

PRESS RELEASE

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First-ever global bladder cancer patient experience survey launches online today, led by the World Bladder Cancer Patient Coalition

The findings will fill a critical evidence gap, on patient and carer experiences

Brussels, October 1, 2021 – Today, the World Bladder Cancer Patient Coalition (WBCPC) launches the first-ever global bladder cancer patient experience survey. The survey represents a collaborative effort between the WBCPC and its 11 member organisations from around the world.

Globally there are over 570,000 people newly diagnosed with bladder cancer each year, and 1.7 million people currently living with this disease.¹

"The worldwide unique insights and experiences of patients and carers have not previously been measured, and are thus not appropriately integrated into policy, advocacy, and research decisions" said Ken Bagshaw, bladder cancer patient in Canada and Founding President of the World Bladder Cancer Patient Coalition.

Patient and carer experience data help to identify what is important to them, and in turn, drive patient-centred care improvements. Yet currently, this data is lacking and there's an urgent need to fill this evidence gap.

"We will fill this knowledge gap and amplify the voice of bladder cancer patients and carers, by quantifying patient experiences and preferences on a global scale" said Dr Lydia Makaroff, President of the World Bladder Cancer Patient Coalition. *"These insights will help us as a global patient organisation to align our work with patient needs, and champion their views to drive care improvements using evidence-based advocacy."*

The survey covers the entire bladder cancer patient pathway – from symptoms, screening, diagnosis, treatment and care, through to follow-up and survivorship. The survey is global, and available in 10 languages. Findings will be translated into a well-argued report analysing the strengths, weaknesses, and gaps in the bladder cancer care pathway from the patient perspective.

The survey has benefitted from various contributors, including patients, patient advocates, researchers, and healthcare professionals – with a specialist Expert Advisory Committee providing strategic guidance and oversight to enhance this work.

"Patient experience data can be often overlooked, but they are key to understanding how our healthcare systems are performing for those they are designed to serve" said Dr Ashish Kamat, Chair of the WBCPC Expert Advisory Committee, and Professor of Urologic Oncology (Surgery) at University of Texas MD Anderson Cancer Center; *"I'm*

¹ IARC. 2020. Globocan: World Fact Sheet. Online: <https://gco.iarc.fr/today/data/factsheets/populations/900-world-fact-sheets.pdf>

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delighted to contribute to this important work, that will eventually paint a fuller picture of bladder cancer care”.

The survey is now available in English. To complete the survey, click here: <https://bit.ly/WBCPC-EN>

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NOTES TO EDITOR:

Impact of bladder cancer:

- Over 570,000 people are newly diagnosed with bladder cancer each year and more than 1.7 million people are living with the disease globally (2020).²
- Bladder cancer is the 6th most common cancer in men and the 17th most common cancer in women worldwide.³
- More than 80% of people with bladder cancer will survive their disease for 5 year or more, when diagnosed at the earliest stage of disease.⁴
- Bladder cancer is often overlooked due to symptoms often being associated with less serious, more common issues such as urinary infections, back pain and needing to urinate frequently, amongst others.⁵
- Despite being the 5th most common cancer in Europe, only 1% of money spent on cancer research is spent on bladder cancer.⁶

Survey governance:

The survey is initiated and funded by the World Bladder Cancer Patient Coalition. It is being conducted in collaboration with its 11 member organisations from around the world, who are listed online [here](#). A Patient Advisory Panel, consisting of bladder cancer patients and survivors, regularly provide guidance throughout this project. In addition, an Expert Advisory Committee was established to provide strategic guidance and oversight to this work. Members of this Committee are listed online [here](#). Quality Health, an experience survey provider, has been contracted to lead the survey creation, data collection and analysis (<https://quality-health.co.uk/>)

About the survey:

Survey questions span the entire patient pathway. The survey is available online only and takes approximately 20 minutes to complete. It is a mix between multiple choice and free text questions. The survey is available in English immediately, and in the

² IARC. 2020. Globocan: World Fact Sheet. Online: <https://qco.iarc.fr/today/data/factsheets/populations/900-world-fact-sheets.pdf>

³ Bray et al. 2018. Global cancer statistics 2018. Online: <https://acsjournals.onlinelibrary.wiley.com/doi/full/10.3322/caac.21492>

⁴ Ferlay et al. 2015. Cancer incidence and mortality worldwide: Online: <https://pubmed.ncbi.nlm.nih.gov/25220842/>

⁵ ECPC. 2021. Bladder cancer awareness month campaign. Online: <https://ecpc.org/get-involved/bladder-cancer-awareness-month-campaign/>

⁶ ECPC. 2021. Bladder cancer awareness month campaign. Online: <https://ecpc.org/get-involved/bladder-cancer-awareness-month-campaign/>

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coming two weeks will launch in Spanish, Portuguese, Italian, Norwegian, Arabic, Japanese, French, Russian and Hindi. The survey will remain open until December 1, 2021, or until we have reached the minimum number of respondents required to have a meaningful analysis.

About World Bladder Cancer Patient Coalition:

The World Bladder Cancer Patient Coalition (WBCPC) was established in January 2019 by a group of dedicated patient advocates from three major national bladder cancer organisations that saw the need for a global bladder cancer coalition. It represents the collective voice of Bladder Cancer Patients across the globe, bringing together 11 patient organisations from four continents. Their mission is to foster an international community of people affected by bladder cancer, to ensure the best possible outcomes for bladder cancer patients across the world.

For further information, please contact:

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