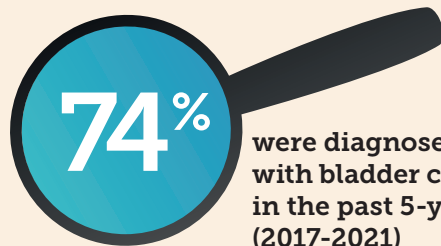


About the global patient survey



In 2021–2022, Fight Bladder Cancer, Action Bladder Cancer, and UK-based bladder cancer patients and carers participated in the global bladder cancer patient survey that was led by the World Bladder Cancer Patient Coalition (WBCPC). This was the first global survey of bladder cancer patients, covering the entire pathway of patient experiences. The survey was available online, in 11 languages. The key findings for the UK respondent cohort are presented in this infographic.

Respondent profile in the United Kingdom

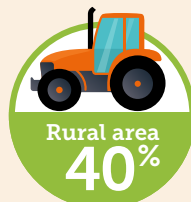
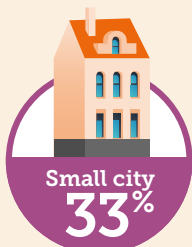


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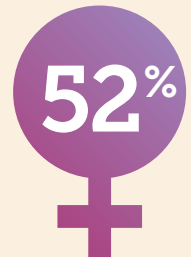
Patient responses

17

Carer responses

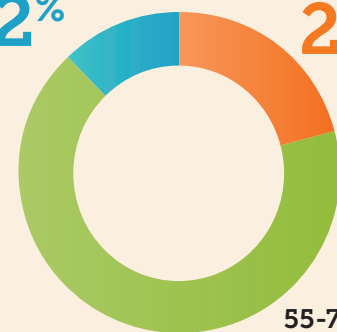


Respondents were



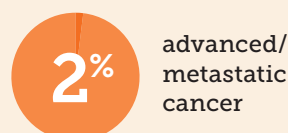
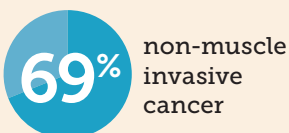
Most respondents were over the age of 55 years

75 yrs + **12%**



Under 55 yrs **21%**

55–74 yrs **67%**



Survey Findings

Diagnosis

- **58%** were not aware of any signs and symptoms of bladder cancer before diagnosis
- **64%** did not know visible blood in urine was a sign and symptom of bladder cancer before diagnosis
- **73%** had visible blood in urine prior to being diagnosed with bladder cancer
- **63%** were diagnosed with another condition before bladder cancer
 - **37%** were mis-diagnosed with a urinary tract infection before bladder cancer
- **38%** received their diagnosis during a medical procedure
- **55%** said the length of time it took to be diagnosed caused them concern or extra worry
- **48%** needed more information about their diagnosis and what it means





Treatment

- **90%** did not receive information about clinical trials, and only **5%** took part in one
- **30%** of respondents had a radical cystectomy, of them
 - **47%** said it was the only treatment option discussed with them
 - **52%** were not counselled before surgery about the sexual side effects
- **59%** needed more information about treatment options and duration
- **41%** needed more information about the side effects of treatment

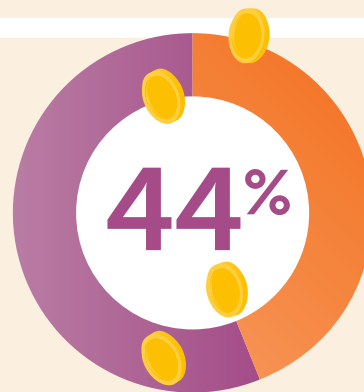


Supportive and complementary

- **51%** were not offered emotional support to help cope with their diagnosis
- **50%** needed financial support throughout their treatment and care, but **68%** of them did not get it
- **50%** did not receive information on peer-support groups or charities

Impact on daily life

- **44%** said their financial situation was impacted due to bladder cancer
 - **11%** severely
 - **19%** to some extent,
 - **15%** slightly
- **15%** took an early retirement and **10%** were temporarily off work due to bladder cancer
- **24%** said treatment impacted their ability to carry out daily activities (extremely, or a lot)
- **10%** were not able to live a full life following their diagnosis and treatment
- **12%** were not able to cope with the impact of their diagnosis and treatment
- **47%** said the long-term emotional impact of treatment for bladder cancer has not been fully addressed and treated



Said their financial situation was impacted due to bladder cancer



About Fight Bladder Cancer

Fight Bladder Cancer is a registered Charitable Incorporated Organisation in Scotland (SC051881), England and Wales (1198773), and was initially an unincorporated charity in England and Wales (1157763). It also operates in Northern Ireland. Fight Bladder Cancer is a proud founding member of the World Bladder Cancer Patient Coalition (WBCPC).

About the World Bladder Cancer Patient Coalition

The World Bladder Cancer Patient Coalition (WBCPC) worldbladdercancer.org was established in January 2019. The Coalition brings together patient groups across continents, uniting the vision and goals of bladder cancer patient groups.

For more information on the global patient survey, please visit the WBCPC project page:

worldbladdercancer.org/bladder-cancer-patient-survey