POLICY WHITE PAPER

Bladder cancer services:
A roadmap for change

By **Fight Bladder Cancer**

May 2024

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FOREWORD

The Fight Bladder Cancer Exemplar Review Meeting on “Improving the Bladder Cancer Pathway” was convened in Birmingham on 7th September 2023. The meeting offered a unique opportunity for all stakeholders to engage in discussions aimed at enhancing the care framework for bladder cancer.

The Exemplar Meeting was well-attended by a diverse group of stakeholders, underscoring the multidisciplinary nature of the challenges faced in bladder cancer care. The attendee list, comprising patients, carers, patient advocates, healthcare providers from various NHS trusts, academic researchers, members of pharmaceutical companies, and patient advocacy groups, brought together a wealth of experience, with attendee job titles and affiliations ranging from clinical leads and consultants, to nursing staff and medical directors. Academic researchers from institutions, including King’s College London and the University of Sheffield, also contributed their insights.

The attendees played pivotal roles in the breakout sessions, which focused on establishing an updated exemplar pathway for bladder cancer care that involved strengthening the workforce, and enhancing awareness and patient involvement. Their varied yet interconnected skills and experiences greatly enriched the conversation, contributing to a holistic understanding of both the challenges and opportunities in the bladder cancer care pathway.

This work builds on Fight Bladder Cancer’s past exemplar pathway developed in our May 2021 **Exemplar Research Report**. This white paper encapsulates key findings, insights, and proposed strategies emerging from this landmark event, intended to inform and guide future decision making.

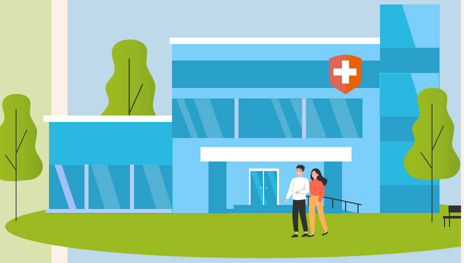
Andrew Dearden

Chair of Fight Bladder Cancer

ENHANCING BLADDER CANCER CARE IN THE UK

A national bladder cancer audit & updated guidelines

Creation of more one-stop haematuria clinics, diagnostic centres and urgent investigation units



Pathway for patient self referrals

Better access to innovative medicines, devices and equipment

Better referral to patient groups

More accessible clinical trial information & dedicated time for research within the NHS

Pathway for high risk women with recurrent UTIs to be referred to a specialist

Better NHS symptom awareness campaigns

More educational resources for GPs & nurses

Genomic testing for people with advanced cancer

Optimising the ‘blood in pee’ NHS 111 referral pathway

INTRODUCTION

About bladder cancer in the UK

Even though it is a common cancer, bladder cancer remains an underrepresented issue. Early diagnosis could substantially improve survival rates, which highlights the importance of public awareness. Around 20,000 bladder cancer cases are diagnosed yearly in the UK alone.

Around 20,000 people are diagnosed with bladder cancer each year in the UK*

SPOTLIGHT ON MISDIAGNOSIS

A recent UK survey co-commissioned by Fight Bladder Cancer and the World Bladder Cancer Patient Coalition revealed startling figures around misdiagnosis, particularly among women. 63% of female patients initially received incorrect diagnoses, with UTIs being the most common.
The consequences of delayed diagnosis are often severe, disproportionately affecting women. (Makaroff et al., 2023)

Why we need an exemplar pathway

Despite being one of the most common cancers in the United Kingdom, public awareness and investment into bladder cancer research and care is low (Barclay et al., 2021).

It is well established that delayed diagnosis leads to poorer outcomes, yet, whilst bladder cancer is a common form of cancer, it is often overlooked, and symptoms are not well understood. Patients continue to have their symptoms, such as frequent urination or pain, brushed aside or mistaken for less severe conditions, despite prompt diagnosis having considerable impact on prognosis and survival rates (Makaroff et al., 2023).

An additional consideration, particularly for stakeholders, is that bladder cancer carries the highest cost of any cancer globally on a per-patient basis (Richters et al., 2020), with bladder cancer patients experiencing a high rate of recurrence, long and invasive surveillance and expensive treatment (Dyrskjøt et al., 2023). Patients also report worse overall experiences than most other common cancers (Hansen et al., 2022), (Catto et al., 2021), (Gomez-Cano et al., 2020).

There is an urgent need for change to ensure consistent, exemplary care for bladder cancer patients across the United Kingdom.

Therefore, putting in place an exemplar pathway to improve bladder cancer services (including raising awareness, delivering faster referral and diagnosis for those with suspected bladder cancer, and encouraging implementation of a standardised pathway across the United Kingdom) would not only seek to improve patient outcomes but have a potentially significant impact on the cost of provision too.

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*See ref: https://www.fightbladdercancer.co.uk/get-help/what-bladder-cancer

ABOUT THE EXEMPLAR REVIEW MEETING

The Fight Bladder Cancer Exemplar Review Meeting on “**Improving the Bladder Cancer Pathway**” convened in Birmingham on 7th September 2023. The Exemplar Review Meeting brought together experts to discuss vital aspects of bladder cancer care and patient support.

Dr Lena Mandrik called for a national bladder cancer audit, while **Mr John McGrath** and **Hilary Baker** highlighted, respectively, the importance of reducing clinical care variation and addressing the looming exodus in the nursing profession. **Alex Filicevas** and **Melanie Costin** shared insights from a global patient survey that underscored the issues of misdiagnosis and the critical need for emotional support.

Breakout sessions focused on establishing exemplar pathways through Urgent Investigation Units and patient self-referral, enhancing the Bladder Cancer Workforce by defining career pathways and education, and improving awareness and patient support by updating NICE guidelines and integrating mental wellbeing markers.

EXPERT INSIGHTS

2.1

Advocating for a national bladder cancer audit

Statistical Analysis: The experiences of bladder cancer patients in England

Dr Lena Mandrik presented a study that she led with Prof. Jim Catto (The University of Sheffield), co-authored by professionals from various medical institutions, underscoring an urgent need for improvements in the diagnostic pathways for bladder cancer.

There is an urgent need for improvements in the diagnostic pathways for bladder cancer. There are significant opportunities for enhancing the diagnostic and treatment frameworks for bladder cancer.

The study used data from the National Cancer Registration and Analysis Service (NCRAS) to investigate trends in diagnosis, treatment, and other urothelial cell cancers in England from 2013 to 2019. The study underscored an urgent need for improvements in the diagnostic pathways for bladder cancer.

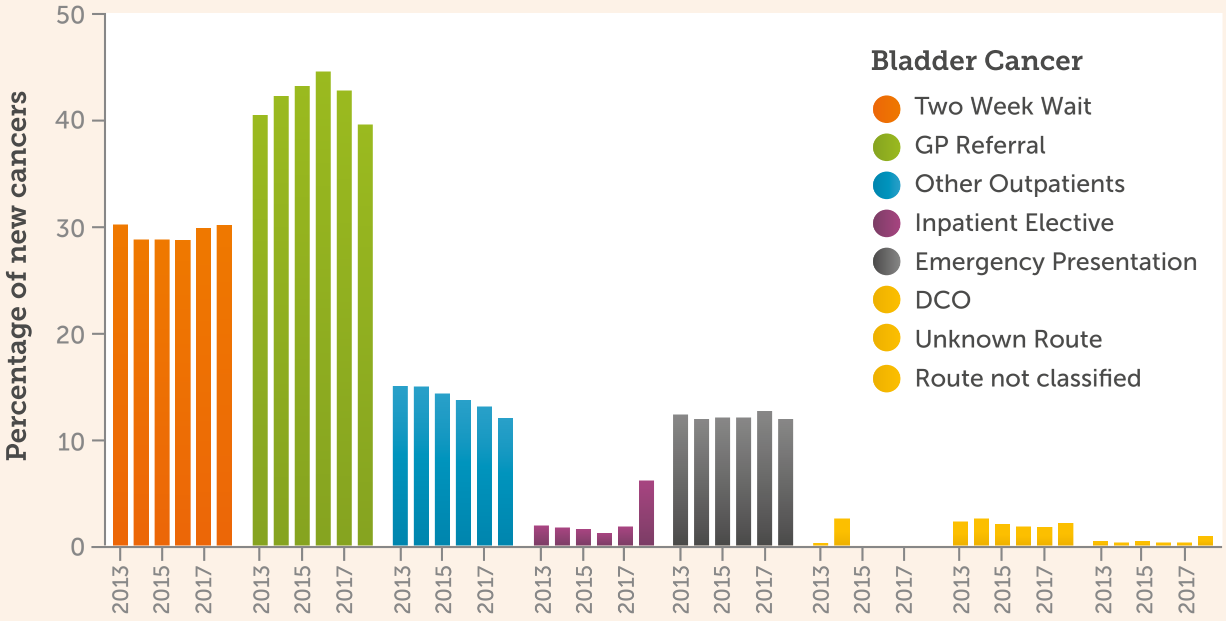
The methodologies employed included an in-depth examination of the routes to diagnosis for T1–T4 tumours and survival rates at 12-month intervals up to 72 months post-diagnosis.

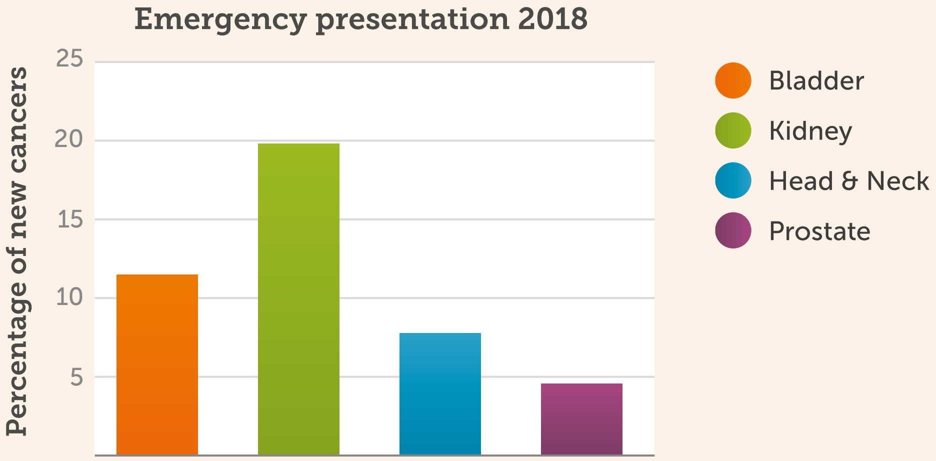
According to the National Health Service (NHS) England data extending from 2013 to 2019, there were 150,816 individuals living with a bladder cancer diagnosis in 2019, a majority of whom were men, elderly, and Caucasian. Approximately 8.3% of people diagnosed with bladder cancer had Asian, Black, mixed race, other, or unknown ethnicity.

