

# EXEMPLAR Research Report

Striving for exceptional services for  
people affected by bladder cancer

May 2021



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# Foreword

The words that no one ever expects to hear: 'You have bladder cancer'.

Fight Bladder Cancer 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.

In addition to providing direct support, part of our mission is also working to improve the services bladder cancer patients receive. We want to change the face of bladder cancer care in the UK to guarantee that every bladder cancer patient, no matter where they live, receives the fastest possible diagnosis and the highest quality treatment and care, along with the support and information they need.

That's why we've conducted this research; to better understand what an Exemplar bladder cancer service would look like. We heard directly from the bladder cancer patients and carers who access services, along with the healthcare professionals who deliver them, to find out where the gaps, as well as strengths, are in current bladder cancer services.

We are deeply grateful to all of those who contributed to the governance, research and production of this project and report, especially those who have been directly affected by bladder cancer.

Our findings paint a mixed picture, one in which bladder cancer healthcare professionals work incredibly hard to deliver outstanding care for their patients but, in the face of squeezed resources, staffing shortages, and rising demand, too often bladder cancer patients are left without the high-quality care and support they desperately need.

At Fight Bladder Cancer, we recognise the incredible work of the dedicated healthcare professionals who treat and support people with bladder cancer. We also welcome the efforts made by each of the national governments to support people with bladder cancer, and we are pleased to see where progress is being made. However, much more work is needed. We need to ensure that early diagnosis becomes the norm, variations in the quality of care are overcome and, above all, we invest in the specialised bladder cancer staff we need.

We know this research is far from the final word on the future of bladder cancer services. Fight Bladder Cancer will do all in our power to work with the whole bladder cancer community to generate a critical mass of research, advocacy and action to convince decision makers across the UK to invest in bladder cancer services, and secure necessary service changes.

**Together, we can deliver the Exemplar care bladder cancer patients deserve.**

Dr Lydia Makaroff  
Fight Bladder Cancer Chief Executive

John Hester  
Fight Bladder Cancer Chair of  
Trustees & bladder cancer patient

'I felt dreadfully alone at the start, thinking 'I'm the only person in the world that's got bladder cancer ... I joined Fight Bladder Cancer and found a lot of support, which was brilliant. Once I went on the Fight Bladder Cancer forum, I felt that was where I needed to be for me... It's trying to get to the people right at the start, so that they can be helped if they want to be.'

**Diana, Patient, Aged 55–64, South West**





# Introduction

**Bladder cancer has the highest cost of any cancer, when considered on a per-patient basis.**

Over 20,500 people are diagnosed with bladder cancer every year (ICD-10 C67, D09.0 & D41.4) (Fight Bladder Cancer, 2020) making bladder cancer the fifth most common cancer in the UK after breast cancer (55,109 cases/year), prostate cancer (48,588 cases/year), lung cancer (47,968 cases/year), and bowel cancer (42,081 cases/year) (Cancer Research UK, 2021). However, survival for patients with bladder cancer has not improved over the last three decades, with certain groups affected by bladder cancer, including women and those from lower socioeconomic backgrounds, experiencing poorer outcomes (Huddart, Jones, & Choudhury, 2015).

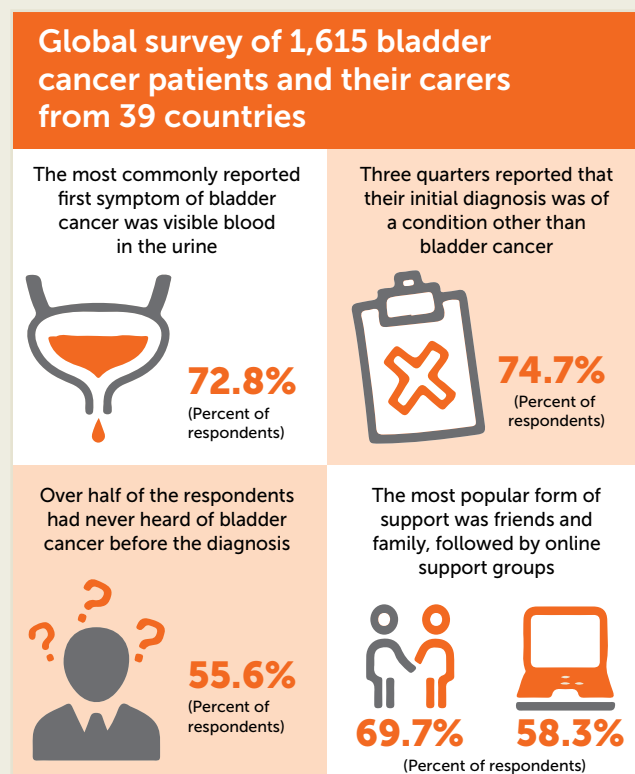
Despite being one of the most common cancers in the United Kingdom, public awareness and investment in bladder cancer research and care is low (Boormans & Zwarthoff, 2016). Bladder cancer patients experience a high rate of recurrence, long and invasive surveillance and expensive treatment (Cox, Saramago, Kelly, Porta, & Hall, 2019). Patients also report worse overall experiences than most other common cancers (Turabi, Abel, Roland, & Lyratzopoulos, 2013).

The high costs of non-muscle invasive bladder cancer are due in part to the need for extensive follow up, including lifelong cystoscopic examinations (Mossanen & Gore, 2014). People affected by bladder cancer are less likely to receive a needs assessment, care plan or be provided with information about support services than other cancers (National Collaborating Centre for Cancer, 2015). The mental health impact of a bladder cancer diagnosis, long term invasive testing, treatment and sometimes life-changing surgery for bladder cancer patients and their families is significant. One UK study found that bladder cancer patients are nearly five times more likely to take their own life than the general population and 1.6 times more likely to take their own life compared to patients with other common cancers (Afshar, et al., 2018).

More work is needed to understand the experience of bladder cancer patients, their journey through the healthcare system, and factors that can improve their outcomes. Three-quarters of patients reported that their initial diagnosis was a condition other than bladder cancer. Over half of patients surveyed had never heard of bladder cancer before their diagnosis. The most popular forms of support reported is friends and family, followed by online support groups (Elliott, et al., 2019). Previous research has identified a need to access patient-reported outcomes and improve services for people affected by bladder cancer (Mason, et al., 2018) (Edmondson, Birtwistle, Catto, & Twiddy, 2017).

There is an urgent need for change for people affected by bladder cancer in the United Kingdom. Fight Bladder Cancer has kick-started this vital work with the Exemplar project 'Striving for Exceptional Services for People Affected by Bladder Cancer'.

By conducting qualitative interviews with bladder cancer patients, informal carers, family members and health care professionals working with bladder cancer patients, Fight Bladder Cancer has gained a comprehensive understanding from first-hand experiences, of where current bladder cancer services fail, and also where they succeed. This report outlines the key findings from these interviews along with a survey of 106 British bladder cancer patients to provide recommendations for how the bladder cancer community can work together to improve the experience, outcomes and lives of the 20,500+ people diagnosed with bladder cancer in the UK every year.



**Figure 1.** Results from a global bladder cancer patient survey on awareness and treatment of bladder cancer (Elliott, et al., 2019).



# Executive Summary

## PROJECT AIMS AND CONTEXT

**Fight Bladder Cancer's Exemplar Project, 'Striving for Exceptional Services for People Affected by Bladder Cancer', explores the current strengths and gaps in bladder cancer services in the UK and makes recommendations for transforming the experience, outcomes and lives of the over 20,500 people diagnosed with bladder cancer in the UK every year, and their families. As well as being the fifth most common cancer in the United Kingdom, people affected by bladder cancer experience a high rate of recurrence, require long and invasive surveillance and treatment, and report having worse patient experience and less involvement in treatment decisions than those with many other cancers. The ongoing burden of bladder cancer, surveillance and treatment including sometimes life-changing surgery has a profound psychological impact on patients, carers and their families who endure anxiety, uncertainty and fear when they are diagnosed and then for years in follow up. Amidst the toll taken on all people by the COVID-19 pandemic, it is more important than ever to place cancer services, including bladder cancer, at the heart of national and local plans. Now is the time to move forward with change and strive for exceptional bladder cancer services.**

## METHODOLOGY

For the development of this report, a series of qualitative interviews were conducted with 30 bladder cancer patients, 10 informal carers and family members, and 17 health care professionals working with bladder cancer patients to gain a comprehensive understanding, from first-hand experiences, of where current bladder cancer services fail, but also where they succeed. Using quotes from anonymised interviews and patient case studies throughout, the report highlights the pressures on services and health care professionals, and also brings to life the burden of bladder cancer and gaps in services for patients. Building on the insights gained from these interviews, the report highlights key areas where improvements are needed to support bladder cancer care.

