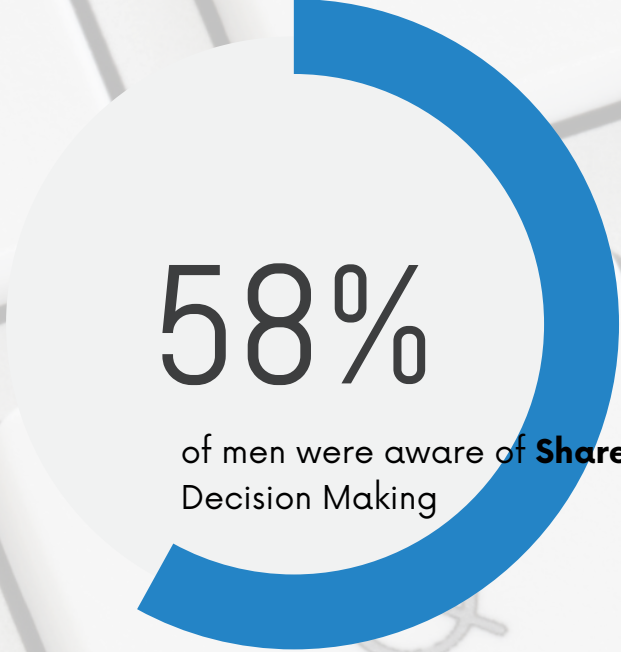


64%

were not offered **any form of** psychological **support**.

Shared Decision Making

Shared Decision Making (SDM) ensures that patients are supported to make decisions that are right for them. It is a collaboration between an individual and their clinician to decide what treatment is best, based on treatment options, evidence, risks, and benefits. It also considers their preferences, personal circumstances, feelings, values and beliefs.

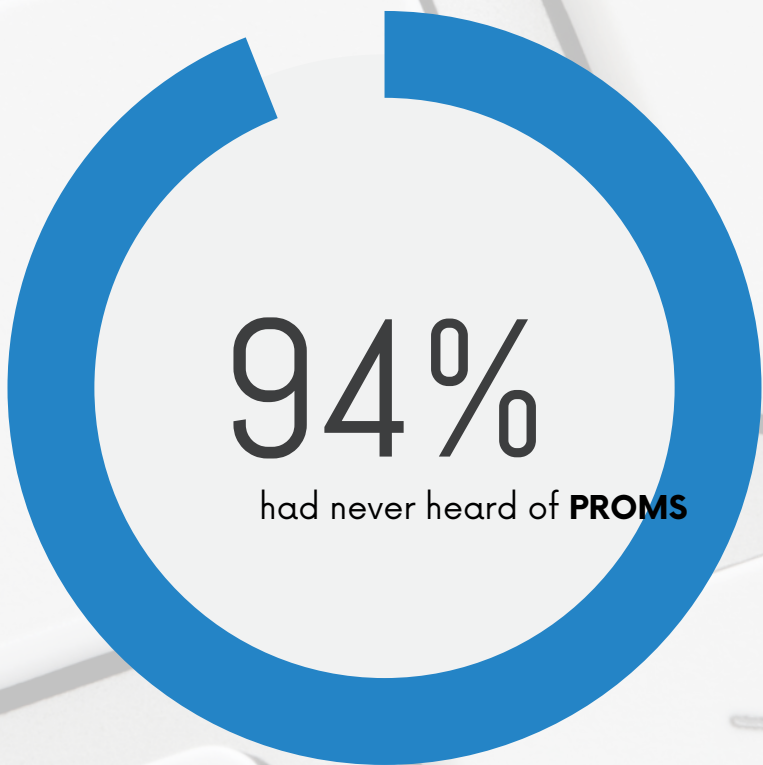


58%

of men were aware of **Shared Decision Making**

Patient Reported Outcome Measures (PROMs)

Currently no specific PROMS for penile cancer exists. In the UK some supranetworks distribute generic PROMS but this is inconsistent.



94%

had never heard of **PROMS**

SUMMARY AND NEXT STEPS

This initial report highlights several areas of concern, notably the route to diagnosis, reduction in quality of life and the psychological impact of penile cancer.

Where do we go from here?

01

Expansion of the survey

The continued dissemination of the survey via international networks. The survey has been translated into ten European languages targeting those countries with a high incidence of penile cancer. A further, more expansive report will be published in 2025.

02

Continued data collection

Aim to obtain responses from 200+ men worldwide, over the next 12-months.

03

Further analysis

Analyse data and compare unmet needs in different global regions.

04

Recommendations for focusing future support

Recruit a small cohort of 20 men from the survey who are willing to provide a more in-depth narrative of their experience, to help healthcare professionals develop supportive services, and act as a patient focused guide for anyone affected by the disease.

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ACKNOWLEDGEMENTS

[Survey link](#)

[Video summary](#)

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Together we can make a difference.



EAUPI
Patient Information

ORCHID
FIGHTING MALE CANCER



European
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