The data highlighted alarming trends, such as 41% of patients not being referred within the standard two-week-wait pathway for urgent cancer referrals and a considerable variance in treatment modalities, influenced by factors like disease stage and patient demographics.

The data from this study were supplemented with analysis of GP referrals. The Urinary Symptoms Partnership study in England aimed to identify bladder and kidney cancer cases among patients displaying relevant symptoms. This approach involved case note reviews and interviews across nine primary care practices.

Routes to diagnosis

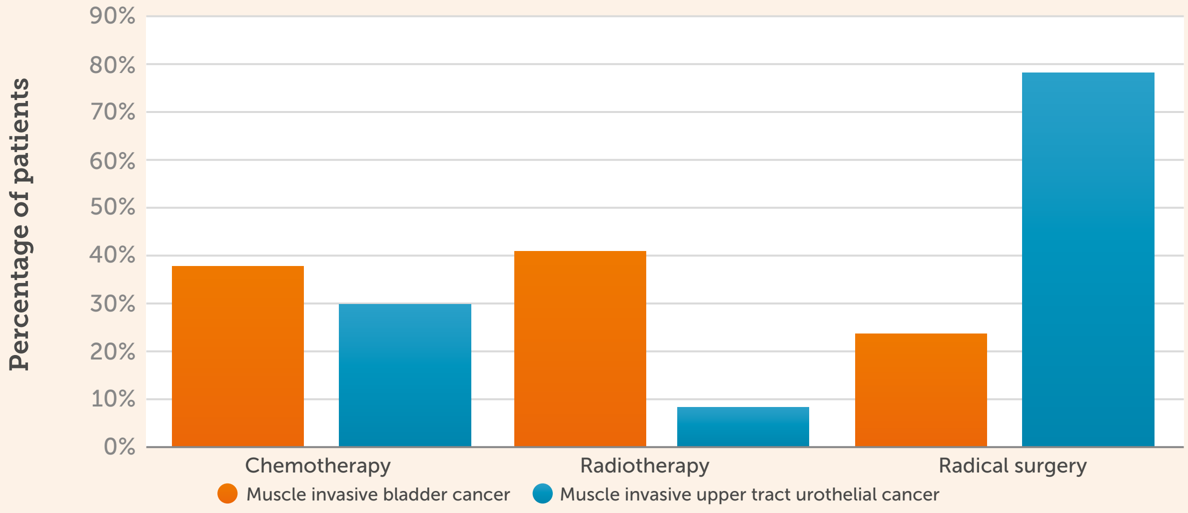




Among 710 patients reviewed, 3.5% were diagnosed with cancer, including bladder cancer. Approximately 41% of people were not referred by their GP using the urgent referral pathway. When referred, 80% of men were referred to urology, whilst the referrals for women were distributed among urology (42%), gynaecology (16%), and ultrasound (17%).

The odds of referral were significantly higher among males and those presenting with blood in pee. These data highlight the potential benefit of faster bladder cancer diagnoses through encouraging GPs to refer suspected bladder cancer using the urgent referral pathway (Zhou et al (2023).

Muscle-invasive bladder and upper tract cancers: treatment



When it comes to treatment rates, the analysis of NCRAS data indicated that 27–29% of people with muscle-invasive bladder cancers did not receive radical surgery or radiotherapy treatment. Given that 75% of the diagnosed were men and 57% were aged over 75, an age- and gender-sensitive approach might further refine the diagnostic and treatment frameworks for bladder cancer in England. Treatment plans should also be influenced by the patient's demographic details and the Cancer Alliance responsible for care. There are significant opportunities for enhancing both diagnostic and treatment frameworks to improve survival rates for bladder cancer patients.

The treatment section of the study showcased yearly trends in therapies used for muscle-invasive bladder and upper urinary tract cancers, including chemotherapy, radiotherapy, and radical surgery.

In terms of survival, the data were compared with other types of cancers and stratified by stage. The comparative survival rate was particularly poor for muscle invasive bladder cancer. The survival rates for bladder cancer were carefully stratified by stage, grade, and cancer location, which allowed for a nuanced understanding of patient outcomes.

Unfortunately, this detailed analysis showed no significant improvement in survival rates over the examined period, which starkly contrasts with advancements seen in the management of other cancer types.

The presence of muscle invasion significantly impacted survival outcomes for bladder cancer. Non-muscle-invasive bladder cancer showed similar survival rates for Grade 1 and 2 cancers, but significantly poorer outcomes for Grade 3. Women experienced worse survival outcomes across all stages when compared to men.

The analysis underscores a worrying stagnation in bladder cancer survival improvements, less than 1% over two years - a tiny and troubling improvement when compared to other types of cancer. This lack of significant progress highlights a pressing need for healthcare systems to address and prioritise the treatment of bladder cancer with the same vigour and innovation applied to other cancers.

Another significant finding was that most bladder cancers and upper tract urothelial carcinomas were not diagnosed via 2-week-wait referrals, highlighting the need to revise the criteria for such referrals to include various patient features and symptoms.

Survival compared to other: (a) average; (b) stratified by stage

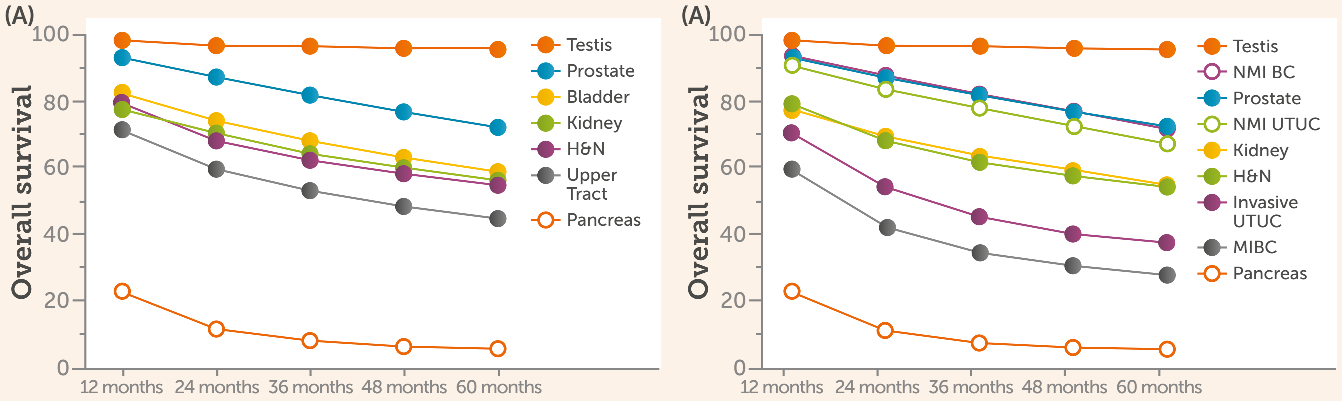
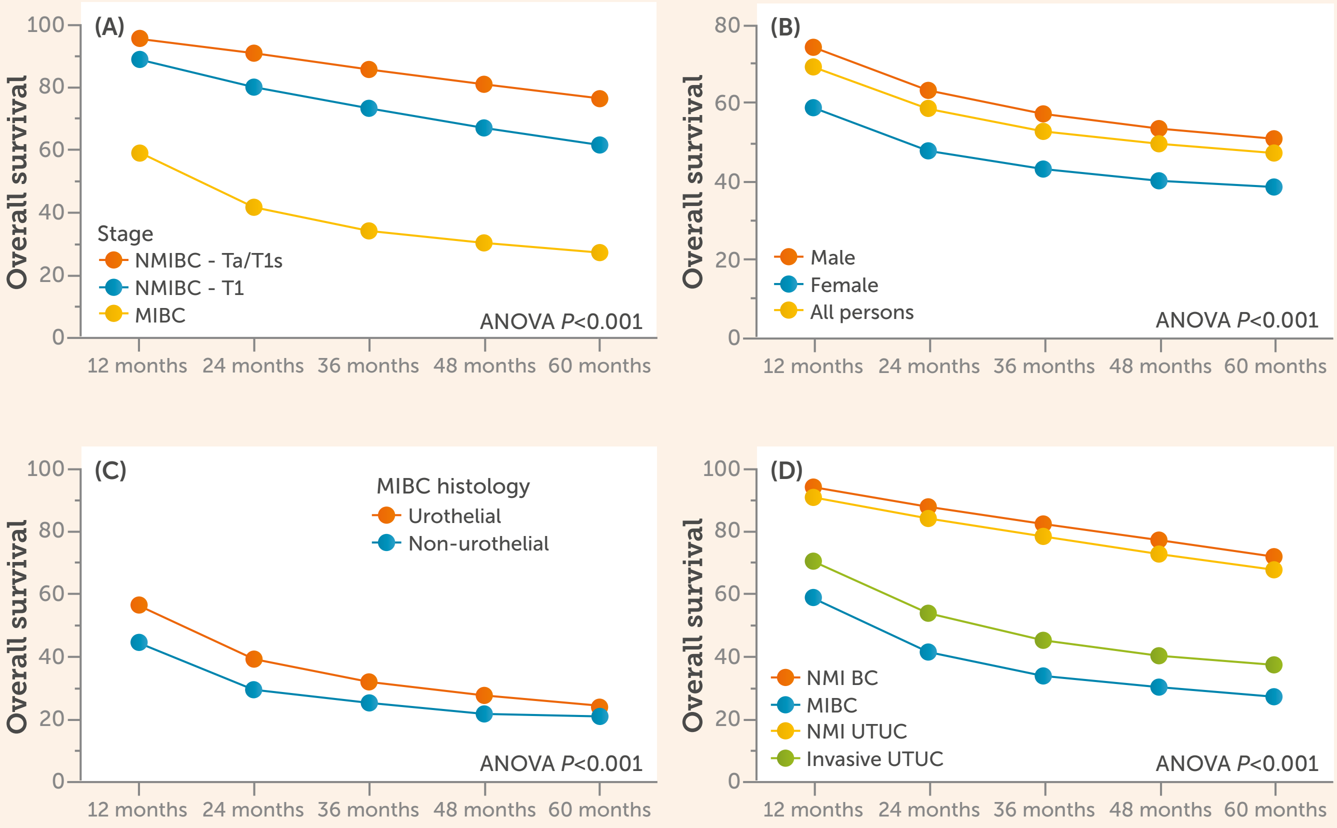


Fig. 5 Overall survival plotted using the Kaplan-Meier method for patients with (**A**) BC with respect to stage. (**B**) sex, (**C**) MIBC with respect to histology, and (**D**) UCC with respect to location (bladder [BC] and upper urothelial tract [UTUC]) and stage.