## RESEARCH FINDINGS

Most prominently, the findings demonstrate variation in the different bladder cancer pathways across the UK, and in the standard of care being provided. Seen between individual hospitals and general practices, these inconsistencies are evident in approaches to diagnostic services, the continuity of care after diagnosis, as well as in the speed of initial GP referral which is shown to be particularly slow for women. The lack of a standardised pathway, and the discrepancies in the standard of care being provided, are areas where urgent action was called for in interviews with the bladder cancer professional and advocacy community (bladder cancer community). The clear outlining of a standardised pathway would be welcomed by both people affected by bladder cancer and health care professionals. There is a need to make the pathway clearer for patients so that they are more informed about where they are in their treatment journey and what the next steps could be for them.

The findings also highlight the challenges hindering service improvement, including long diagnostic service waiting times, stretched resources for both diagnosis and follow up, and workforce shortages. Health care professionals, in particular, give insights into the struggle to give specialised, robust and holistic care, as roles become more generalised with growing workloads and waiting lists as a result. This is the case for Clinical Nurse Specialists, as well as surgeons, urologists and oncologists. Despite Clinical Nurse Specialists being recognised by many interview participants as integral to specialised bladder cancer-focused care, they continue to have the scope of their roles and their geographical remit widened.



As a result, they find they are stretched too thinly to provide optimum support for bladder cancer patients.

Bladder cancer can involve some incredibly difficult decisions, with treatment options such as bladder removal (radical cystectomy) which have substantial life-changing implications on lifestyle, sexual life, body image, mental health and wellbeing for patients and their families. This report demonstrates that patients, their carers and families often do not have access to the support they need when they need it, from health care professionals or the wider bladder cancer community.



## OUR RECOMMENDATIONS

Building on these insights, we have developed a set of ambitious yet achievable recommendations across the bladder cancer pathway, in pursuit of an exemplar pathway that transforms experiences and outcomes for all bladder cancer patients. Highlighting areas where action can be taken now to support improvements, as well as areas where solutions should be co-created with the bladder cancer community, the report and its recommendations are spread across three pillars:

**1 PUTTING IN PLACE AN EXEMPLAR PATHWAY:** improving bladder cancer services as a whole, including delivering quicker referral and diagnosis for those with suspected bladder cancer, and exploring the need for a standardised pathway across the UK

**2 GROWING AND DEVELOPING THE BLADDER CANCER WORKFORCE:** ensuring that the whole bladder cancer workforce is sustainable now and in the future, with Clinical Nurse Specialists in particular, supported to deliver comprehensive and high-quality holistic care

**3 IMPROVING AWARENESS, SUPPORT AND INVOLVEMENT IN CARE ACROSS THE PATHWAY:** developing best-practice procedures and guidelines for communicating holistic and psychological support to patients, carers and family members, ensuring that patients are empowered to make informed decisions about their care

The Fight Bladder Cancer Exemplar Research report and recommendations set out an initial blueprint for the transformation of bladder cancer services, and there is much more to be done. Fight Bladder Cancer is committed to working with patients, family members, carers, clinical leaders, researchers, industry and professional organisations to form a community consensus and build a plan for further research and exploration of the recommendations.

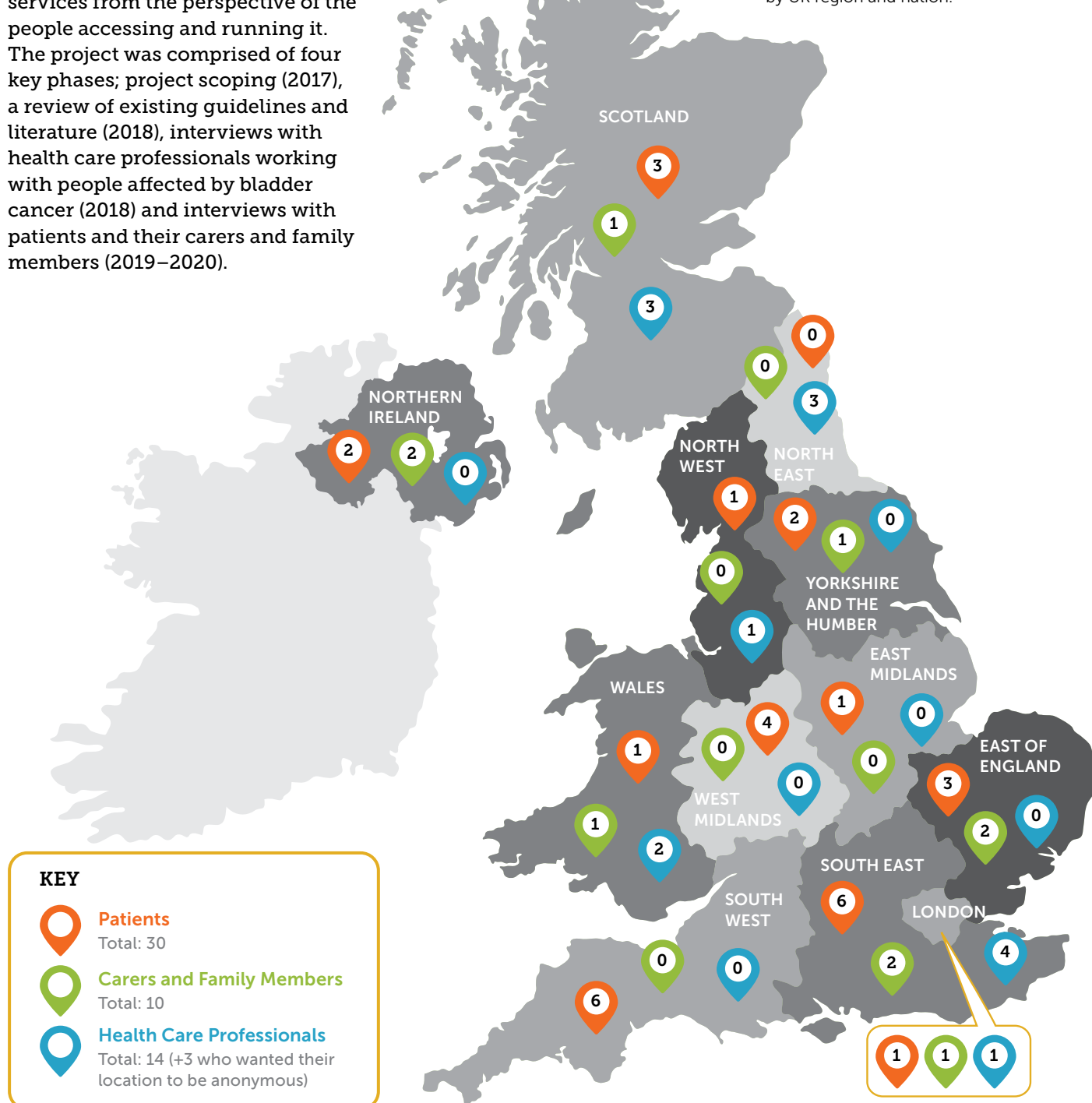
**Together with policymakers across the system, we must recognise the key limitations of current bladder cancer services and push for the implementation of this report's recommendations, driving the momentum to deliver the service transformation bladder cancer patients in the United Kingdom desperately need.**



# Methodology & Sample

The Exemplar project was designed to collect 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 from the perspective of the people accessing and running it. The project was comprised of four key phases; project scoping (2017), a review of existing guidelines and literature (2018), interviews with health care professionals working with people affected by bladder cancer (2018) and interviews with patients and their carers and family members (2019–2020).

