

Patient Awareness, Diagnosis and Treatment of Bladder Cancer: Survey Results From 45 Countries

Lydia E. Makaroff^{1,2}, Alex Filicevas¹, Shannon Boldon¹, Patrick Hensley^{3,12}, Peter C. Black^{4,5,6,7}, Stephanie Chisolm^{1,8}, Stephanie Demkiw^{1,9,10}, Mario I. Fernández^{11,12}, Mikio Sugimoto¹³, Bente Thoft Jensen^{14,19}, Wim P. J. Witjes¹⁵, Ken Bagshaw^{1,7}, Lori Cirefice-Funk^{1,16}, Allen Knight^{1,17}, Ashish M. Kamat^{1,5,6,12,18}

1. World Bladder Cancer Patient Coalition; 2. Fight Bladder Cancer (UK); 3. University of Kentucky (USA); 4. University of British Columbia (Canada); 5. International Bladder Cancer Network; 6. Société Internationale d'Urologie; 7. Bladder Cancer Canada; 8. Bladder Cancer Advocacy Network (USA); 9. Bladder Cancer Awareness Australia; 10. Access Health and Community (Australia); 11. Department of Urology, Clínica Alemana Universidad del Desarrollo, Santiago, Chile; 12. International Bladder Cancer Group; 13. Kagawa University (Japan); 14. European Association of Urology Nurses; Aarhus University Hospital (Denmark); 15. European Association of Urology Research Foundation (Netherlands); 16. Cancer Vessie France; 17. Action Bladder Cancer UK; 18. MD Anderson Cancer Center (USA) 19. Department of Urology, Aarhus University Hospital (Denmark)

PURPOSE / OBJECTIVES

Few global studies exist detailing the lived experiences of bladder cancer patients. The objective was to collect the views and experiences of people with bladder cancer worldwide.

MATERIAL & METHOD

A comprehensive survey consisting of 65 questions was administered by the World Bladder Cancer Patient Coalition and Quality Health, an IQVIA business, from October 2021 to February 2022 and was disseminated online in Arabic, English, French, Hindi, Italian, Japanese, Norwegian, Polish, Portuguese, Russian, and Spanish.

The survey results were cleaned by removing duplicates and incorrectly formatted data. The dataset was analysed using the software SPSS to produce descriptive and comparative statistics. The percentage responses were calculated after excluding respondents that did not answer that question.

Sub-analyses were conducted for sex, time to diagnosis, age, geographic region, and stage.

Our survey was distributed online, via social media and patient support organisations. While stage distribution and sociodemographic characteristics in this cohort reflect real-world bladder cancer patients, there may be disproportionately represented patient populations. The online nature of the survey means that older people, people without internet access, and disabled people may have been excluded. There were few responses from low- and middle-income countries.

RESPONDENT CHARACTERISTICS

Respondents came from a total of 45 countries

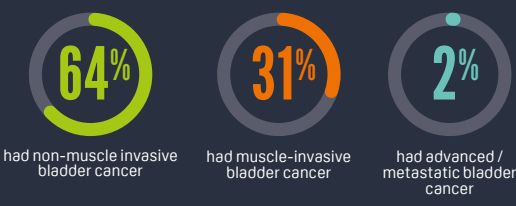
The percentage of respondents by geographic area was:



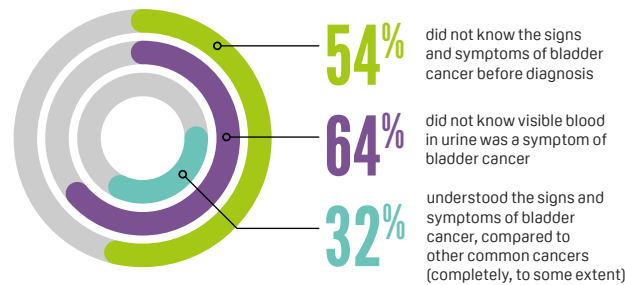
Breakdown of respondents by country, (n)