Improvements in survival could be achieved through greater use of radical treatment, including surgery, radiotherapy, and chemotherapy, especially for those with muscle-invasive disease. A significant portion of muscle-invasive bladder cancer patients do not receive the radical treatment they could benefit from, potentially due to variations in practice, patient factors, or limitations in healthcare access.

By ensuring more patients have access to, and are offered radical treatments tailored to their specific disease stage and overall health, healthcare systems can directly impact survival outcomes. A concerted effort to increase the application of radical treatments where appropriate could significantly reduce mortality rates and improve the quality of life for bladder cancer patients.

2.2

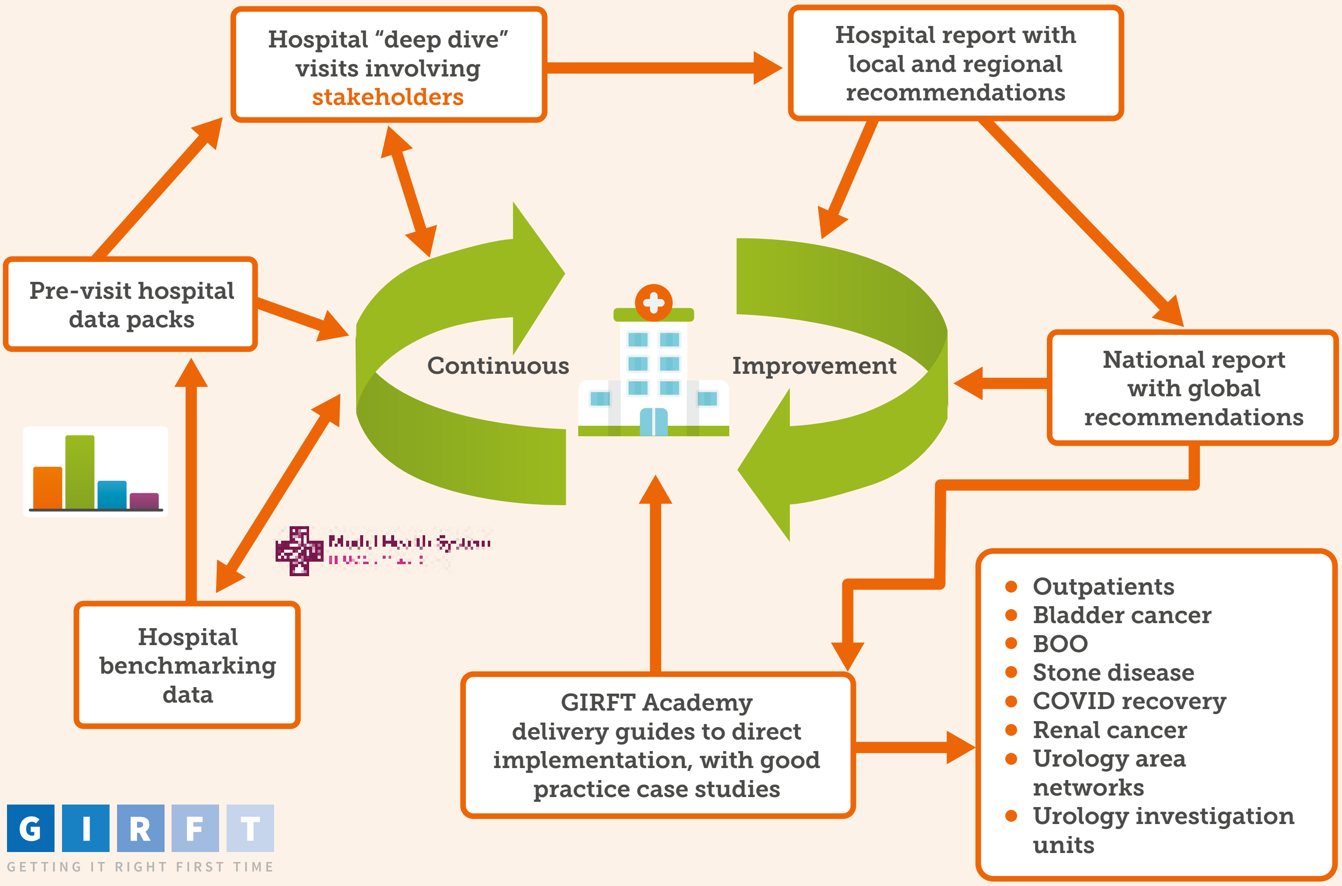
Focus on minimising clinical care variation

GIRFT Urology Pathway: Plans, recent achievements, and challenges in implementation.

Mr John McGrath, as National Clinical Lead for the Getting it Right First Time (GIRFT) programme within NHS England, presented the programme's aims to reduce variation in clinical care and promote best practice in patient care.

The National Health Service (NHS) England and NHS Improvement have collaborated on the 'Getting It Right First Time' (GIRFT) programme, under the guidance of John McGrath, the National Co-Lead for GIRFT Urology. The overarching objective of GIRFT is to streamline the healthcare driven approach and aims to accomplish multiple goals: improve care, reduce variation, benchmark performance, and implement tailored solutions.

GIRFT (urology methodology)



GIRFT
GETTING IT RIGHT FIRST TIME

To this end, the GIRFT methodology includes a range of strategies such as 'deep dives' into specific healthcare units, analysing data packs before visits, and providing post-visit reports that detail observations, workforce recommendations, and areas of best practice.

One of the primary challenges identified by GIRFT is the variation in bladder cancer care, which manifests in a range of issues such as varying performance levels, backlogs in treatment, and recruitment problems. The current model is disproportionately focused on major surgeries, with 17,000 major cancer operations and 173,000 procedures like TURP, TURBT, and URS occurring annually. The programme highlights the need for a more equitable approach that also considers outpatient services, as urology is largely an outpatient/ambulatory specialty, accounting for 750,000 new consultations and 1.5 million follow-up consultations per annum.

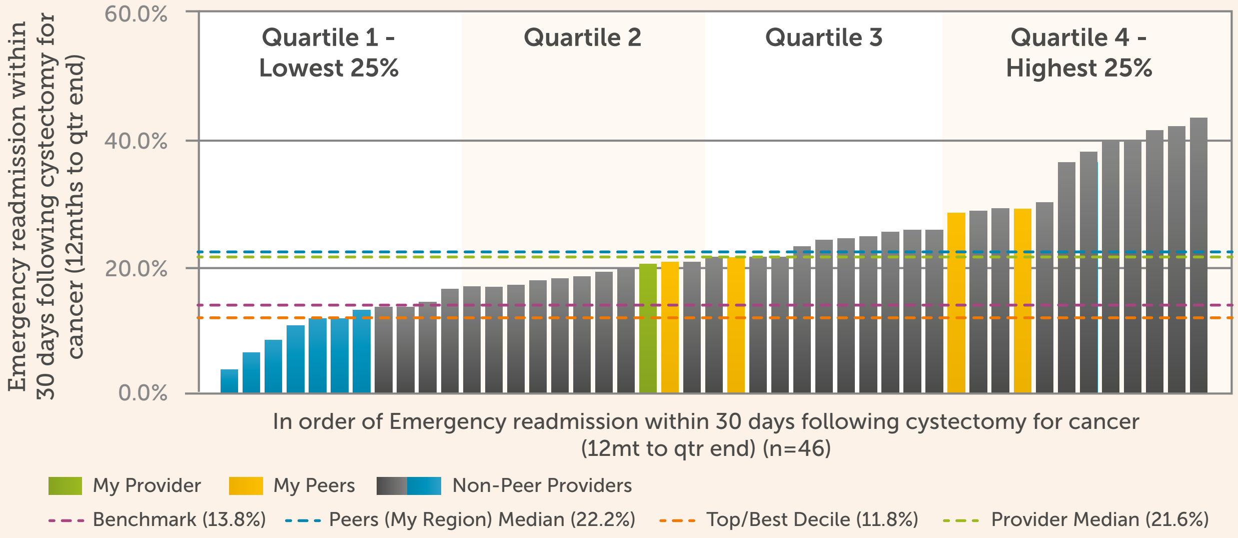
Bladder cancer care per annum:

17,000
major cancer operations

173,000
procedures

750,000
new consultations

Emergency readmission within 30 days following cystectomy for cancer (12mths to qtr end), National Distribution



As part of the solution, the GIRFT programme suggests key pathway components for effective bladder cancer care, which include the ability to see all patients within two weeks of referral, the establishment of Urology Investigation Units for one-stop assessments, and enhanced informational support for patients. These measures are not only aligned with the GIRFT Academy's guidelines but also aim to transform patient experience positively. For instance, GIRFT proposes the standardisation of day-case bladder tumour resections, based on semi-structured qualitative interviews that demonstrated patients' preference for such an approach. Finally, the programme also brings attention to the environmental impact of healthcare, suggesting modifiable hotspots that could significantly reduce carbon footprint, thereby underscoring the need for a holistic, sustainable approach to urology care.

2.3

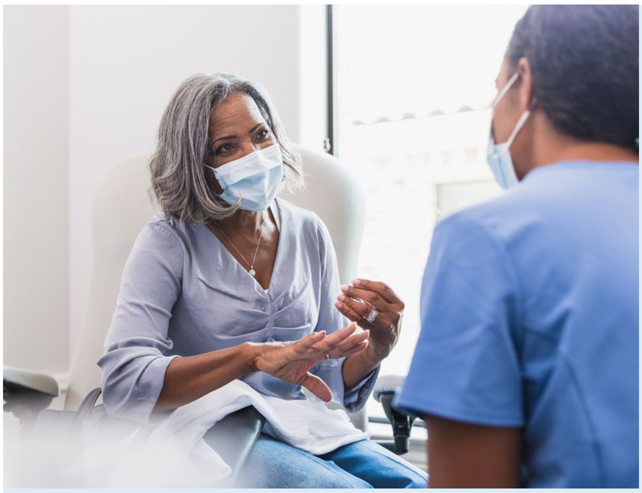
Workforce growth and development

Supporting the development of new Cancer Clinical Nurse Specialists (CNSs)

Hilary Baker presented a nursing workforce development programme that aims to address workforce challenges and barriers faced by NHS Urology Teams.

In response to a range of challenges facing the cancer nursing workforce in the capital, the Pan London Cancer CNS Workforce Development Programme was established in 2021. The programme sets out to pilot a new role that supports the development of Cancer Clinical Nurse Specialists (CNSs).

This new clinical role – the Cancer CNS Development Lead (CDL) provides structured support to new CNSs through their transition to becoming skilled, knowledgeable, confident and autonomous professionals.



