# The 'P' Word

The challenge of urinary problems in people living with prostate and bladder cancer Prostate cancer is Europe's most common male cancer with over 400,000 men diagnosed each year. Considering the increasing ageing population across Europe, a growing proportion of people are being diagnosed. Bladder cancer is the 5th most commonly diagnosed cancer in Europe, and 4th in men, with over 120 000 men diagnosed each year.

Urinary continence (voluntarily keeping urine in the bladder) and normal voiding (fully emptying the bladder) are very important functions in humans. Problems with both are a frequent and troublesome problem faced by people living with cancer, especially if pelvic organs, such as the prostate or bladder, are involved.<sup>1</sup> Several specific causes and reasons for these problems may be present in patients with prostate or bladder cancer, principally due to:

- Changes to the body and it's functions as a consequence of prostate or bladder cancer, or the treatment thereof;
- Non-cancer related factors, causing dysfunctions of the lower urinary tract.

Furthermore, cancer in general may cause urinary problems or aggravate them, due to a decrease in central nervous control as a consequence of physical deterioration and/or the psychological impact of the health problem.

Several cancer treatments for bladder and/or prostate cancer may cause or aggravate prior existing lack of urinary continence, possibly also in combination with severe trouble with voiding<sup>2</sup>. Continence and voiding problems are more prevalent, and can be more severe after treatment for prostate or bladder cancer.<sup>2</sup> These problems have a major impact on quality of life, creating many physical psychological and social challenges for people directly concerned<sup>1, 3</sup> and their relatives. It is estimated that approximately 80% of long-term care is provided by spouses, relatives and friends, without whom many acute needs would remain unattended to.4 Continence care can be a burdensome and time consuming activity, that significantly increases the difficulties and stress derived from caring for an elderly person. Despite its wide prevalence (estimated

at 400 million globally), severe continence and voiding problems remain as one of the most stigmatising health problems and can lead to isolation, anxiety and depression.

Often, these conditions cannot be completely cured – or the cure is not provided– which makes continence management products such as the adult incontinence pad a widely used commodity. Although incontinence can be treated successfully in the majority of patients, often an incontinence pad is still the only solution offered because of a lack of clinical knowledge and/or motivation from caregivers. Such lack of knowledge within healthcare itself, can normalise pad usage, even in situations where treatments or more suitable products are available.

As elaborated by Dr Tiina Vaittinen, a specialist in sustainable continence care; the incontinence pad is perhaps the best known and most widely used product for continence management. And its usage is growing globally in both mature and emerging markets.<sup>5</sup> The growth has to do with the ageing of populations across the world, but also with innovation, new product families, accessible pricing and reduction of stigma, etc.<sup>6</sup>

The rapid growth of the global pad markets means that increasing numbers of people will have access to this hygiene product, which helps them manage their condition better. But this in turn means that, on aggregate, the households living with issues of incontinence are likely to spend more money on pads than before. Similarly, public spending on pads tends to increase in countries where incontinence products are publicly subsidised.

The growth of the worldwide pad sales inevitably adds to the burden of waste that humankind accumulates on the planet every day. While there are washable pads for adults, the growth in pad sales refers particularly to disposable products, that do not compost. In OECD countries 4.8% or municipal waste is generated by adult incontinence pads. It takes over 500 years for the microplastics in absorbents to be broken down. Moreover, each disposable pad produced, sold, and used adds to the mountain of waste that is challenging and still often impossible to dispose of in ecologically sustainable ways. In the era of climate and environmental crisis, it is here that there is a need for innovative and urgent solutions – and the concern should be shared by different interest groups, despite their sometimes conflicting interests.<sup>18</sup>

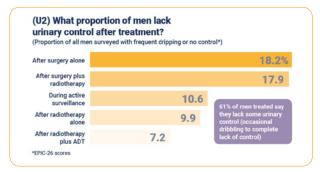
# **Prostate Cancer and Urinary Problems**

Europa Uomo conducted the Europa Uomo Patient Reported Outcome Study (EUPROMS) in 2019 and 2022.<sup>7</sup> It is the first ever prostate cancer quality of life survey conducted by patients for patients.