20%	United Kingdom (227)	3%	Argentina (29) Poland (34)
13%	United States of America (150)	2%	Chile (21) Ireland (24) Japan (24) Spain (22)
10%	Australia (112)	1%	Belgium (9) Finland (7) Mexico (6) New Zealand (10) Pakistan (1) Sweden (7) Tunisia (8) Venezuela (8)
9%	France (103) Italy (106) Norway (103)	<1%	Algeria (4) Bahamas (1) Colombia (4) Cyprus (1) Denmark (1) Ecuador (3) Georgia (1) Germany (1) Greece (3) India (4) Iraq (1) Israel (6) Jordan (1) Kuwait (1) Lebanon (1) Netherlands (4) Peru (3) Portugal (1) Russia (4) Senegal (2) Slovenia (1) Switzerland (3) Turkey (2) UAE (4)

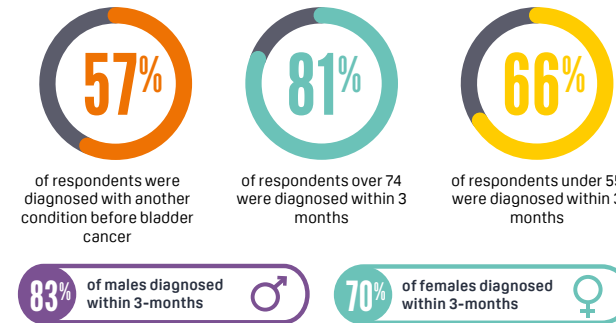
Initial bladder cancer diagnoses for survey respondents



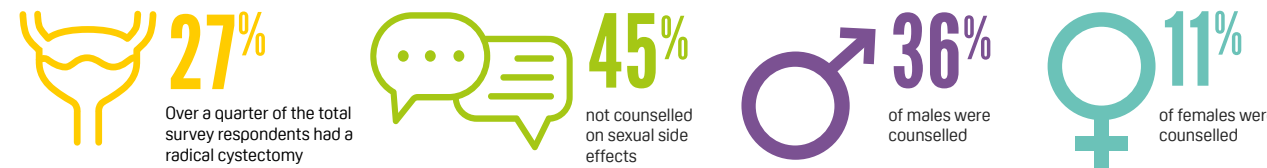
RESULTS - AWARENESS



RESULTS - DIAGNOSIS



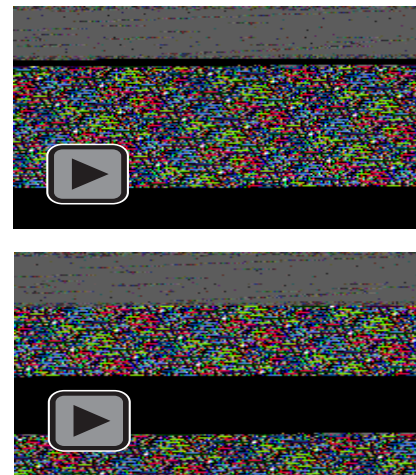
RESULTS - CYSTECTOMIES



RESULTS - SUPPORT



AWARENESS VIDEOS



SUMMARY

Before diagnosis, awareness of the signs and symptoms of bladder cancer was low. Women were twice as likely to be misdiagnosed with a UTI than men. More women and younger respondents had delays in diagnosis. Many respondents were not counselled about sexual side effects before surgery.

We thank Alessandro Boni, Tony Cornacchia, Melanie Costin, Ferg Devins, Dr Makarand Khochikar, Dr Rajeev Kumar, Dr Mohammed Shahait, Dr Ignacio Duran, David Guttman, Ekaterina Iarkova-Vizuroiu, Helen Lacy, Robert McConkey, Jack Moon, Lauren Pretorius, Anita Eik Roald (Norwegian Bladder Cancer Society), Laura Magenta (Associazione PaLiNUro, Italy), Jim Scott, Brittney Tellekamp, Laura Magenta (Associazione PaLiNUro, Italy), Liesbeth de Boer-Oosterhuis (Living with Bladder / Kidney Cancer, Netherlands), All.Can International, Association of Cancer Patients in Finland, European Association of Urology, European Association of Urology Nurses, European Cancer Organisation, Friends of Cancer Patients UAE, Polish Coalition of Oncological Patient Organisations, Société Internationale d'Urologie, Uro-today.com, Marylou Bosco & Adam Taylor (IQVIA), and Emma Moore & Hatty O'Sullivan (formerly IQVIA) for contributing to the survey and report.