“The introduction of the Cancer CNS Development Lead (CDL) role marks a transformative step in cancer care. This role ensures that new Clinical Nurse Specialists (CNSs) are equipped with the support, knowledge, and confidence needed to excel independently. Through this pilot programme, we are committed to nurturing skilled professionals who can provide exceptional, empathetic care to those affected by bladder cancer.”

— Hilary Baker

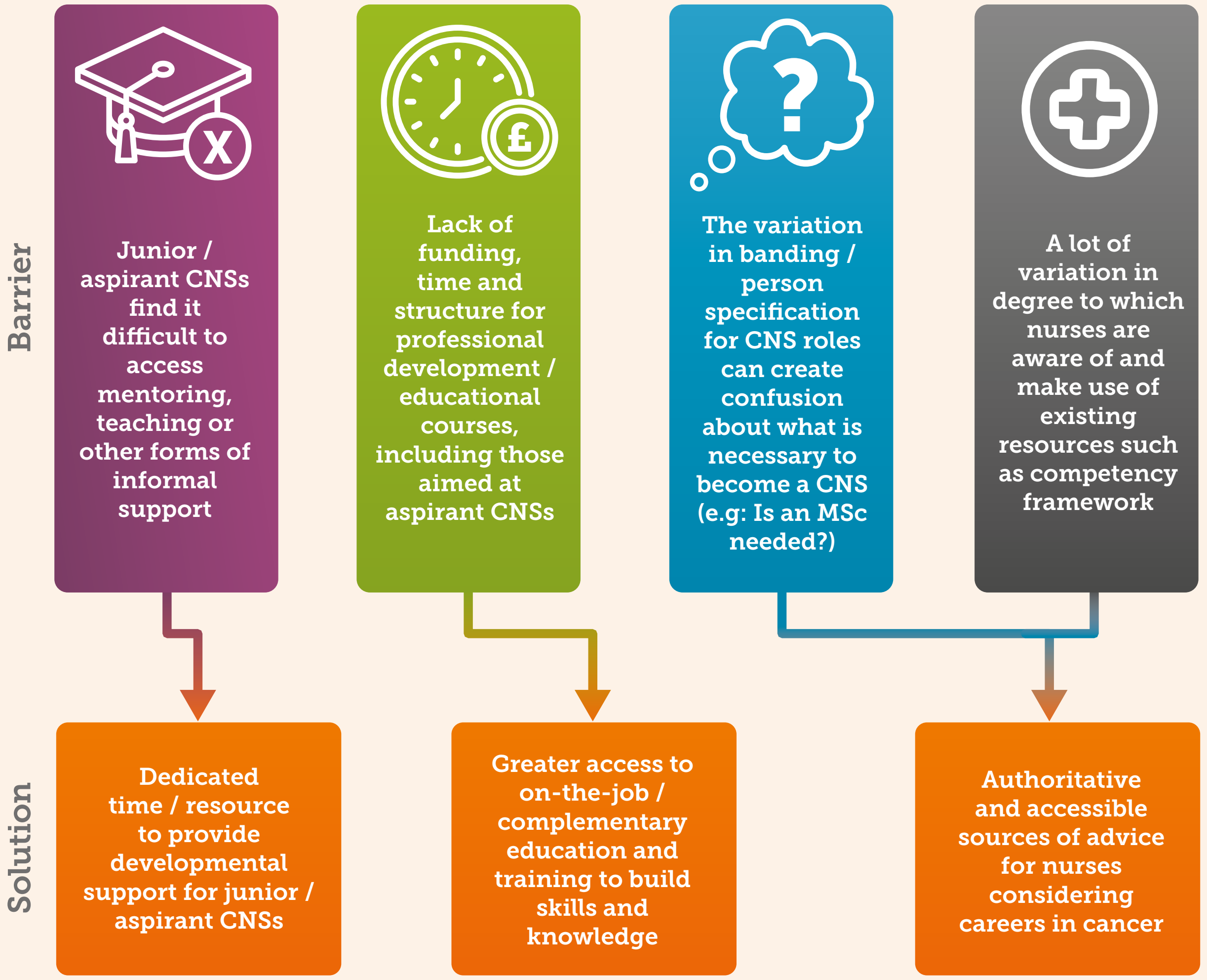
About the pilot programme

The CDL pilot programme of a new nursing leadership role, aimed at supporting aspirant and new CNSs across London, will run for 2 years, and would assess to what end introducing this role would impact on the following objectives:

- Increased numbers of suitable applicants applying for CNS roles in London
- Faster professional development of new CNSs, provides hands-on support to new CNSs, supporting their transition to becoming skilled and knowledgeable autonomous professionals mitigating the impact of the upcoming retirement of large numbers of experienced CNSs
- Improved retention of CNSs
- Provides outreach to other nurses, to encourage transition to CNS roles

The North Central London Cancer Alliance (NCLCA) Pilot Project Team will coordinate this work – in collaboration with Macmillan, Health Education England (HEE) and the clusters of Trusts.

How the new role would help to overcome practical barriers to cancer nursing progression



Barrier

Junior / aspirant CNSs find it difficult to access mentoring, teaching or other forms of informal support

Lack of funding, time and structure for professional development / educational courses, including those aimed at aspirant CNSs

The variation in banding / person specification for CNS roles can create confusion about what is necessary to become a CNS (e.g: Is an MSc needed?)

A lot of variation in degree to which nurses are aware of and make use of existing resources such as competency framework

Solution

Dedicated time / resource to provide developmental support for junior / aspirant CNSs

Greater access to on-the-job / complementary education and training to build skills and knowledge

Authoritative and accessible sources of advice for nurses considering careers in cancer

Evaluating the impact

The target audience includes nurses working in cancer care, student nurses, newly qualified nurses, and internationally trained nurses.

An evaluation agency has been commissioned to evaluate the CDL pilot project and impact of the new nursing role.

The evaluation methodology has been co-developed with the Macmillan Evaluation Team and the LLCNF, adopting an action research approach for continuous learning and adaptation. The final assessment aims to understand the impact of these new roles on personalised care targets, gather staff feedback, and assess the project's overall success and sustainability.

By implementing these measures, the Pan London Cancer CNS Workforce Development Programme aims to provide a comprehensive solution to the staffing challenges in London's cancer nursing workforce in urology, paving the way for improved patient care and career development in the field, and acting as an exemplar for nationwide implementation.

2.4

UK Patient Experience Survey

Key findings from the UK bladder cancer patient survey

Alex Filicevas & Melanie Costin shared insights from a global patient survey that underscored the issues of misdiagnosis and the critical need for emotional support.

The 2021–2022 global bladder cancer patient survey, spearheaded by the World Bladder Cancer Patient Coalition (WBCPC), marked a significant step in understanding the patient experience in bladder cancer. UK-based organisations Fight Bladder Cancer and Action Bladder Cancer participated in this groundbreaking research, along with UK-based bladder cancer patients and carers. The survey was financially supported by multiple pharmaceutical companies and aimed to cover the entire spectrum of patient experiences.

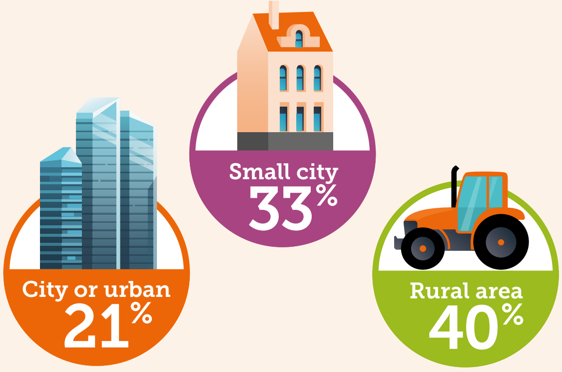
With a total of 208 patient responses and 17 carer responses primarily from respondents over the age of 55, the survey provided comprehensive insights into the UK cohort. Most respondents lived in urban or small-city settings, and the cancers ranged from non-muscle invasive to advanced or metastatic forms of bladder cancer.

Respondent profile in the UK

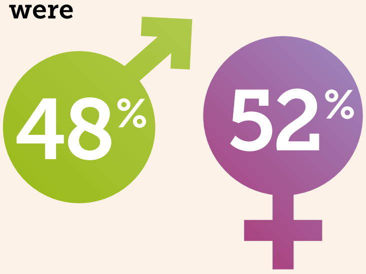
74% were diagnosed with bladder cancer in the past 5-years (2017–2021)

208 Patient responses

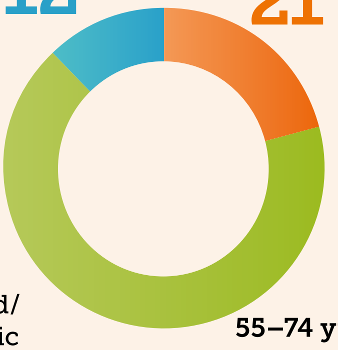
17 Carer responses

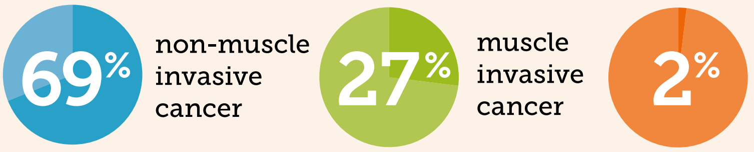


Respondents were



Most respondents were over the age of 55 years





69% non-muscle invasive cancer

27% muscle invasive cancer

2% advanced/ metastatic cancer

50%
did not receive information on peer-support groups or charities

PSYCHOLOGICAL SUPPORT IN THE UK

Lack of effective psychological support at every stage of their cancer pathway

51% were not offered emotional support to help cope with their diagnosis

47% said the long-term emotional impact of treatment for bladder cancer had not been fully addressed and treated

12% were not able to cope with the impact of their diagnosis and treatment

Patient experiences with diagnosis revealed alarming gaps in awareness and information.

A majority, 58%, were not aware of any signs or symptoms of bladder cancer before their diagnosis, and 64% did not know that visible blood in urine could be a sign. Misdiagnosis was also prevalent, with 37% initially diagnosed with a urinary tract infection.