**Figure 2.** Interviewee numbers by UK region and nation.

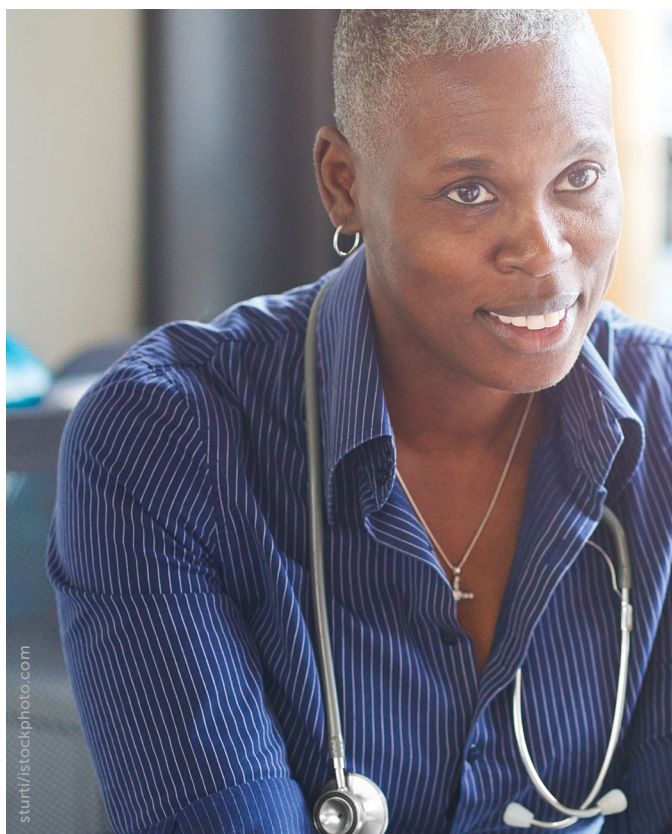


To supplement the in-depth interviews with a limited number of people affected by bladder cancer and health care professionals, Fight Bladder Cancer worked in partnership with market research consultancy Brainsell to survey 106 UK bladder cancer patients about their experience of bladder cancer services. This allowed for the qualitative findings to be triangulated with quantitative survey results and the opportunity for more patients' experiences to be included in the project findings.

Draft findings and recommendations were presented to a Steering Group including patients, carers and health care professionals to provide feedback and to check the findings and recommendations resonated with their experience.

**The Fight Bladder Cancer Research Steering Group was comprised of patients, carers, clinicians, and academics, who met regularly to lead, design and govern the project.**

This process has informed the structure and design of the project. It has allowed Fight Bladder Cancer to identify the key features of quality services for people affected by bladder cancer and provide actionable recommendations to inform future service provision and research projects.



## INTERVIEWS OF HEALTH CARE PROFESSIONALS

**Seventeen semi-structured interviews with health care professionals working in bladder cancer took place between August and October 2018.**

Interviews were conducted over the phone and lasted 30–60 minutes. Interviewees were recruited from around the UK, and included health care professionals based in England, Wales and Scotland. Although specific job titles varied around the United Kingdom, interviewees reported that their roles lay within the following areas:

- Consultant Surgical Urology/Oncology
- Consultant Medical Oncology
- Clinical Nurse Specialists (Urology, Oncology and Uro-oncology)

Health care professionals were recruited from Fight Bladder Cancer's existing network and an announcement in the British Association of Urological Nurses' President's monthly e-newsletter, as well as snowball sampling as interviewees suggested other health care professionals who may have wanted to take part in the study.

All interviews took place over the phone. To allow health care professionals to feel able to talk freely, interviews were not recorded, interviewees were told their comments would be anonymised, and no quotes from health care professionals have been included in the report. Notes from interviews with health care professionals were transcribed by the researcher and analysed thematically (Braun & Clarke, 2006).

## INTERVIEWS OF PATIENTS, CARERS AND FAMILY MEMBERS

**Forty people affected by bladder cancer took part in in-depth qualitative interviews about their experience of bladder cancer and bladder cancer services including diagnosis, treatment, follow up and support.**

Interviews took place between March and October 2020, including 30 patients and 10 informal carers or family members. All patients, carers and family members interviewed received an information sheet and completed a consent form.

Interviews lasted around an hour, were conducted over the phone, were recorded, and were transcribed and analysed thematically (Braun & Clarke, 2006) using NVivo. Interviewees were told that they could stop the interview at any time and while quotes would be reported these would be anonymised to protect their identity. All quotes presented in this report use pseudonyms. A small group of patients and carers met to discuss a sample of anonymised interview transcripts and identified key themes to inform the coding framework for the thematic analysis.

The patient, carer and family member interview schedule was developed in partnership with the Fight Bladder Cancer Research Steering Group and was piloted with a small number of patients and carers in 2019 before the main interview collection took place in 2020. This allowed for a review and improvement of the data collection tools before the main collection.

Patients, carers and family members were asked the same open questions which encouraged them to tell the story of their personal experience with bladder cancer from initial symptoms to diagnosis, treatment and any support they received with a focus on what was handled well and how their experience could have been improved. The questions were informed by a review of the most recent NICE *Bladder cancer: diagnosis and management* guidelines (National Institute for Health and Care Excellence, 2015), existing literature and the findings from the prior health care professional interviews.



### PATIENT AND CARER INTERVIEW RECRUITMENT

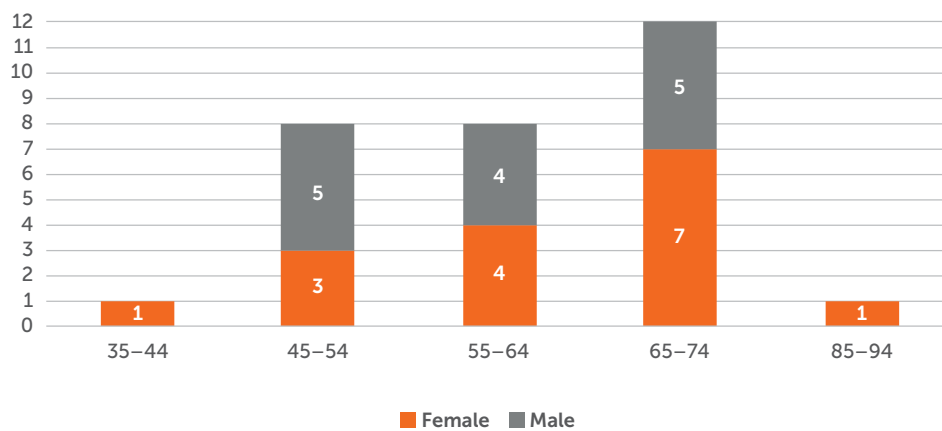
Interviewees were recruited through the Fight Bladder Cancer network and announcements placed in Fight Bladder Cancer newsletters and social media posts, which allowed people affected by bladder cancer to volunteer and take part in an interview. Interviewees were also recruited through snowball sampling as interviewees suggested other suitable participants who may wish to take part.

The study aimed to interview an equal number of men and women affected by bladder cancer from around the UK, and to include participants from England (30 interviewees), Scotland (4 interviewees), Wales (2 interviewees) and Northern Ireland (4 interviewees). Interviewees were asked a small number of quantitative questions at the start of the interview to collect recruitment statistics to ensure the interview sample reflected a range of experiences relevant to the UK bladder cancer patient journey. The Research Steering Group monitored the recruitment progress and additional effort was taken to recruit men, participants from outside of England, and BAME patients and carers.

Sixteen women and fourteen men who had been diagnosed with bladder cancer were interviewed. The age of patients interviewed ranged from 43–87 with an average age of 62.

