

Fight Bladder Cancer

Priorities for action 2023



bladder
CANCER

Over 21,000 people are diagnosed with bladder cancer every year,¹ making it the fifth most common form of cancer in the UK, after breast cancer, prostate cancer, lung cancer and bowel cancer.²

Despite this, bladder cancer treatment remains highly variable, with patients experiencing very different patterns of referral, diagnosis, assessment and treatment pathways across the UK.³ Whereas outcomes for other cancers are improving⁴, bladder cancer survival rates have remained flat or have fallen over the last three decades.⁵

There is an urgent need for action to improve the experience and outcomes of people affected by bladder cancer.

Between 2017 and 2022, Fight Bladder Cancer undertook the Exemplar Project, a national project to capture the views and experiences of bladder cancer patients, carers and health care professionals in the UK, to summarise the strengths and gaps in current bladder cancer services.⁶ Through this project, Fight Bladder Cancer has identified a range of actions which can be taken by governments, NHS bodies and others, to improve care and support for patients with bladder cancer.

We are calling for action to be taken across four priority areas:

- 1** Develop and implement an exemplar pathway for bladder cancer,
- 2** Invest in the bladder cancer workforce,
- 3** Improve patient support and involvement in bladder cancer care,
- 4** Enhance the collection and publication of bladder cancer data.

We believe that these four actions will ultimately lead to better experiences and outcomes for bladder cancer patients. This disease has been ignored for too long; together we can change patients' lives for the better.

About Fight Bladder Cancer

Fight Bladder Cancer is a national patient-led charity which provides information and support on what to expect at the various stages of bladder cancer. We connect people, so those affected by bladder cancer can share their experiences and help each other. We lead the fight against bladder cancer, driven by patient and family insights.



Dr Lydia Makaroff
Chief Executive,
Fight Bladder Cancer

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**WORKING
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Priority 1

Develop and implement an exemplar pathway

CALL TO ACTION:

Update key national guidelines for bladder cancer:

In 2023, the following guidelines should be reviewed and updated, *Bladder cancer: diagnosis and management NICE guideline (2015)*; *Scottish Clinical Management Guideline for Bladder Cancer (2017)*; *Wales National Optimal Pathway for Bladder Cancer (2020)*; and the *Northern Ireland NICaN Urology Cancer Clinical Guidelines (2018)*.

By 2025, NHS England, NHS Scotland, NHS Wales & Health and Social Care Northern Ireland should work with healthcare systems (including Integrated Care Systems, Health Boards and Trusts), patients and bladder cancer experts, to establish and implement national pathways for the diagnosis, assessment, treatment and support of patients with bladder cancer.

The central finding of the Exemplar Research Report is that service provision and patient experiences in bladder cancer are highly variable.⁷

This is primarily because, in contrast to other cancers, bladder cancer lacks a standardised pathway for diagnosis, assessment and treatment.

Developing exemplar pathways will reduce variability, spread best practice, and improve continuity of care. Given the different structures of the NHS in each nation, pathways will necessarily vary between nations, however NHS bodies are encouraged to explore best practice across the UK when developing pathways.

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Priority 2

Invest in the bladder cancer workforce

Support from expert healthcare professionals can have a significant impact on the quality of individual experiences of care, as well as on wider outcomes. However, there

are serious challenges in the bladder cancer workforce. The UK already faces a shortfall of 189 consultant clinical oncologists (equating to 17% of the required total), which is expected to grow over the coming years.⁸ Additionally, one fifth (21%) of patients report not having support from a urology Clinical Nurse Specialist (CNS),⁹ while non-specialist staff may lack appropriate training to support patients with bladder cancer. Staff training can take several years, and the implementation of exemplar pathways is likely to increase demand and pressure on staff, so it is important to begin investing in these roles as soon as possible.

CALL TO ACTION:

Invest in ongoing education of bladder cancer workforce:

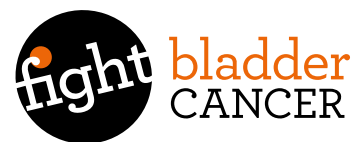
From 2023, Health Education England, NHS Education for Scotland, Health Education and Improvement Wales and the Northern Ireland Department of Health should work with local systems to ensure urology CNSs and other staff have access to ongoing training and professional development, which allows them to better support patients with bladder cancer.