TREATMENT PATHWAYS IN THE UK

55% reported time taken for diagnosis caused them additional worry

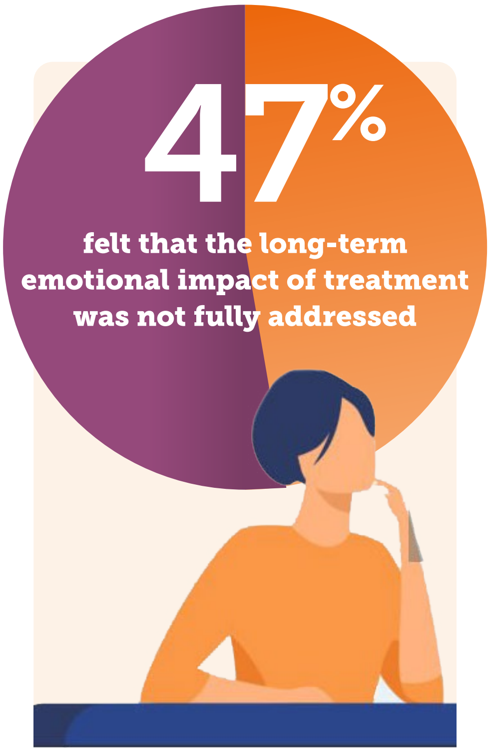
90% did not receive information about clinical trials

TREATMENT INFORMATION

59% needed more information about treatment options and duration

41% needed more information about the side effects of treatment

Concerningly, 55% reported that the time taken for diagnosis caused them additional worry, and nearly half needed more information about what their diagnosis meant. Treatment pathways also displayed room for improvement; for example, 90% did not receive information about clinical trials and 59% needed more details about treatment options.



47%

felt that the long-term emotional impact of treatment was not fully addressed

The impact of bladder cancer and its treatment on daily life was another crucial aspect highlighted in the survey. Financial burdens were felt by 44% of respondents, 24% reported that treatment severely impacted their ability to carry out daily activities, and 15% had to take early retirement due to their condition. Emotional well-being was also negatively affected; 47% felt that the long-term emotional impact of treatment was not fully addressed, and over half were not offered any emotional support.

The survey underscores the urgent need for comprehensive patient education, timely diagnosis, and emotional, as well as financial, support systems.

44%

said their financial situation was impacted due to bladder cancer

FINANCIAL TOXICITY IN THE UK

The financial implications of cancer care and treatment are significant for many people affected by bladder cancer

44% said their financial situation was impacted due to bladder cancer

11% severely

19% to some extent

15% slightly

GROUP SESSIONS

A summary of discussions, findings, and proposals from the group sessions on the three pivotal themes.

The Exemplar Summit engaged attendees in structured breakout groups facilitated by Alex Filicevas, Executive Director of the World Bladder Cancer Patient Coalition. These groups were focused on three critical areas:

1. **Establishing an exemplar pathway for bladder cancer care**
2. **Growing and developing the bladder cancer workforce**
3. **Improving awareness, support, and patient involvement**

In these sessions, participants shared examples of best practices in their experience, identified areas where current practice falls short, and discussed who is best placed to address these gaps. The role of Fight Bladder Cancer in supporting these initiatives was also explored.

This was followed by 45 minutes of group presentations where priorities were set based on the discussions, thereby providing actionable insights and setting the stage for collaborative efforts in bladder cancer care improvement.

3.1 Putting in place an exemplar pathway

A What concrete steps are needed to deliver quicker referral and diagnosis for those with suspected bladder cancer and implement a standardised pathway across the UK?

Suggestion 1: Patient self referral, possibly to a community diagnostic centre (e.g. Patients with frank haematuria). Trained individual for triage (e.g. CNS)

Suggestion 2: Dedicated Bladder Cancer outpatient lists

Suggestion 3: GP education / training, improved 2 week wait form

B What are examples of best practice at work in your experience?

Example 1: Triage of 2 week wait (suspected GU Cancer)

Example 2: Pre investigation with CT / ultrasound scan

C What are examples of where current practice is falling short of best practice?

Example 1: Capacity, Workforce

Example 2: Lack of GP education / awareness

D What can Fight Bladder Cancer do to support?

Continued GP education

Health promotion

E What can be done at the local level?

Robust diagnostic pathways

Agreed 2 week wait form

One group presented a comprehensive strategy to enhance care for people affected by bladder cancer. This includes advocating for patient self-referrals to hasten diagnoses and addressing challenges like limited operating capacity. They stressed the necessity of structured operating schedules, ample pre-assessment opportunities, and sufficient surgeon availability. Additionally, they recommended pre-screening patients to ensure swift and accurate test allocation. Furthermore, the group emphasised the importance of continuous education for General Practitioners, considering their limited experience with bladder cancer. By advocating for the development of standardised educational materials and diagnostic timelines, they aim to foster coordinated, high-quality care across healthcare providers.

A What concrete steps are needed to deliver quicker referral and diagnosis for those with suspected bladder cancer and implement a standardised pathway across the UK?

Suggestion 1: *Primary care education*

Suggestion 2: *Standardised national fast track criteria*

Suggestion 3: *One stop haematuria clinic / extended CNS role*

B What are examples of best practice at work in your experience?

Example 1: *Bladder cancer CNS / Cystoscopist*

Example 2: *Implementation of UIU's*

C What are examples of where current practice is falling short of best practice?

Example 1: *Lack of capacity to achieve recommended pathways*

Example 2: *Lack of standardised pathway*

D What can Fight Bladder Cancer do to support?

Raising awareness

Lobbying national drivers for change

E What can be done at the local level?

UIU's

Faster diagnosis designated staff

Addressing the issue of quicker referral and diagnosis for suspected bladder cancer patients in the UK requires a unified, systemic approach that tackles multiple dimensions. One group spotlighted key areas needing improvement, including the call for enhanced education within community GP practices and improved coordination between GPs and nurse specialists. Another concern is the lack of standardisation in Fast-Track criteria forms across the UK, which particularly delays the diagnosis of women treated for urinary tract infections before discovering underlying bladder tumours.

A proposed 'one-stop haematuria clinic' could alleviate some of these issues by expanding the role of Clinical Nurse Specialists (CNSs) to conduct flexible cystoscopies and ultrasounds, taking some pressure off consultants.

Best practices suggest the incorporation of more CNSs as Tier 2 practitioners trained in specific procedures like diathermy, as well as the establishment of Urgent Investigation Units (UIU's), offering comprehensive diagnostic tests in one visit. Standardising treatment pathways across trusts is crucial for preventing disparities in patient care.

On a broader scale, there is a consensus on engaging with national platforms like Urological Surgeon's meetings and working with advocacy groups such as 'Fight Bladder Cancer' to stimulate change. Local priorities encompass faster diagnostics, designated staff training, value-adding educational programmes for CNSs, and crucially, the allocation of time for CNSs to comprehensively discuss diagnosis and treatment plans with patients.

3.2 Growing and developing the bladder cancer workforce

A What concrete steps are needed to ensure that the bladder cancer workforce is sustainable, and that CNSs and other clinicians are supported to deliver comprehensive and high-quality holistic care?

Suggestion 1: *Clearer cancer development path required*

Suggestion 2: *Greater protection for research time*

Suggestion 3: *Improved succession planning*

B What are examples of best practice at work in your experience?

Example 1: *Recording patient consultations for patients to take home*

Example 2: *Introducing junior CNS role*

D What can Fight Bladder Cancer do to support?

Sponsor education

Online education modules and F2F

Nurse surveys and forum groups to lobby management

E What can be done at the local level?

Cancer Alliance sponsoring posts

Succession planning

Dedicated support for patients while waiting

Delays in pathology

Introduce one stop shops / CT

Investing in diagnostic centres

One group focused on the sustainability of the workforce, especially within the context of broader challenges facing the NHS. Key recommendations include establishing clear career development paths for new nurses, carving out dedicated time for research activities within the nursing workforce, and enhancing succession planning to ensure a smooth transition between retiring and incoming nurses. Best practices cited include recording patient consultations to reduce the need for follow-up calls and introducing junior Clinical Nurse Specialist (CNS) roles to bridge the experience gap for aspiring nurses.

To support these initiatives, proposals were made for sponsoring nurse education, developing online modules, conducting surveys or focus groups to understand need, and appealing to management for necessary changes. At the local level, conversation touched on potential funding of dedicated nursing posts through cancer alliances, offering patient support during waiting periods, and the necessity for ongoing investment in diagnostic centres. The underlying theme was a comprehensive approach to workforce development and patient support to enhance overall healthcare delivery.

A What concrete steps are needed to ensure that the bladder cancer workforce is sustainable, and that CNSs and other clinicians are supported to deliver comprehensive and high-quality holistic care?

Suggestion 1: *Providing & supporting education of current workforce*
Suggestion 2: *Dedicating pathways for rotating student nurses through CNS teams*
Suggestion 3: *Policy documents to support business cases & data collection. Mapping the pathway*

B What are examples of best practice at work in your experience?

Example 1: *Pathway navigators to free up CNS time*
Example 2: *One stop haematuria clinics and use of TULA. Dedicated TURBT lists*
Example 3: *Dedicated bladder MDT*

C What are examples of where current practice is falling short of best practice?

Example 1: *Radiology / Histology reporting*
Example 2: *Urology workforce, failure to recruit and retain*
Example 3: *No urology unit*

D What can Fight Bladder Cancer do to support?

Support funding requests
National campaigns comparable to prostate cancer / breast cancer
Need a figurehead
Social media presence

E What can be done at the local level?

Bladder cancer support groups
Visit GP practices & practice nurses

Addressing the CNS workforce, one group focused on evidence-based data sourcing information from various reports and policy documents, including the GIRFT report and the National Cancer Experience, to support the compelling business case for dedicated bladder cancer CNS roles. Demonstrating their necessity in managing patient pathways from non-muscle invasive stages, through to end-of-life care. They explored innovative approaches to education, encouraging student nurse rotations through different oncology settings, with an emphasis on urology.

Best practices experience pointed to the efficacy of pathway navigators – new roles that assist CNSs with administrative duties – and implementation of one-stop haematuria clinics and dedicated TURBT lists. Additionally, there is a growing need to address the broader urology workforce gap, from radiologists to consultant urologists. For public advocacy and awareness, they highlighted the need for high-profile figureheads and social media outreach. Local action plans could also include more bladder cancer support groups and educational initiatives within GP practices for both GPs and practice nurses.

3.3

Improving awareness, support, and patient involvement in care

A What concrete steps are needed to implement best-practice procedures and guidelines for communicating holistic and psychological support to patients, carers and family members and to ensure that patients are empowered to make informed decisions about their care?

Suggestion 1: Stronger consistent use of holistic needs assessment with involvement from the right specialists / members of staff

Suggestion 2: Clear information to be communicated from point of diagnosis and stronger communication at point of GP referral

Suggestion 3: Investment is needed across entire workforce e.g. booking teams could be upskilled to support patients better (look after and nurture workforce)

B What are examples of best practice at work in your experience?