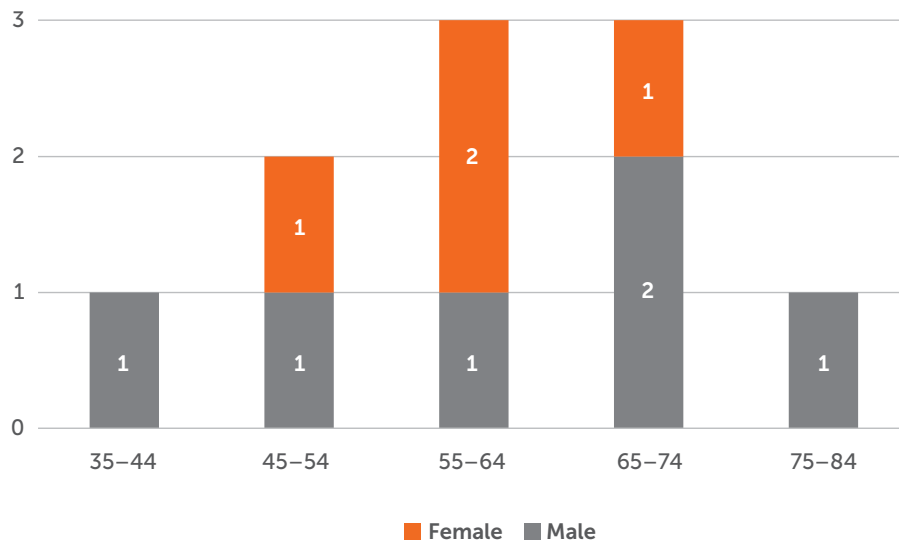


**Patient Age and Gender (N=30)**



**Figure 3.** The age of patients interviewed ranged from 43–87 with an average age of 62.

**Carer Age and Gender (N=10)**



**Figure 4.** Carers and family member's ages ranged from 41–76 with an average age of 59.

The majority of patients interviewed reported that they had undergone a transurethral resection of bladder tumour (TURBT) (93%), under half (43%) had had their bladder removed and one had had a partial bladder removal. Two-thirds (66%) had experienced treatment directly to their bladder such as BCG and a minority had had chemotherapy into a vein (16%). All but one patient and one carer/family member interviewed identified as white.

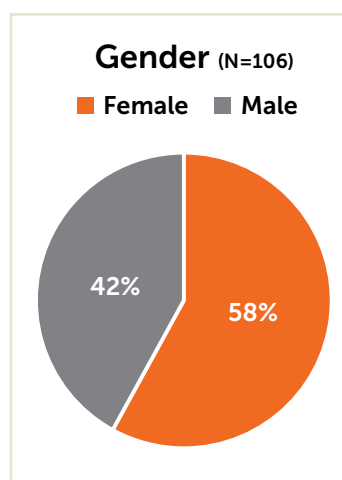
## ONLINE PATIENT SURVEY

One hundred and six British bladder cancer patients completed an online survey about their experience of bladder cancer services. The survey included selected validated questions from the National Cancer Patient Experience Survey, in which patients were asked to rate their overall treatment and care, whether they were provided with the details of a Clinical Nurse Specialist, and if they were signposted to support services. Respondents were also asked about their experience of being referred from primary to secondary care.

Participants were recruited through the Fight Bladder Cancer network. Patients were asked to volunteer to take part in the survey. Questions at the start of the survey screened out people who had not been diagnosed with bladder cancer within the last 10 years (initial or follow up test).

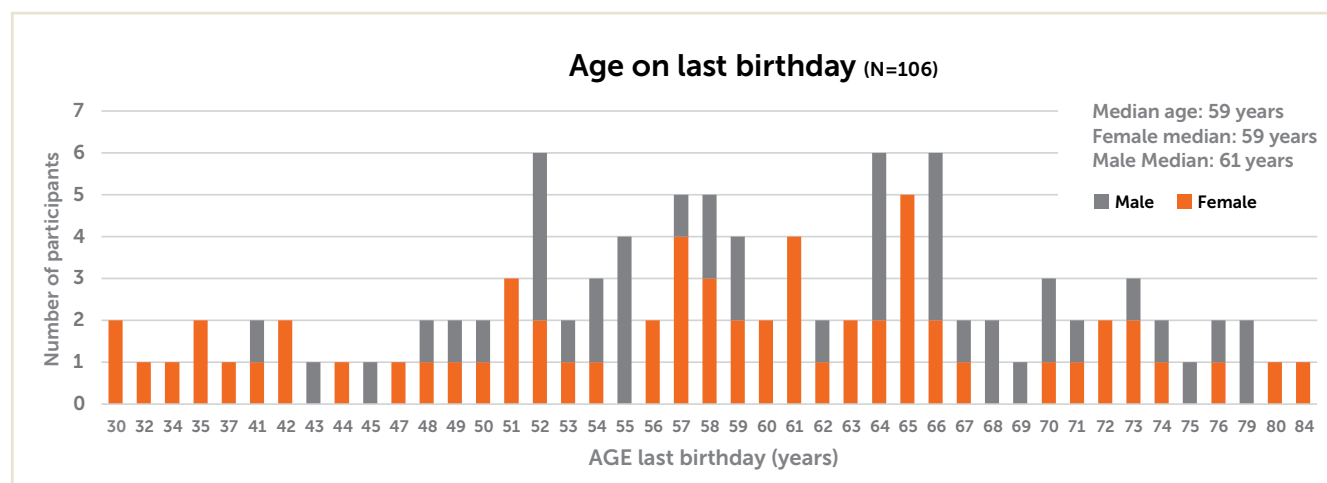
Over half of the respondents were women (58%, n=62) and 42% were male (n=44). The majority were from England (90%, n=95), 6 were from Scotland, 3 from Wales and 2 from Northern Ireland.

Respondent's ages ranged from 30–84, with a median age of 59. The vast majority of patients who completed the survey identified themselves as White, 2 identified as Asian and 1 chose not to specify their ethnicity.



**Figure 5.** Over half of the bladder cancer patients who responded to the online survey were female.

**Figure 6.** The median age of patients who responded to the online survey was 59 years.



## SUMMARY BLADDER CANCER PATHWAY

A trans urethral resection of bladder tumour (TURBT) is usually needed to formally diagnose bladder cancer, and can be used as a treatment for some kinds of early non-muscle-invasive bladder cancer. The surgeon removes part or all of the tumour in the bladder by inserting very thin surgical instruments through the urethra.

BCG is one of the main treatments for non-muscle-invasive bladder cancer. It is called Bacillus Calmette–Guérin (BCG) because it is a type of Bacillus bacteria that was created by two researchers named Dr Calmette and Dr Guérin. The bladder is filled with BCG bacteria, which then encourages white blood cells to become active and kill off the bladder cancer cells.

Patients with muscle-invasive bladder cancer normally need definitive treatment following diagnosis via TURBT. This can include chemotherapy, radiotherapy, full or partial bladder removal (RC – radical cystectomy), and/or immunotherapy.

# Structure of the report

Our research findings and our recommendations are spread across three pillars:



We have divided our findings into these three pillars, with summaries of our findings and recommendations for each. We highlight areas where action can be taken now to support improvements, as well as areas where longer term approaches should be co-created among the bladder cancer community.

## RESEARCH FINDINGS

### 1 PUTTING IN PLACE AN EXEMPLAR PATHWAY

#### KEY FINDINGS

- The structure and quality of bladder cancer services vary across and within the UK. People affected by bladder cancer reported experiencing different standards of service depending on the centre they accessed. Women living with bladder cancer reported a worse overall experience of care than men
- Both health care professionals and people affected by bladder cancer highlighted that delay in initial diagnosis is a key area in need of urgent improvement. Women with repeated urinary tract infections (UTIs), in particular, reported long delays in referral from primary care for diagnostic tests. Women reported experiencing psychological and physical distress due to long periods of unexplained symptoms, as well as the potential for poorer long-term outcomes due to delays in diagnosis and treatment
- Some interviewees reported that their or their family member's patient journey through diagnosis, treatment and follow up was smooth, particularly if they had support from a Clinical Nurse Specialist

However, some reported experiencing extended delays and a lack of communication, which caused distress and anxiety and potentially impacted their long-term outcomes. These issues were exacerbated during COVID-19

- Health care professionals called for urgent changes to treat patients more effectively and reduce patient wait times. Some people affected by bladder cancer reported a relatively positive diagnostic experience accessing a 'one-stop shop' or rapid diagnostic clinic in which all tests for suspected bladder cancer cases were delivered in one place on one day, however these centres are not available everywhere
- Many patients and family members reported experiencing extended delays in receiving a firm diagnosis and appropriate treatment. Health care professionals interviewed expressed an urgent need for changes in their current pathway, to treat suspected bladder cancer patients more effectively





- For health care professionals, the reclassification of the TURBT from treatment to a diagnostic test, for the purposes of the national cancer waiting times, is seen as a key opportunity to improve accountability for timely bladder cancer treatment. While this policy change was made in England in September 2020, this is not yet the case in Wales, Scotland and Northern Ireland. So far, it is unclear the extent to which this policy change has affected practice within NHS trusts in England
- People affected by bladder cancer who required support for themselves or their family members after leaving hospital (for example after having their bladder removed or due to other health conditions) reported a lack of needs assessment to ensure they had the right support to manage at home after being discharged from hospital
- Patients with existing co-morbidities experienced additional difficulties and delays in treatment, due to their need for additional support during the pathway including navigating the variety of services for their competing health conditions