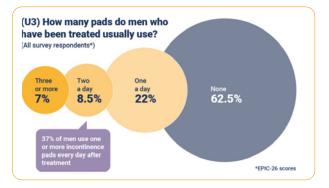
Based on nearly 3,000 responses to an online questionnaire by men with prostate cancer across Europe, it provides a new perspective.

# EU PROMS findings on urinary incontinence

Looking at incontinence, overall, 61% of the men surveyed said they lacked some urinary control (frequent dripping or no control) and 17% judged it to be a major or moderate problem. Those who have had a prostatectomy report less urinary control than those who have had radiotherapy or other treatments, and this results in a lesser quality of life related to urinary symptoms. Comparing the surgery figures with active surveillance suggests that surgery doubles the rate of incontinence.







What does this mean for patients in practical terms? The survey asked men how many incontinence pads they use each day, and across all the survey respondents over a third use one or more pads a day. Of respondents who had had a prostatectomy, half were using pads. To put this into context, a 2017 study of men with roughly the same age profile who had NOT been treated for prostate cancer found that around 5% wear pads, so there is clearly a significant effect here.<sup>8</sup>

### **Bladder cancer and urinary problems**

Patients diagnosed with high-risk non-muscle-invasive bladder cancer have a significantly greater decline in their physical health and emotional health, and are more likely to report worsened urinary leakage compared to people without cancer.<sup>9</sup> People with muscle-invasive bladder cancer have worse urinary and sexual function after radical cystectomy, compared to the general population.<sup>10</sup>

Following surgery, many patients are not told how they can deal with incontinence. In the absence of education from healthcare services, many people initiate their own strategies such as wearing pads at night, changing underwear style, only wearing black trousers so leakage would not show, and establishing urinating (miction or urination) schedules. Finding a clean place to selfcatheterise away from home was described as difficult, particularly for men.<sup>11</sup>

Approximately 20% of women report incontinence after radical cystectomy. Sexual function is slightly better among women undergoing genitalia-sparing radical cystectomy, but generally poor outcomes have been observed among women undergoing routine radical cystectomy.<sup>12</sup> The solutions: Recommendations to the European Commission and the EU Beating Cancer Plan on how to increase the quality of life of people living with prostate and bladder cancer, while tackling the challenges of urinary incontinence, including use of products which damage the environment.

# **Prevention and Early detection**

- Prevention of cancers is essential. Incidence of bladder cancer in particular can be impacted by exposure to carcinogens in the workplace and will benefit from rigorous implementation of the updated Directive on the protection of workers from the risks related to exposure to carcinogens or mutagens at work.<sup>13</sup>
- 2. Early detection of prostate cancer and bladder cancer is of the utmost importance. Early detection will catch cancers early before the need for treatment. The more advanced the prostate cancer or bladder cancer at diagnosis, the worse the effects of treatment on quality of life. The research clearly shows that many symptoms that affect quality of life are experienced more severely with treatments associated with more advanced prostate cancer or bladder cancer. EU wide guidance for risk-stratified early detection is needed. The update of the EU Screening Recommendations in 2022 should include prostate cancer in the list of cancers to benefit from this guidance, and ideally the Screening Recommendations should evolve to become Screening and Early Detection Recommendations, to help advise EU Member States on early detection policies more generally, including for specific cancers such as Bladder Cancer.<sup>14</sup> Both prostate and bladder cancers will benefit from the definition of essential quality standards which have been achieved in the European Commission Initiative on Breast Cancer.<sup>15</sup>