Example 1: GPSI – GP with specialist interests

Late affects clinic – to bridge gap between primary and secondary care and signpost patients to bespoke care services (open door policy)

Example 2: CNS teams deliver results – check understanding for patients etc.
All patients leave clinical rooms with CNS contact details / printed info and booklets / support group info

C What are examples of where current practice is falling short of best practice?

Example 1: Feeling that MDT expertise is there but not enough specialists to go round – lack of resources

Example 2: GP referrals / communication / no CNS consistently at 2WW one stop

D What can Fight Bladder Cancer do to support?

Providing information booklets with questions patients might want to ask

E What can be done at the local level?

Greater involvement from community local centres

Drive greater peer support

Another group placed a premium on patient engagement and holistic support, aiming to ensure that every patient knows who to contact for various healthcare needs. While a range of multidisciplinary services is offered—including psychological and dietary guidance as well as physical therapy—many clinics grapple with a dearth of resources across all areas. To address this, participants called for a more consistent approach to holistic needs assessments so that every person with bladder cancer leaves with a detailed care plan. This should be orchestrated by team members with specialised skills who can identify and signpost patient needs effectively. Information dissemination is also critical, especially at the challenging point of diagnosis. Investment in communication skills is needed not just among healthcare professionals but also across administrative teams, underscoring the importance of broad-based training in customer support for everyone involved in patient care. The Fight Bladder Cancer charity was identified as a valuable external resource that could be better leveraged, particularly for its educational materials and potential role in setting up peer support groups. The group emphasised that there is an urgent need for greater resources and more integrated communication between primary and secondary healthcare providers to improve patient care and overall experience.

A What concrete steps are needed to implement best-practice procedures and guidelines for communicating holistic and psychological support to patients, carers and family members and to ensure that patients are empowered to make informed decisions about their care?

Suggestion 1: Dedicated bladder cancer team (urologist, CNS, oncologist)
Suggestion 2: Appropriate signposting to appropriate resources (inc videos)
Suggestion 3: Review / update NICE guidelines – implementation
Suggestion 4: Better appreciation of mental wellbeing

B What are examples of best practice at work in your experience?

Example 1: Joint clinics (Urology / Oncology)
Example 2: Holistic / Personalised care

C What are examples of where current practice is falling short of best practice?

Example 1: Not every patient has dedicated CNS
Example 2: GP referral delay

D What can Fight Bladder Cancer do to support?

Produce accessible & inclusive unbiased information

Collaborate with BAUS / BAUN

E What can be done at the local level?

Discussion!

One group proposed to elevate best practices in the delivery of holistic and psychological support for bladder cancer patients, carers, and families. The conversation underscored the need for dedicated bladder cancer teams – comprising urologists, CNSs, and oncologists – specifically for high-risk, non-muscle invasive cancer cases. Such specialised teams would ensure continuity of care, enabling rapid and informed decision-making for patients.

The proposal highlighted the necessity for clear signposting to appropriate resources, especially since some patients experience delays in treatment decision-making due to literacy issues. Collaborative efforts are essential, working in conjunction with organisations to produce accessible, unbiased, and inclusive information that supports patient and carer decision-making.

Updating and revising NICE guidelines were identified as crucial, both for treatment procedures and holistic patient care.

Addressing mental well-being and the psychological challenges faced by patients was also emphasised. Best practices, such as the introduction of joint oncology and urology clinics were discussed as vital tools for evaluating radical treatments, especially for muscle-invasive bladder cancer cases.

However, there was recognition that a standardised approach may not be suitable for all patients, particularly those who are overwhelmed by a cancer diagnosis, necessitating additional interventions for these individuals to be empowered in their care. Gaps in the current system were also noted, including the lack of dedicated CNSs in all settings and delays related to GP education and primary care involvement.

The role of Fight Bladder Cancer and other external organisations in producing comprehensive, easy-to-understand resources, potentially even in video format, was highlighted, along with the need for collaboration with professional associations like the British Association of Urological Nurses and the British Association of Urological Surgeons to address information gaps. The discussion concluded with an urgent call for local-level initiatives to tackle these challenges effectively.

EXPERT PANEL DISCUSSION

A synthesis of viewpoints from the diverse panel, highlighting common themes, unique perspectives, and potential actionable steps

Following the breakout sessions and group presentations, an expert panel discussion offered a multifaceted analysis of the key themes that emerged. Chaired by Alex Filicevas, Executive Director of the World Bladder Cancer Patient Coalition, the panel featured esteemed representatives from diverse sectors including Melanie Costin, Bladder Cancer Patient & Support Services Manager from Fight Bladder Cancer; Dr. Vinay Patroe, former Medical Director at Janssen UK; Hilary Baker, Clinical Lead for the North Central London Cancer Alliance; and John McGrath, Consultant Urologist at the Royal Devon & Exeter NHS Foundation Trust.

The panellists had the opportunity to respond to ideas presented earlier, providing their valuable insights based on individual expertise in areas like clinical oncology, urology, nursing, and patient support. The discussion thus served as a convergence point for various stakeholders to align their understanding and commitment towards improving bladder cancer care.

One of the most striking areas of consensus reached during the discussion was the urgent need to **raise awareness** about the early detection of bladder cancer. The panel agreed that a lack of awareness often leads to delayed diagnosis and, consequently, hampers effective early-stage treatment.

This area of agreement closely related to another recurring theme: **the importance of primary care providers**. Panellists emphasised that general practitioners and primary care services often serve as the initial point of contact for patients, and thus play a crucial role in guiding them toward specialised treatment pathways.

Workforce issues were another key topic. There was a pointed discussion about the challenges specific to staffing in the field of urology. The panellists unanimously agreed on the need for dedicated multidisciplinary teams that can manage bladder cancer treatment effectively. The panel noted the potential for senior nurses to engage more deeply in research and data collection. This underscores the importance of a strong workforce that is versatile. Through research and data collection, the workforce will become better prepared to commission changes that will improve patient care.

The conversation also underscored the vital importance of tools for **shared decision-making** between patients and healthcare professionals. Such tools are seen as indispensable in navigating the myriad of treatment options available.

The discussion also illuminated several unique viewpoints. For instance, while there was talk about ideal solutions, the panel cautioned against letting "the perfect be the enemy of the good." Instead, they advocated for practical and actionable solutions that could bring about immediate improvements in patient care.

Another aspect that received attention was **patient-centricity**. The development of resources like patient information booklets and educational videos was cited as a promising approach to empower patients in their healthcare journey.

Data-driven change was another topic that generated a lot of interest. The panel agreed that **transparent and accurate data** could be transformative in creating meaningful changes in patient care. This was tied to an observation about an emerging national momentum for **standardised treatment protocols** in bladder cancer care. The panellists urged all stakeholders to seize this enthusiasm and translate it into collective benefits for patients and healthcare providers alike.

The group highlighted the critical role of **personalised medicine in cancer treatment**, particularly for patients with high-risk, muscle-invasive, advanced, or inoperable bladder cancer. Access to genomic testing is essential for these people to receive effective, tailored treatment strategies.

To bring about effective changes, the panel proposed several actionable steps. These included the **development of public awareness campaigns** targeted at both the general populace and healthcare providers, **the creation of shared decision-making tools**, the development of **training modules for general practitioners, enhanced collaboration** among different stakeholders, the **utilisation of data analytics tools** for better care pathways and outcomes, and the acceleration of the **development of educational materials and resources** for patients, including those in digital formats like videos.

When asked which single intervention could have the most impact on patient care if money were no object, the consensus leaned heavily toward investing in the workforce, emphasising that facilities are secondary to skilled and knowledgeable personnel. The idea of self-referral was also floated as a potential life-saving measure that could empower patients.

RECOMMENDATIONS

1 Establishing an exemplar pathway for bladder cancer care in the UK

The following are recommendations to improve bladder cancer services by delivering quicker referral and diagnosis for those with suspected bladder cancer and to implement a standardised pathway across the UK.

PATIENT SELF-REFERRALS: Enable self-referral pathways for quicker diagnosis.

Driving Stakeholders: NHS England Transformation Directorate (previously NHS Digital), NHS Wales Informatics Service, Northern Ireland Health and Social Care Board, Private Healthcare Providers, Getting It Right First Time (GIRFT)

STANDARDISATION OF FAST-TRACK CRITERIA: Uniformly implement Fast-Track criteria forms across the UK to expedite diagnoses, particularly for women misdiagnosed with urinary tract infections.

Driving Stakeholders: NICE (National Institute for Health and Care Excellence), All Wales Medicines Strategy Group, Northern Ireland Regulation and Quality Improvement Authority, Getting It Right First Time (GIRFT)

ONE-STOP HAEMATURIA CLINICS: Develop these clinics to expand the role of Clinical Nurse Specialists (CNSs) in conducting diagnostic tests and expedite diagnosis.

Driving Stakeholders: NHS England, Cancer Alliances, NHS Wales, All Wales Medicines Strategy Group (AWMSG), Local Health Boards, Health and Social Care (HSC) Northern Ireland, Individual Hospitals, NHS Trusts, Getting It Right First Time (GIRFT), British Association of Urological Surgeons (BAUS)

COLLABORATION WITH NHS DIRECT SERVICES: Advocate for a multidisciplinary review team comprising clinical experts, IT specialists, and patient representatives to optimise the ‘blood in pee’ NHS 111 referral pathway.

Driving Stakeholders: NHS111, NHS 111 Wales, and Northern Ireland Direct

INTEGRATED GENOMIC TESTING ACCESS: Ensure that patients with high-risk, muscle-invasive, advanced, or inoperable bladder cancer have guaranteed access to genomic testing.

Driving Stakeholders: National Health Service (NHS) Genomic Medicine Service, Cancer Research UK, Genomics England, NHS Trusts, and Private Healthcare Providers.

ENGAGEMENT WITH REGULATORY BODIES: Encourage NICE, the All-Wales Medicines Strategy Group, and Northern Ireland Medicines Optimisation Quality Framework to review and update their Bladder Cancer Guidelines.

Driving Stakeholders: Charities like Fight Bladder Cancer as well as professional bodies like the British Association of Urological Nurses (BAUN), Royal College of Nursing (RCN), Royal College of General Practitioners (RCGP), British Association of Urological Surgeons (BAUS)

OPERATIONAL EFFICIENCY: Increase operating capacity through dedicated operating lists, pre-assessment slots, and ensuring adequate surgeon availability.

Driving Stakeholders: Individual Hospitals and NHS Trusts

ROUTINE AUDITS: Advocate for National Clinical Audit and Patient Outcomes Programme and the Northern Ireland Health and Social Care Board to conduct regular audits of bladder cancer care pathways to highlight bottlenecks and areas of potential improvement.