## STANDARDISED BLADDER CANCER PATHWAY

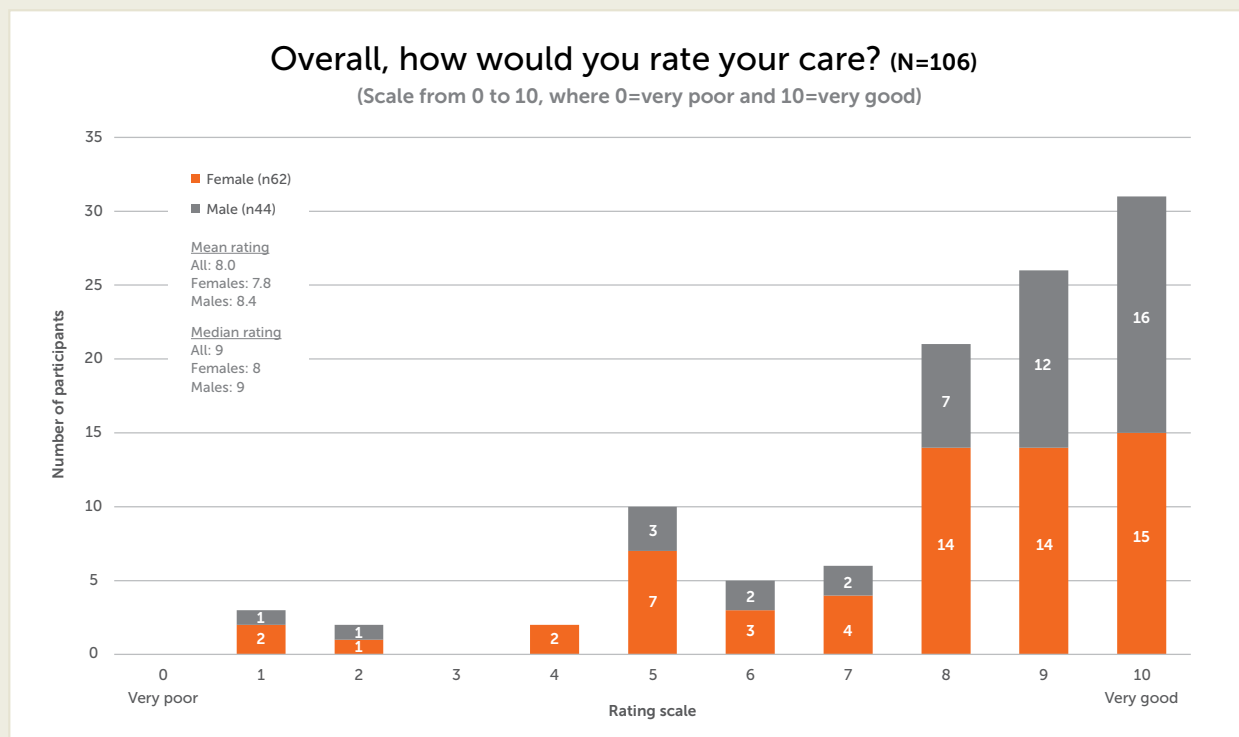
All health care professionals interviewed reported different ways of delivering bladder cancer services at their site. There is currently no single standardised patient pathway in the United Kingdom. The pathways identified by health care professionals were all based around patients initially presenting in primary care (usually with blood in the urine) and then being referred for further investigation. Some patients were referred through incidental findings while undergoing scans or investigations for non-related symptoms or conditions, such as pregnancy.

Interviewees affected by bladder cancer reported very different experiences between centres around the United Kingdom. While some did report a positive experience, others did not, and participants who had been transferred between centres reported very different standards of care at different hospitals.

'It's a bit chalk and cheese, to be honest...everybody was so much happier and it was such a better clinical atmosphere in [Hospital 1]. [Hospital 2], I have to say, is quite a poor relation in lots of ways... I don't feel that the staff have the same buy-in to the patient experience.'

Mathew, Patient Age 55–64, Patient, West Midlands

**Figure 7.** The median score that bladder cancer patients who responded to the survey gave to their care was 8 out of 10.



'Because I used to live in [Area 1] and they were brilliant down there... They were absolutely amazing when it comes to scheduling appointments, cystoscopies, everything like that. But since I've moved up here, they're not as good. I'm the one that does the chasing. Like, last year sometime I knew I was due a cystoscopy and I'd heard nothing. And I was constantly emailing, ringing saying, "Look, I should have had this by now. What's happening?" And eventually I did get it, but they just don't seem as on the ball up here as much as they were down in [Area 1].'

**Michelle, Patient, Aged 55–64, East Midlands**

The 106 bladder cancer patients who completed the online survey were asked to rate their overall care experience. On average patients reported a mean score of 8 of out 10 when asked to rate their care from 0 (very poor) to 10 (very good) and over half (54%) rated their care as 9 or 10. Men reported a median score of 9/10, and women reported a lower median score of 8/10.

## REFERRAL AND DIAGNOSIS

For people affected by bladder cancer, a fast diagnosis can be very important.

'To me, cancer's all about catching it early, that's how it seems... On the whole if you get it early, you've got a bloody good chance of getting over it and having a long life.'

**Jack, Patient, Aged 45–54, Yorkshire and the Humber**

'I think it's all been handled well, from our point of view, it's flowed. It's the waiting time, I think, between appointments and results is the only thing. It would be nice if you knew the result the next day but, equally, you understand that they can't always give you the results the next day.'

**Dawn, Carer, Aged 75–84, South East**

**While some said they were referred very quickly from their GP, many women with repeated UTI (Urinary Tract Infection) symptoms in particular reported long delays in being referred from their GP for diagnostic tests.**

Several women reported that they were prescribed repeated antibiotics over months or even years, or were referred to gynaecological services.

For some, this caused a long delay before diagnosis, a lot of psychological and physical distress with unexplained symptoms, and negative interactions with GP practices as well as the potential for poorer long-term outcomes.

'Two weeks later I go back and get different antibiotics and this went on five or six times and I knew then there was something wrong and I didn't know what it was, but I knew it wasn't right. I left it for two months, because I thought I was being a nuisance at the doctor's. I think people get like that, especially older people, they think they're making a fuss over nothing.'

**Bella, Patient, Aged 65–74, South East**

'Roughly three years before my diagnosis and the doctor said I had an overactive bladder. So, there was blood in my urine and abdominal cramps that really got to me... they thought it was all gynaecological... I knew that if I took myself to A&E twice in a short period they'd have to look at me again properly. And they did. In those two years inbetween I actually thought it was merely mind over matter, trying to train my bladder. I thought it was a really bad habit, running to the loo all the time.'

**Natasha, Patient, Aged 45–54, Northern Ireland**

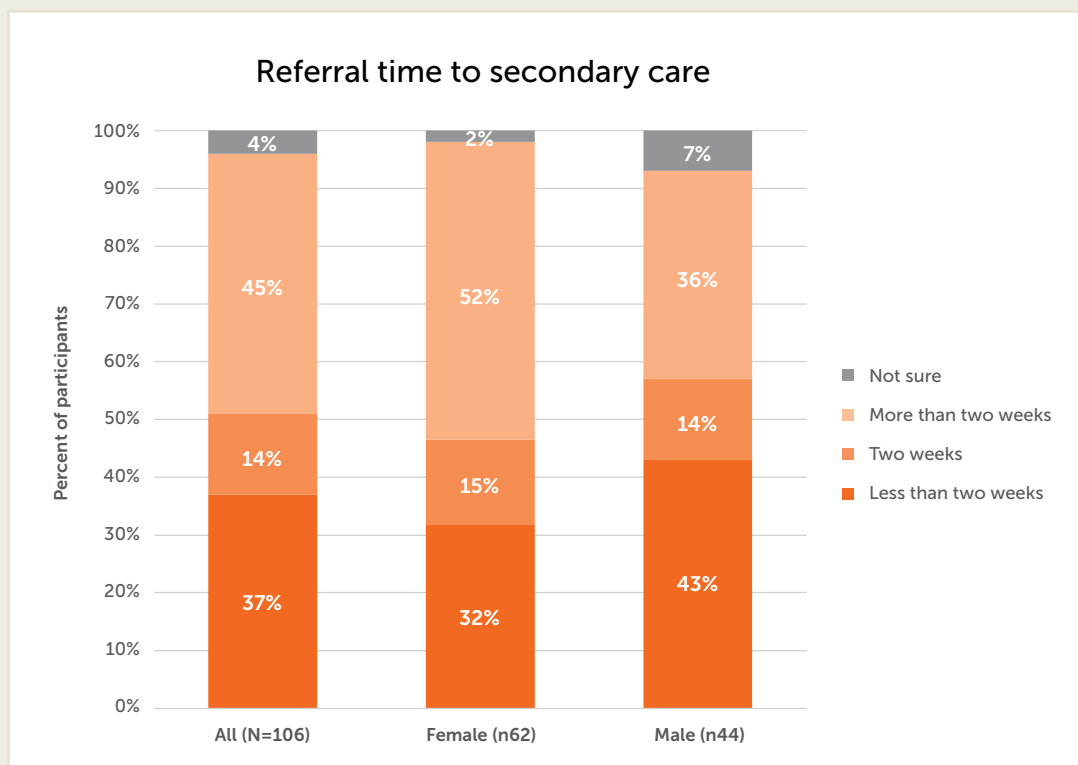
Several participants were told by health care professionals that they were 'too young for bladder cancer' before being diagnosed with the condition.