Expand the current bladder cancer workforce:

From 2023, governments across the four nations should fund national education bodies to expand clinical oncology specialty training, in order to bridge the current workforce gap. It will also be important to identify the number of additional CNSs required and ensure recruitment of additional workforce to meet patient needs.

Priority 3

Improve patient support and involvement in bladder cancer care



Bladder cancer patients are often required to make major decisions which have lifelong implications for lifestyle, sex and quality of life, early in the care process, and with little external support.

Following treatment, some patients will need ongoing physical or psychological support, while other patients may prefer to manage their own care.

Supportive resources are often available from charities, however patients may not know how to access them or may not be signposted to these services by their care teams. Where appropriate, supporting patients to self-manage their ongoing care can free up capacity for other patients, and reduce pressures on the NHS, especially as it recovers from the COVID-19 pandemic.

CALL TO ACTION:

Improve signposting to support services: From 2023, NHS service providers should ensure that patients with bladder cancer are signposted to relevant resources, peer-support and organisations which can enable patients to fully explore the implications of their diagnosis and make informed decisions about their care.

Create more personalised follow-up pathways:

From 2023, where appropriate, personalised stratified follow-up (PSFU) models should be implemented, which tailor ongoing support to individual needs, ensuring that patients with the greatest needs can access additional support.

NHS service providers should ensure that patients with bladder cancer are signposted to relevant resources.

Priority 4

Enhance the collection and publication of bladder cancer data

CALL TO ACTION:

Ensure data is published on all types of bladder cancer:

From 2023, public bodies which publish data on urological cancers including cancer incidence, referral to treatment times and survival data, should publish bladder cancer data separately and routinely include all cancers of the bladder, not just invasive bladder cancers, to provide a more accurate understanding of the disease.

Over 21,000 people in the UK are diagnosed with bladder cancer every year.¹⁰ Yet this prevalence is not reflected in official data, due to the routine exclusion of two common forms of non-invasive bladder cancer; *D09.0 Carcinoma in situ of bladder* and *D41.4 Neoplasm of uncertain behaviour of bladder*. Excluding this data devalues the experiences of these patients and misleads the health service in terms of resources required for the care of bladder cancer patients.

Insights from patients with bladder cancer are often not separated out from those of patients with other urological cancers in key datasets, which can mean the distinctive voices and experiences of these patients are not heard or understood.

We want to make sure the distinctive voices and experiences of patients are heard and understood.



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¹ Fight Bladder Cancer, *What is bladder cancer* (2022).

<https://fightbladdercancer.co.uk/get-help/what-bladder-cancer>

² Cancer Research UK, *Cancer Statistics for the UK*.

<https://www.cancerresearchuk.org/health-professional/cancer-statistics-for-the-uk>

³ Fight Bladder Cancer, *Exemplar Research Report* (2021).

<https://www.fightbladdercancer.co.uk/sites/default/files/downloads/20210518-Fight-Bladder-Cancer-Exemplar.pdf>

⁴ Cancer Research UK, *Cancer survival statistics for all cancers combined*,

<https://www.cancerresearchuk.org/health-professional/cancer-statistics/survival/all-cancers-combined#heading-One>

⁵ Cancer Research UK, *Bladder Cancer Survival Statistics*.

<https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/bladder-cancer/survival#heading-Two>

⁶ Fight Bladder Cancer, *Work for a better patient experience*.

<https://www.fightbladdercancer.co.uk/get-involved/work-better-patient-experience>

⁷ Fight Bladder Cancer, *Exemplar Research Report* (2021).

<https://www.fightbladdercancer.co.uk/sites/default/files/downloads/20210518-Fight-Bladder-Cancer-Exemplar.pdf>

⁸ Royal College of Radiologists, *Clinical oncology: UK workforce census report 2020* (July 2021).

https://www.rcr.ac.uk/system/files/publication/field_publication_files/clinical-oncology-uk-workforce-census-2020-report.pdf

⁹ Fight Bladder Cancer, *Exemplar Research Report* (2021).

<https://www.fightbladdercancer.co.uk/sites/default/files/downloads/20210518-Fight-Bladder-Cancer-Exemplar.pdf>

¹⁰ Fight Bladder Cancer, *What is bladder cancer* (2022).

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ENDORSED BY

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