Driving Stakeholders: Charities like Fight Bladder Cancer, and professional bodies like the Royal College of Radiologists (RCR), the British Association of Urological Nurses (BAUN), the Royal College of Nursing (RCN), the Royal College of General Practitioners (RCGP), and the British Association of Urological Surgeons (BAUS)

PHARMACEUTICAL ENGAGEMENT: Engage pharmaceutical companies to accelerate access to novel treatments through more UK clinical trials, compassionate use programmes, and early access programmes.

Driving Stakeholders: Charities like Fight Bladder Cancer, and professional bodies like the Royal College of Radiologists (RCR), the British Association of Urological Nurses (BAUN), the Royal College of Nursing (RCN), the Royal College of General Practitioners (RCGP), and the British Association of Urological Surgeons (BAUS)

STANDARDISATION OF CARE RECORDS: Enable a unified system of care records focused around using the Service User's NHS Number/N&C Number as the primary identifier.

Driving Stakeholders: NHS England Technology Live Services directorate, NHS Wales Informatics Service (NWIS), Northern Ireland Health and Social Care Board (HSCB)

IMPROVING HEALTH TECHNOLOGY ASSESSMENT: Collaborative meetings should be held to identify current bottlenecks or challenges in adopting Project Orbis and the Innovative Licensing and Access Programme. Based on these discussions, short-term and medium-term objectives with clear timelines should be set to allocate resources and streamline processes to expand these programmes and improve access to innovative medicines and treatments for bladder cancer.

Driving Stakeholders: The Medicines and Healthcare Products Regulatory Agency, the Welsh Medicines Information Centre, and the Northern Ireland Medicines Optimisation Quality Framework

2 Strengthening the bladder cancer healthcare workforce

The following are recommendations to ensure that the whole bladder cancer workforce is sustainable now and in the future, with Clinical Nurse Specialists and other clinicians supported to deliver comprehensive and high-quality holistic care to bladder cancer patients.

EDUCATION AND COORDINATION: Develop nationally agreed-upon educational content and diagnosis timelines for General Practitioners (GPs) and CNSs. Allocate resources to fund education for nurses, specifically on bladder cancer, enhancing the skills and competencies necessary for improved patient care in this area.

Driving Stakeholders: Getting It Right First Time (GIRFT), The Workforce, Training and Education Directorate (previously Health Education England), Health Education and Improvement Wales, and the Department of Health in Northern Ireland, as well as professional bodies like the British Association of Urological Nurses (BAUN), Royal College of Nursing (RCN), Royal College of General Practitioners (RCGP), British Association of Urological Surgeons (BAUS)

CAREER DEVELOPMENT: Establish clear career paths for new nurses and promote career progression programmes specifically for bladder cancer care professionals that involve leadership training, opportunities for research and innovation, and enhanced professional development resources.

Driving Stakeholders: Getting It Right First Time (GIRFT), the Workforce, Training and Education Directorate (previously Health Education England), Health Education and Improvement Wales, and the Department of Health in Northern Ireland, as well as professional Bodies like the British Association of Urological Nurses (BAUN), Royal College of Nursing (RCN), and British Association of Urological Surgeons (BAUS)

RESEARCH TIME: Allocate dedicated time for research within the nursing workforce.

Driving Stakeholders: NHS Trusts and Academic Institutions, Getting It Right First Time (GIRFT)

SUCCESSION PLANNING: Implement robust succession and career plans for retiring and incoming nurses respectively, to better support bladder cancer experts throughout their careers.

Driving Stakeholders: Integrated Care Boards, Health Boards, and Health and Social Care Trusts, Individual Hospitals and NHS Trusts, Getting It Right First Time (GIRFT)

JUNIOR CNS ROLES: Introduce junior CNS roles to bridge experience gaps and sponsor further education.

Driving Stakeholders: NHS England, NHS Wales, Health and Social Care (HSC) Northern Ireland, Getting It Right First Time (GIRFT)

FUNDING: Explore local funding options for dedicated nursing posts through Cancer Alliances.

Driving Stakeholders: Cancer Alliances, Local Health Boards, Individual Hospitals, Local Authorities, NHS Trusts, Getting It Right First Time (GIRFT)

WORKFORCE EVALUATION: Conduct a comprehensive assessment of Clinical Nurse Specialist capacity in alignment with the NHS Long Term Workforce Plan to ensure adequate staffing and resource allocation for bladder cancer.

Driving Stakeholders: NHS England, NHS Wales, Health and Social Care (HSC) Northern Ireland

3 Boosting awareness, support, and participation throughout the bladder cancer pathway

The following are recommendations to implement best-practice procedures and guidelines for communicating holistic and psychological support to patients, carers and family members, and ensure that patients are empowered to make informed decisions about their care.

AWARENESS CAMPAIGNS: Collaborate with NHS bodies to conduct national awareness campaigns to improve early diagnosis rates.

Driving Stakeholders: Fight Bladder Cancer, NHS England, Public Health England, Public Health Wales, Public Health Agency Northern Ireland

EXTERNAL COLLABORATION: Leverage external charities like Fight Bladder Cancer for educational materials and peer support.

Driving Stakeholders: Healthcare professionals and hospitals

CLEAR SIGNPOSTING: Incorporate references to patient support services in NHS bladder cancer resources.

Driving Stakeholders: NHS England, NHS Wales Informatics Service, Health and Social Care Northern Ireland

MENTAL WELL-BEING: Address mental well-being challenges faced by patients.

Driving Stakeholders: Mental Health Trusts (England), Health Boards (Wales), Health and Social Care Trusts (Northern Ireland), and Fight Bladder Cancer

TECHNOLOGY UTILISATION: Commission pilot projects within select regions or hospitals with a focus on upgrading the NHS Wayfinder Service / HSCNI Online to enable people with bladder cancer to access information about their referrals, appointments, test results, and waiting times more easily.

Driving Stakeholders: NHS England Transformation Directorate (previously NHS Digital), NHS Wales, and Health and Social Care in Northern Ireland

MONITORING PATIENT EXPERIENCE: Regularly report on the National Cancer Patient Experience Surveys specific to bladder cancer.

Driving Stakeholders: NHS England, Care Quality Commission (CQC), Healthcare Inspectorate Wales, Regulation and Quality Improvement Authority (RQIA), Fight Bladder Cancer, Getting It Right First Time (GIRFT)

PROMOTING CLINICAL RESEARCH: Increase availability and accessibility of information about clinical research and new treatments for bladder cancer, while providing clear guidelines on how individuals can get involved.

Driving Stakeholders: National Institute for Health Research (NIHR), Health and Care Research Wales, Northern Ireland Clinical Trials Unit (NICTU)

POTENTIAL CHALLENGES AND SOLUTIONS

Implementing the comprehensive recommendations outlined for the improvement of bladder cancer care in the UK faces multiple challenges. These range from the complexities of a diversified healthcare system across England, Wales, Scotland and Northern Ireland, to potential bottlenecks in operational efficiency and regulatory approvals. Another layer of uncertainty stems from the upcoming general election in the near future. A change in the UK government could lead to shifts in healthcare policy priorities, funding, and leadership, thereby affecting the momentum of these initiatives.

To overcome these challenges, a multi-pronged approach is vital. Stakeholder alignment from NHS bodies, private healthcare providers, and relevant professional associations is key to the success of these recommendations. Regular audits and feedback mechanisms can help to adapt strategies in real-time and to ensure that guidelines, such as Fast-Track Criteria and 'blood in pee' referral pathways, are uniformly implemented across regions. Moreover, to buffer against the potential impact of political changes, early engagement with policymakers and the creation of non-partisan advocacy groups can help secure long-term commitment to these initiatives.

Partnerships with educational institutions, professional bodies, and charities can also fill resource and knowledge gaps, thereby fortifying the implementation of these recommendations across the board.

THE WAY FORWARD

Next steps in improving bladder cancer care

It is crucial to acknowledge that while the challenges facing bladder cancer care are multifaceted, they are not insurmountable. The policies and initiatives outlined provide a comprehensive roadmap for stakeholders, ranging from healthcare professionals and administrative staff, to patients and their support networks. It is a call to action for a collaborative approach that involves regulatory bodies, educational institutions, and the healthcare workforce. The aim is to build a bladder cancer care ecosystem that is resilient, efficient, and, most importantly, patient-centric.

The next immediate steps involve garnering support for the initiatives detailed in the 'Recommendations' section. Stakeholders must come together to advocate for the adoption and implementation of these policies at both national and local level. Advocacy efforts should focus on securing commitments for educational investments, workforce development, and technological enhancements that will tangibly improve patient care. Moreover, data collection and monitoring systems must be put in place to regularly evaluate the efficacy of the newly implemented policies and to highlight areas that require further intervention.

Looking ahead, it is essential that all stakeholders remain committed to a continuous cycle of evaluation, adaptation, and implementation. The healthcare landscape is ever-evolving, influenced by advancements in medical research, technology, and best practices in patient care. In this dynamic context, maintaining the status quo is not an option.

This white paper should therefore serve not only as a guide but also as a living document that will be updated regularly to reflect new insights, challenges, and opportunities for enhancing bladder cancer care in the UK.

GLOSSARY

All.Can International: An organisation aiming to improve efficiency in cancer care.

BAUN: British Association of Urological Nurses, a professional community for urology nurses.

BCG Treatment: Bacillus Calmette-Guerin treatment, a type of in-bladder treatment for bladder cancer.

Bladder Buddy: A patient or carer support role within the Fight Bladder Cancer community.

Bladder Cancer Workforce: The team of medical professionals and others specialising in treating and managing bladder cancer.

BOO: Bladder outlet obstruction. A condition in which the flow of urine is partially or completely blocked, leading to difficulty in emptying the bladder.

Care Quality Commission (CQC): Independent regulator of health and social care services in England.

Clinical Care Variations: Differences in the quality or type of medical care provided to patients.

CNS: Clinical Nurse Specialist.

Department of Health in Northern Ireland: Department responsible for public health policy and healthcare services in Northern Ireland.

Early Diagnosis: Detecting a disease in its initial stages, often crucial for effective treatment.

Exemplar Pathway: A proposed ideal sequence of steps for bladder cancer diagnosis and care.

FBC: Fight Bladder Cancer.

Fight Bladder Cancer: A charitable organisation focused on supporting those affected by bladder cancer.

Framework: The care framework for bladder cancer.

GIRFT: Getting It Right First Time, a programme aimed at reducing variations in clinical care.

Health and Care Research Wales: A Welsh organisation responsible for overseeing and coordinating health and social care research.

HSCNI (Health and Social Care in Northern Ireland): The publicly funded service providing healthcare in Northern Ireland.

Health and Social Care Trusts (Northern Ireland): Organisations that provide health and social care services in Northern Ireland.