'He said, "You're far too young, he won't see anything sinister like this but we have to check". So I wasn't at all worried about it being cancer... I didn't know what it would be, but I didn't think it would be cancer.'

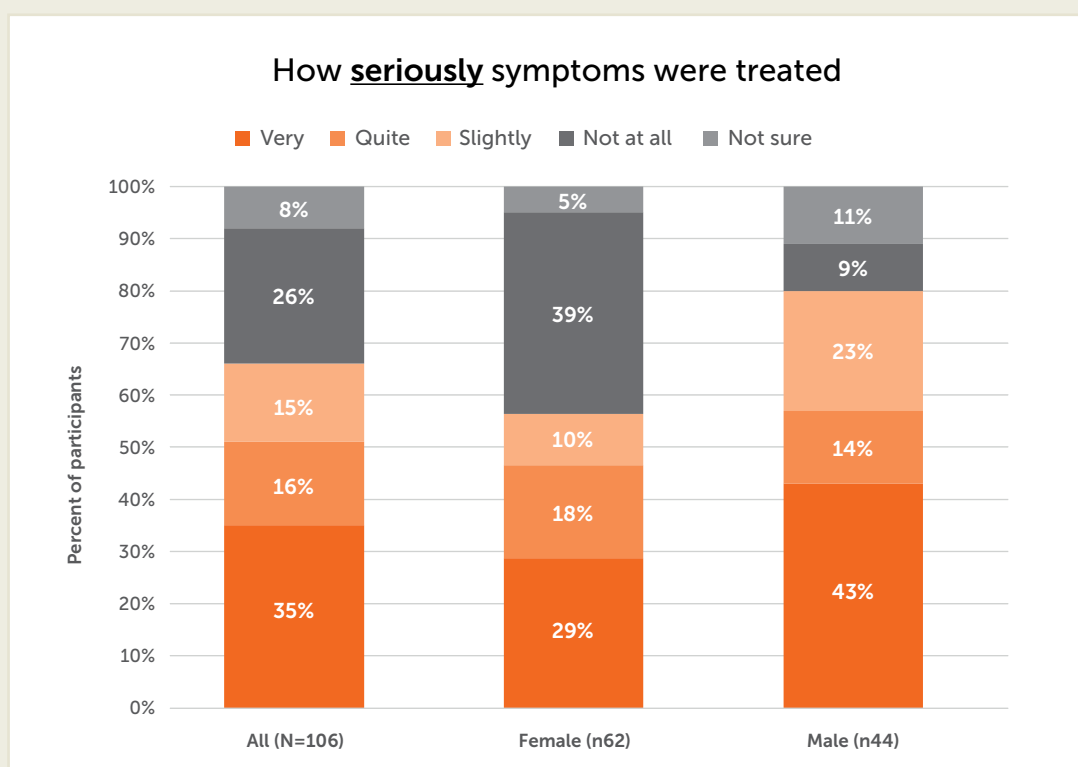
**Aaron, Patient, Aged 45–54, South West**

Of the 106 patients who took part in the online survey, 51% reported that they were referred to secondary care for diagnostic tests within 2 weeks. However, men (57%) were more likely to have been referred within two weeks than women (47%) supporting the observation that women wait longer to be referred from primary care with suspected bladder cancer.

Fifty one percent of patients surveyed reported that their symptoms were taken seriously during their initial GP visit (Very 35%, Quite 16%). However women were more likely to report that their symptoms were 'Not taken at all seriously' (39% women compared to just 9% of men), with UTI-like symptoms being the most common reason women cited for why their symptoms had not been taken seriously.



**Figure 8.** 45% of bladder cancer patients who responded to the survey reported that their referral time to secondary care was more than two weeks.



**Figure 9.** One quarter of all patients who responded to the survey reported that their early bladder cancer symptoms were not treated seriously by their GP.



**The health care professionals who were interviewed expressed an urgent need for changes to the current pathway, to treat suspected bladder cancer patients more effectively.**



Many reported that patients experienced an extended wait for additional investigations following a 'first presentation' and had to travel to different locations to get all the requested and required tests and investigations before getting a firm diagnosis and appropriate treatment.

Similarly, people affected by bladder cancer reported experiencing delays in receiving their diagnosis and a lack of communication following initial tests, causing anxiety and uncertainty.

'I think the only anxiety during those early stages was that I'd had a CT scan and a week had gone by, I hadn't heard anything, and then at seven to 10 days, I still hadn't heard anything. Then you're thinking 'Perhaps I'll be alright because, if there was something on the CT scan, and it was bad, they would have got me back fairly quickly.'...I remember thinking 'Yes, but I wonder if someone's misinterpreted the results. I wonder if somebody has put my results against Fred Bloggs.'

**Simon, Patient, Aged 65–74, South East**

Many health care professionals interviewed spoke of the success of the 'One Stop Shop' Breast Cancer Model, and a need to explore whether a similar approach could be adopted for bladder and other urological cancers. The Breast Clinic Model sees patient consultations (usually referred from their GP or a routine screening) and all diagnostic tests carried out during one visit to the clinic, with the results available later that day. However, the health care professionals we interviewed stated that this has proved challenging to implement due to long waiting lists for other diagnostic services.

Some people affected by bladder cancer did state that they had a good experience with a quick referral from a GP and reported that they were able to access all diagnostic tests on one day.

'I think the GP was absolutely fantastic at that first bit, the one stop clinic and getting the diagnosis that there was a tumour.'

**Felicity, Patient, Aged 55–64, East of England**

'It was actually pretty slick. It was clear that, on that day, that's what they did and even with the bloods, it was almost like queuing up at the meat counter in a supermarket. You took a ticket, you sat down, you went in there and it was slick, you were in and out, bloods were done and you were onto the next stage and the next stage. At no point do I really remember hanging around.'

**Jack, Patient, Aged 45–54, Yorkshire and the Humber**

However, patients and carers did indicate that they thought different regions of the UK experience different wait times for diagnostic tests.

'Following that biopsy it took about six to seven weeks and it was then that I was told I had carcinoma in situ. That's fairly normal here in Northern Ireland. I know if you're in the Isle of Man it would be about a week. In the South of Ireland it would be probably about a week to two weeks for results from biopsies, but in Northern Ireland results from biopsies usually take about six or seven weeks.'

**Melissa, Patient Aged 55–64, Northern Ireland**

Others found some parts of their journey very satisfactory, with other parts lacking. This included negative experiences in being referred by their GP, but positive experiences of the bladder cancer pathway once they were referred.

'The surgery part on the whole, what's it called the whole, sort of, BCG has been handled well. The NHS part has been handled well. The hospital has been really good. The thing that hasn't been handled well was the pre-part really. So it was the GP part that could have been handled better I would say.'

**Nathan, Patient, Aged 45–54, West Midlands**

## A TURBT (Transurethral Resection of Bladder Tumour)

To investigate further when some abnormalities have been found and to make a full diagnosis, the urologist may suggest that the patient have a procedure to take a sample – a biopsy – of some of the abnormal cells, or even to remove any abnormal tissue or cancerous cells, if possible. This is known as a TURBT, which stands for Transurethral Resection of Bladder Tumour, and is performed in the same way as a cystoscopy. It is an 'incision-less' surgery, usually done as a day or overnight case in your local hospital under either a general anaesthetic or a spinal block.