# **Treatment and care**

- 3. Quality treatment and support are essential. The EUPROMS results show the severe effects that can come with treatment for prostate cancer. Men need all the expertise and experience they can get during treatment and after, with information and support at each stage of the journey. Everyone with prostate cancer and bladder cancer should be treated in a cancer centre with multidisciplinary teams. Comprehensive Cancer Centres supported through the EU Cancer Plan must address the criteria for high quality multi-disciplinary care for these two cancer types. The EAU has already defined the criteria for the identification of European Prostate Cancer Centres of Excellence, in order to certify the high-quality centres for prostate cancer management.<sup>16</sup> The European Cancer Organisation has also defined Essential Requirements for Quality Prostate Cancer care.<sup>17</sup>
- 4. Active surveillance should always be considered for prostate cancer and low-risk bladder cancer, if it can be applied safely, because overall, it best protects quality of life. The contrast between active surveillance and other approaches is obvious in terms of incontinence and sexual function. This should be considered as part of the information given to patients.
- 5. The EU4Health funded INTERACT Interspecialty Cancer Training Programme should set a blueprint for multi-disciplinary training which can be used for prostate and bladder cancer which includes information and communication between healthcare professionals and patients on urinary problems associated with these cancers and their effective management. It should also include methods for assessing the proficiency of healthcare professionals in obtaining predefined outcomes through proficiency based progression, including for minimally invasive robotic surgery.

#### Survivorship and quality of life

6. The 'European Cancer Patient Digital Centre' which will become operational in 2023 must include Patient Reported Outcomes and, for prostate cancer, the issues highlighted by the EUPROMS survey must be monitored and addressed. These findings can eventually be fed into the European Cancer Inequalities Registry which is under development by the OECD.

# **Research and Innovation**

- 7. Un.Can and the European Health Data Space should assist in unlocking the power of genomic and Big Data so that multidisciplinary teams can better understand prostate and bladder cancer.
- 8. The Horizon 2020 project called AMPLITUDE (Advanced Multimodal Photonics Laser Imaging Tool for Urothelial Diagnosis in Endoscopy) can develop an integrated imaging platform that can capture high-resolution images at depths up to 10 times greater than existing diagnostic tools enabling doctors to more accurately identify and monitor tumours.
- 9. The Cancer research mission and the flagship programme on early detection and treatment for all should scale up funding for minimally invasive treatment options and new technologies to treat prostate cancer and bladder cancer effectively. It is also imperative to fund projects that strengthen understanding of cancer and co-morbidities, including urinary problems, and to guide personalized decision making.
- 10. Horizon Europe can also support a topic which fosters eco-responsible innovation and development of adult incontinence pads, which will be a growing market for an increasingly elderly European population.

# EU Cancer Plan links with EU Green Deal

11. In terms of a holistic solution for sustainable continence care, the Commission can play a role in convening a multistakeholder forum on this issue (possibly through future priorities of the NCD initiative, or through DG Sante HPP Thematic Networks) to find politically and economically sustainable solutions, which are also equitable and accessible. The European Commission should support research and innovation projects which focus on the reduction of waste and climate impact using a full life cycle approach. Regional funds should also provide blended support for the development of wider infrastructures, technologies and logistics that will be necessary beyond healthcare, and to support SMEs to develop innovative ways of dealing with absorbent waste. A holistic strategy would also need to address the gaps, such as lack of preventative care and inadequate treatment, lack of knowledge and knowledge-sharing especially within primary care, and the fact that the products are not tailored to individual needs (wrong size, absorbency). Additionally there is a need for increased planning for public toilets, and availability of special bins for disposal of incontinence pads in not only female, but also male toilets. There is also the considerable challenge of inadequate staffing care homes, etc. Inadequate help for people to go to the toileting means more need for incontinence products.

# EU Cancer Plan links with Care Strategy.

12. On 7 September 2022, the European Commission adopted a much-needed Care Strategy, intended to address in a consistent and comprehensive manner the multiplicity of care-related issues faced across EU Member States, adopting a life-long perspective, and calling among others for a better integration of health and long-term care. This ambitious strategy, to be supported by relevant EU funding instruments, should also trigger progress regarding the quality of life and the care provided to people with urinary problems associated with prostate and bladder cancer, notably through better recognition and support to professional and informal carers, including through relevant information and training.

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