Health Boards (Wales): Organisations responsible for delivering healthcare services in Wales.

Health Education and Improvement Wales: Body responsible for education, training, and workforce development in the Welsh healthcare sector.

Healthcare Experts: Medical professionals with specialised knowledge in a particular area, such as bladder cancer.

Healthcare Inspectorate Wales: An independent inspectorate and regulator of healthcare services in Wales.

Medicines and Healthcare Products Regulatory Agency: The agency responsible for ensuring that medicines and medical devices are effective and acceptably safe in the UK.

Mental Health Trusts: Organisations providing specialised mental health services in England.

Mental Wellbeing Markers: Indicators used to measure the mental health of patients.

Misdiagnosis: Incorrect identification of a medical condition.

Multi-disciplinary Team (MDT): A team of medical professionals from different specialities who work together to decide on the best treatment for an individual patient.

National Bladder Cancer Audit: A comprehensive review of bladder cancer care and treatment.

National Clinical Audit and Patient Outcomes Programme: A programme to improve the quality of patient care through national clinical audits.

National Institute for Health Research (NIHR): A research organisation in the United Kingdom focused on improving the health and wealth of the nation through research.

NCLCA: North Central London Cancer Alliance.

Neobladder: A urinary diversion that replaces the removed bladder.

NHS England Technology Live Services Directorate: Division focused on live services related to healthcare technology in England.

NHS England Transformation Directorate (previously NHS Digital): The division of NHS England responsible for driving digital transformation in healthcare.

NHS England: The body responsible for commissioning healthcare services in England.

NHS Wales Informatics Service (NWIS): Responsible for developing and delivering an integrated national Information Management and Technology (IM&T) programme in Wales.

NHS Wales: The publicly funded healthcare system in Wales.

NHS Wayfinder Service: A service that enables patients and carers to access additional information about secondary care referrals and their elective care via the NHS App.

NICE Guidance: Guidelines from the National Institute for Health and Care Excellence for England.

Northern Ireland Clinical Trials Unit (NICTU): A unit dedicated to the conduct and support of clinical trials in Northern Ireland.

Northern Ireland Health and Social Care Board (HSCB): The body overseeing the delivery of health and social care services in Northern Ireland.

Northern Ireland Medicines Optimisation Quality Framework: A framework aimed at improving the quality of medicines used in Northern Ireland.

Nursing Profession Exodus: The significant number of nursing professionals leaving the field.

Pathway of Care: The structured journey that a patient goes through from initial symptoms to the various stages of diagnosis, treatment, and follow-up.

Patient Advocates: Individuals who work to protect and advance the interests of patients, often those dealing with specific medical conditions like bladder cancer.

Patient Self-Referral: When patients directly request specific medical services without a primary healthcare provider's referral.

Patient-Centric Care: A healthcare approach where patients are at the centre of all decisions and plans, prioritising their needs and preferences.

Project Orbis: An initiative of the FDA's Oncology Center of Excellence that provides a framework for the collaborative review of promising new cancer treatments among international regulatory partners. It aims to give patients faster access to promising cancer treatments across the globe.

Public Awareness: The level of common understanding about a particular issue, in this context, bladder cancer.

Public Health Agency Northern Ireland: Organisation responsible for public health and social well-being in Northern Ireland.

Public Health England: Executive agency of the Department of Health and Social Care in England focused on public health issues.

Public Health Wales: National public health agency in Wales.

Quality of Life Metrics: These are measures used to evaluate the general well-being of individuals and societies, often considered when evaluating the outcomes of cancer treatment protocols.

Radical Cystectomy: A surgical procedure to remove the bladder.

Regulation and Quality Improvement Authority (RQIA): The independent body responsible for monitoring and inspecting health and social care services in Northern Ireland.

Royal College of Nursing (RCN): A membership organisation and trade union, including nurses, midwives, healthcare assistants and nursing students.

SCHARR: Sheffield Centre for Health and Related Research.

Stakeholders: Individuals or organisations interested in the outcomes of a particular project or issue. In this context, it refers to anyone involved in bladder cancer care.

Stoma: A surgically created opening that allows body waste to be expelled, often used when the bladder is removed.

TURBT (Transurethral Resection of Bladder Tumour): A common surgical procedure used to diagnose bladder cancer or to remove cancerous tissue from the bladder.

TURP (transurethral resection of the prostate): A surgical procedure that involves removing a section of the prostate.

UCLH: University College London Hospitals.

Urgent Investigation Units (UIU): Special units designed for immediate investigation of potential bladder cancer cases.

URS (Ureteroscopy): A procedure used to visually inspect the ureter and if necessary, perform biopsy.

UTIs: Urinary Tract Infections.

WBCPC: World Bladder Cancer Patient Coalition.

Welsh Medicines Information Centre: Provides information and advice about the use of medicines.

Workforce, Training and Education Directorate (previously Health Education England): Focuses on education, training, and workforce development within the healthcare sector.

fight bladder CANCER

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Shannon Boldon is the Policy Manager for Fight Bladder Cancer, covering for a maternity leave (in 2022 and again in 2024). She established a consulting company in 2019, specialised in health policy, and works with a diverse client base to improve the knowledge and understanding of different diseases, and drive policy changes. She has been lucky to be a part of many impactful projects over the years, including a research advisor for the WBCPC Global Bladder Cancer patient survey and as part of the team who established the All.Can initiative. Prior to this, she earned an MSc from University College London (UCL) in Global Health and Development; and interned at the World Health Organization in Geneva, Switzerland supporting the Ebola outbreak.

Melanie Costin

Melanie Costin is a bladder cancer patient and Support Services Manager at Fight Bladder Cancer. Melanie discovered the charity early on after her own bladder cancer diagnosis. Her role has many facets, including providing information and support; speaking at conferences and support groups; raising awareness; running the Bladder Buddy service; and being an administrator on the FBC forum. At medical meetings, she gets the patients' voice out there. Her current job is a far cry from her pre-bladder cancer life as a technical draughtsperson.

David Day

David Day is a dedicated Patient Advocate for Fight Bladder Cancer, actively involved in various capacities including as a Bladder Buddy and Support Group Facilitator. Diagnosed with bladder cancer in 2013, he has been a proactive supporter of the cause. David is also a member of the England, Wales and Northern Ireland Steering Group for Fight Bladder Cancer and offers support through email and Facebook forums. A frequent participant in research, specifically on the topic of BCG (Bacillus Calmette-Guerin) treatment, David is committed to bettering the lives of those affected by bladder cancer.

Alex Filicevas

Alex Filicevas was appointed as the first-ever Executive Director of the World Bladder Cancer Patient Coalition (WBCPC) in 2019. He has been leading the organisation's efforts to foster an international community of bladder cancer patient advocates. Alex previously led EU affairs work at the European Cancer Patient Coalition. Prior to this, he worked as a consultant, supporting private and non-profit organisations in their EU policy and advocacy activities. He has also been an active member of All.Can International where he was appointed President in 2020, and Co-Chairs the Global Cancer Coalitions Network.

Dr. Lydia Makaroff

Dr Lydia Makaroff is the Chief Executive of Fight Bladder Cancer and President of the World Bladder Cancer Patient Coalition. She has a PhD in immunology and a Masters' degree in public health. She has worked in academia, the pharmaceutical industry, and the non-profit sector. She has conducted medical research at the Australian National University, worked as a post-doctoral fellow at the University of Washington, and for the International Diabetes Federation.

Dr. Lena Mandrik

Dr. Lena Mandrik works at the Sheffield Centre for Health and Related Research (SCHARR), University of Sheffield, as a Research Fellow in health economic modelling. She joined SCHARR in 2018 after completion of her two-year post-doctoral training at the International Agency for Research on Cancer of the WHO. Lena undertakes research in healthcare decision science, focusing on the evaluation of public health programmes, especially cancer screening, including breast, bowel, oral, lung, bladder, and multi-cancer detection.

Anne MacDowell

Anne MacDowell, Strategic Advisor for Fight Bladder Cancer, has over 40 years healthcare industry experience in the US, France, the UK and Switzerland. She has an MBA from Harvard Business School and having stopped paid work in 2017, she now works with charities on a volunteer basis. Anne leverages her extensive experience to provide guidance and insight to Fight Bladder Cancer to help us improve outcomes for cancer patients and their families.

Pamela McGowan

Pamela McGowan is a Communications Assistant for Fight Bladder Cancer. She is a versatile professional with 12 years of pharmaceutical industry experience, specialising in oncology. Trained in biomedical science, she transitioned to the field of medical communications, combining her strong clinical background and passion for writing. Pamela is also an active volunteer, serving as a Communications assistant and Awareness Ambassador for CLAPA (Cleft Lip and Palate Association). She has authored a non-fiction book on autism and runs a popular blog focused on special education needs and health issues.

Mr John McGrath

Mr John McGrath is a Consultant Urologist at the Royal Devon University Hospital and is National Clinical Lead for the Getting it Right First Time (GIRFT) programme within NHS England. The programme aims to reduce variation in clinical care and promote best practice in patient care.

Andie Miles

Andie Miles underwent a radical cystectomy with a neobladder in 2011. Despite her health challenges, Andie is an active Fight Bladder Cancer volunteer and contributes her unique expertise. With a background in psychiatric care and nurse education, she's well-equipped to advocate for improved bladder cancer care. Andie uses her personal and professional experience to help refine care pathways and educational modules, offering valuable insights for healthcare professionals and patients alike.

Dr. Vinay Patroe

Dr. Vinay Patroe was the Medical Director at Janssen UK, where he led teams responsible for Medical Affairs, Regulatory Affairs and Medical Information and Governance. Vinay has worked with multiple pharmaceutical companies including Pfizer, Novartis, and Sanofi. Prior to this, he spent a decade at GSK. He studied medicine at Liverpool University, specialising in anaesthesia and intensive care, and is affiliated with the Royal College of Anaesthetists and the Faculty of Pharmaceutical Medicine.

Ravi Ruparel

Ravi Ruparel is a compelling patient advocate. His affiliation with Fight Bladder Cancer fuels impactful campaigns that emphasise prevention and early detection. A bladder cancer patient himself, Ravi brings personal experience to his advocacy. He collaborates with medical professionals and policymakers, serving as a critical link in shaping patient-centric healthcare. Ravi also stays abreast of tech trends like AI and telemedicine, advocating for innovative solutions in bladder cancer care.

Acknowledgements

Fight Bladder Cancer is grateful for the wealth of ideas generated at the Exemplar Meeting and the collaboration demonstrated among healthcare professionals, healthcare professionals, patients, patient advocates, and stakeholders that deepened throughout the day. A special thanks is given to the event speakers and panellists for their invaluable contributions.

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Thank you

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