The instrument used to take the sample or to remove the tumour during the TURBT is called a resectoscope and, like the cystoscope, it is introduced through the urethra into the bladder. Attached to this scope is a small, electrified loop of wire, which is moved back and forth through the tumour to cut away and remove the abnormal tissue. Electricity is used to seal off any bleeding vessels. This is sometimes called electro-cauterisation or fulguration.

The advantage of this procedure is that it can be performed repeatedly at minimal risk to the patient and with excellent results.

**Figure 10.** Fight Bladder Cancer, Patient Information Booklet, *What is a TURBT?* 2020.

### TURBT CLASSIFICATION

**There was consensus from the majority of health care professionals interviewed that TURBT must be challenged with regards to its status as either definitive treatment or a diagnostic procedure.**

Health care professionals said that the 'naming' of this procedure has a substantial impact at a national level on cancer treatment targets and determines when the 'cancer treatment clock' stops and starts. All health care professionals interviewed believed that TURBT should be routinely categorised as a diagnostic procedure rather than definitive treatment, in order to prevent the clock stopping artificially early on the 62-day time to treat waiting target for cancer patients. Interviewees argued that for bladder cancer patients who require further treatment, the reclassification of TURBT may have a substantial impact on their wait time for their definitive treatment with implications for their long term health and wellbeing.

TURBT has been classified as a diagnostic procedure in England as of September 2020, but has not yet been changed in Scotland, Wales or Northern Ireland.

The cancer waiting times systems in the devolved nations operate differently to England. In some circumstances, this means that there is nuance about when and how the reclassification of TURBT should take place to ensure that it does not interfere with progress made on bladder cancer waiting times to date. However these findings suggest that the TURBT classification should be reviewed in each of the devolved nations and a decision should be taken about how to ensure that the classification results in the best results for patients with regard to waiting times for definitive treatment across the UK.

Several health care professionals were of the view that voluntary sector organisations such as Fight Bladder Cancer should lead and advocate for the change of status of TURBT. They felt that we, as a charity, were well placed to raise this important issue with healthcare policy and decision-makers.

**Several people affected by bladder cancer indicated that they experienced extended delays between their diagnosis of bladder cancer and treatment, which also had a negative impact on their psychological wellbeing.**

'I found the waiting in-between each event increased the anxiety... And with all of those initial delays and then I had BCG treatment which failed, I had my cystectomy a year later which is quite a long time, I think, between diagnosis and actually sorting it out. Each time, you go for a CT, you've waited three weeks for that then you wait another three weeks to see the Consultant again, for the results. And it all added up.'

**Simon, Patient, Aged 65–74, South East**

In contrast, several patients and carers did feel they or their family member had received a timely and well-managed service, with smaller challenges often relating to wait-times for surgery.

'Well, both surgeries were handled very well... Very professional and timely, both timely and well monitored from start to finish. There was just a waiting list between, you know when you're diagnosed with cancer and when you get the actual surgery, you know you want it to be the next day but sometimes that's not possible.'

**Peter, Carer, Aged 45–54, Northern Ireland**

## CONTINUITY OF CARE

Health care professionals we interviewed reported that continuity in care needs to be improved, particularly for patients who require follow up visits and ongoing treatment. Many health care professionals reported that there is a battle for resources between the long-term follow up patients and the service to diagnose new patients. They felt that a re-design of existing resources at their sites could be developed to benefit their patients.

Many people affected by bladder cancer reported that they had experienced issues with the continuity of their service which they felt were due to a lack of resources, disorganisation of services or poor communication which caused distress.

'It wasn't particularly that the op was cancelled, it was the fact that I was taken into a room with three other people, it wasn't a one-by-one thing and, "How are you going to feel if we send you home and not knowing when you're going to come back?" I said, "Oh yeah, that's fine we understand" and inside I'm screaming, "It's not alright because I've got a tumour and I want it out today" you know, not even knowing when I was going to come back. So again I think it was how they handled it. It wasn't particularly what happened, although it was devastating.'

**Felicity, Patient, Aged 55–64, East of England**

Health care professionals reported a long wait for their patients to undergo cystoscopy and the lists were usually, if not always, full. Several interviewees said that their centre has tried to streamline their service by avoiding repeat hospital visits by patients who are feeling well but require ongoing monitoring or regular therapy. Some indicated that their centre had a slow pre-op assessment process, with a long waiting list.

**Participants felt that their experience and care had been affected by COVID-19, including delays in operations, diagnostic tests and follow up communication.**

However many felt that the system was not working well even before the pandemic created extra pressure.

'The system doesn't work well, I know it's not the fault of the individuals. I think I've realised that I'm going to have to push for it, when all the COVID thing was in full swing, I had to push to get that final TURBT, because they were saying "Well, we're not really doing things." And I rang several times and just said "Now, come on, there's a long gap since the last BCG. I really need to know." They were trying to put off that final TURBT and I didn't want them to and, as it turned out, I was right, because the tumour had come back.'

**Sharron, Patient, Aged 65–74, West Midlands**

People affected by bladder cancer who required support for themselves or their family members after leaving hospital reported that there was a lack of needs assessment to ensure they had the right support to manage at home. Individuals reported needing to be pushy to receive follow up care or support. Some interviewees reported that they had to seek out and pay for private care. Others reported that while they did need additional support, they were not able to afford to access it privately.

'The care from the council and [council] support services was atrocious. There wasn't any. I only had a Social Worker because I rang the council. I said I needed someone to do an assessment. It wasn't because they offered, I had to ring and ask for someone to do an assessment.'

**Abbie, Patient, Aged 65–74, Scotland**



Patients and family members of patients with existing long-term health conditions reported experiencing additional difficulties and delays in treatment due to their co-morbidities, along with a need for additional support navigating the variety of services for their different health conditions.

'I think we would have wanted it, if the departments had been a bit more joined up, you know, for the problems that we had with the catheter and getting prescriptions for his heart problems. It's like there is not one person overseeing your care, do you know what I mean? You've got your GP in the middle and then you've got catheter people involved and chest people involved, and you don't really know what's happening there. If you've got one person that you can ring and say, "What's happening, can you try and make sense of it for us?"'

Lisa, Carer, Aged 45–54, Yorkshire and the Humber

## PATIENT CASE STUDY

### KATHRYN\*

My bladder and I have always had a strained relationship. As a child, I suffered from frequent UTIs and was even bullied by other children as a result of my bladder problems. Both my parents smoked and I also took up smoking for about 10 years.

With hindsight, I had the right combination of symptoms to be diagnosed with bladder cancer, but I didn't know that at the time, and it didn't make it any easier to get diagnosed. I thought it was possibly another UTI when I was told to go to the chemist where I had to complete a form to get antibiotics. The chemist refused to give me antibiotics as I had blood in my urine and said I needed to go back to my GP. I filled out another form and left a sample at my GP and was told to expect a phone call. Later that day I was told a prescription had been left for me to pick up. I didn't even get to see a GP.

The antibiotics did not help and I was still passing blood and clots, although not constantly it seemed to happen after I'd been active. My lower back started to hurt and eventually, after two weeks of two more courses of antibiotics, I managed to get a GP appointment, who then referred me to urology. Later that week, I passed a large amount of blood and was in a lot of pain, so I went to the out-of-hours GP, who phoned the on-call urologist. He told me not to worry as it was unlikely to be cancer due to my age but to make sure my GP had done an urgent referral



as nothing could be done without a scan and cystoscopy. I checked with my GP the following day only to find out that they had made a general referral. In view of what the urologist had said, the GP surgery agreed to change the referral to urgent. Two more weeks passed without news of an appointment, so I contacted my GP surgery to find out what was happening, only to discover that it had never been changed to urgent.

I finally got a scan and cystoscopy two months after I originally went to my GP with blood in my urine. They discovered a large tumour, it was cancer. By this point, I was relieved to just get an answer! My GP was shocked and apologetic. But I don't blame them for anything as on the balance of probabilities and NICE guidelines, it was unlikely – although not unheard of – for women of my age to be diagnosed with bladder cancer. Awareness is key for patients and GPs – we all know early diagnosis saves lives!

\*pseudonym

# OUR RECOMMENDATIONS:

## PUTTING IN PLACE AN EXEMPLAR PATHWAY

Based on these research findings we recommend a number of specific actions to improve the pathway for bladder cancer patients, including delivering quicker referral and diagnosis. We also call for the development of evidence-based, standardised pathways for bladder cancer diagnosis, treatment and care across each of the four UK nations to overcome the variations present in the current system.

### WHAT WE CAN DO NOW:

- Health service leaders in Scotland, Wales and Northern Ireland should take steps to reclassify TURBT as a diagnostic procedure rather than a definitive treatment for all bladder cancer patients, as appropriate for their own cancer waiting times systems, to support swift patient progression to treatment
- Following the reclassification of TURBT in England in September 2020, NHS England should work with, and support, local systems to ensure this change is consistently implemented across all NHS Trusts – with waiting times for post-TURBT definitive treatment captured under the 62-day waiting time target
- Following the reclassification of TURBT, clinicians should communicate clearly to patients that the hope with a TURBT procedure is still that it will effectively treat their bladder cancer, but if the procedure finds that they have more advanced cancer, there will be no delay for them to receive the first definitive treatment they need
- The NICE *Urological cancers – recognition and referral* guidelines should be reviewed, and the feasibility of two specific changes should be explored to accelerate possible bladder cancer referral and diagnosis:
  1. People of all ages (instead of the current 45 years and over) who have visible haematuria [blood in pee] that persists or recurs after they have been successfully treated for a urinary tract infection should be urgently referred for possible bladder cancer
  2. People of all ages (instead of 60 years and over) with recurrent or persistent unexplained urinary tract infection should be non-urgently referred for bladder cancer
- The *Scottish Referral Guidelines For Suspected Cancer* should be reviewed, and the feasibility should be explored of urgent referral for people of all ages (instead of 45 years and over) who have visible haematuria [blood in pee] that persists or recurs after successful treatment of urinary tract infection, and to consider the introduction of non-urgent referral for bladder cancer in people of all ages and genders with recurrent or persistent unexplained urinary tract infection
- In line with the NICE *Urological cancers – recognition and referral* guidelines and the *Scottish Referral Guidelines For Suspected Cancer*, if a GP determines that an active monitoring strategy is more appropriate than referral, it is important for the GP to provide a 'safety net' and ensure that people know what symptoms to monitor and when they should return for re-evaluation. Systems should be in place to ensure people are not lost before follow up



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- The bladder cancer community should work to evaluate existing haematuria rapid diagnostic clinics and publish case studies in order to share their potential benefits with a wider audience
- Health systems across the UK should commit to examining the benefits from existing haematuria rapid diagnostic clinics and exploring the feasibility of introducing similar solutions in their pathways to support rapid bladder cancer diagnosis
  - In England, this should form a core part of work by Cancer Alliances and Integrated Care Systems to prioritise earlier diagnosis of cancer as part of NHS Long Term Plan implementation
- National policymakers and public health bodies should continue to support bladder cancer patients and the general public with possible bladder cancer symptoms to return to healthcare services following the COVID-19 pandemic, through specific symptom awareness-raising measures in campaigns such as 'Be Clear on Cancer'



## AREAS FOR FURTHER RESEARCH:

- Fight Bladder Cancer will bring together the bladder cancer community to facilitate a national conversation on what an optimal pathway for bladder cancer should look like across the UK, prioritising rapid referrals, assessment, diagnosis and treatment, as well as ensuring smooth data transfers between different stages of the pathway. This work should learn from existing best practice in bladder cancer and other specialties – particularly the faster diagnostic pathways in lung, colorectal and prostate cancer
- The bladder cancer community should also consider commissioning an academic cost/benefit analysis of current bladder cancer services and possible pathway improvements to support the case to senior stakeholders for improvements



# RESEARCH FINDINGS

## 2 DEVELOPING AND GROWING THE BLADDER CANCER WORKFORCE

### KEY FINDINGS

- For people affected by bladder cancer, the people managing their care were very important for their patient experience. Many interviewees reported positive experiences and supportive relationships with health care professionals, however experiences varied
- Health care professionals said that they want to provide the best service possible for the people in their care, but this has become increasingly challenging due to larger care loads and increased patient waiting lists
- Resources are shared with other urological conditions as many roles are not specialised. This can create difficulties in ensuring patients with bladder cancer have the dedicated care and support they need, particularly when demand for or health systems' prioritisation of other urological conditions changes (e.g. prostate cancer)
- Whilst some people affected by bladder cancer reported receiving valuable support from their Clinical Nurse Specialist, not everyone had this access. Further, some interviewees reported very limited interactions with or difficulties contacting their Clinical Nurse Specialist
- Clinical Nurse Specialists interviewed reported challenges associated with a lack of resources and high workload, and most are expected to cover all urological conditions
- Health care professionals called for more specialist bladder cancer Clinical Nurse Specialists and improved specialist training in bladder cancer and support for ongoing development



**During our interviews, many people living with bladder cancer and their family members reported positive experiences and important supportive relationships with their Urology team and other hospital staff.**

This included Consultants, Clinical Nurse Specialists and Stoma Nurses who helped them in difficult times during their diagnosis and treatment.

'My surgeon is great, I really, really like him and the nurse that works with him. They've given time and listened and answered questions... I really feel confident with them and safe in their hands and that I can ring at any time and ask things and [the Clinical Nurse Specialist] has always rung back when I've had a couple of queries about things. They made a slight error in some medication, she got that absolutely sorted for me. Since the op ... I've got the Stoma Nurses, who are going to be the ones if I want help on a practical level with the stoma... There are two places to ring if I need some help.'

Sharron, Patient, Aged 65–74, West Midlands



'All the Nurses, the staff, are all so pleasant and supportive that you don't feel awkward. It's all very personal, but you don't feel exposed or awkward.'

**Sarah, Patient, Aged 65–74, South East**

You know the regulars on urology were fabulous. They couldn't do enough. My partner when she had the chemo prior to the RC she had an infection and honestly [hospital] was like the best of the best. It was fabulous. From the cleaners to the people doing the food, the nursing staff, the consultants, everybody was fabulous. It was just so good there you can't believe it. It was fabulous.

**Ivan, Carer, Aged 55–64, Wales**

**Every health care professional working in bladder cancer who took part in an interview spoke of the desire to provide a robust and holistic service to their bladder cancer patients, but found this hugely challenging.**

They reported that their roles are changing, leading to larger caseloads and increased patient waitlists. For example, health care professionals had been taking on increased management responsibilities, while many previously bladder cancer-specific roles are being generalised to meet the demand in prostate and other urological cancers. Indeed, the vast majority of health care professionals we interviewed reported that their role was not specific to bladder cancer. Many acknowledged the challenges and high level of skill needed to provide quality care in bladder cancer, which they felt may not be available within every centre.

Patient interviewees' experiences of health care professionals managing their treatment did vary.

**Some people affected by bladder cancer reported that they had a poor experience of communication and organisation of their treatment and care.**

'They didn't follow it up right. I was nine months down the line and there'd been no word and I had to go privately in the end, to get the bladder removed. They were trying to push for more BCG treatment and I remember my Cancer Nurse saying 'But, have you not read her notes? She can't take any more of that treatment. That's what's damaged her bladder so much.' I was not happy there at all and then I didn't hear anything for months. I had no choice'

**Eve, Patient, Aged 65–75, Scotland**

Several health care professionals reported that TURBT and cystoscopy were usually performed by generalists rather than a specialist at their centres. Participants argued that best practice would be for patients to be assessed by bladder specialists rather than a generalist at the outset. However, even at some participating sites where bladder specialists were involved right at the start of the patient pathway, this was not the case for all bladder cancer patients, with generalists still performing diagnostic procedures for some patients. If cystoscopy is performed by a bladder cancer specialist, it could mean an increase in bladder cancer being ruled out earlier in the investigation process.

People affected by bladder cancer were also aware of the effect that lack of specialist staff and resources has had on patient waiting times.

'He did explain to us that I think there are only two urology consultants in Northern Ireland and he's one of them...it's a funding issue there as well... that's why. Everybody has to be on the waiting list, unfortunately.'

**Peter, Carer, Aged 45–54, Northern Ireland**

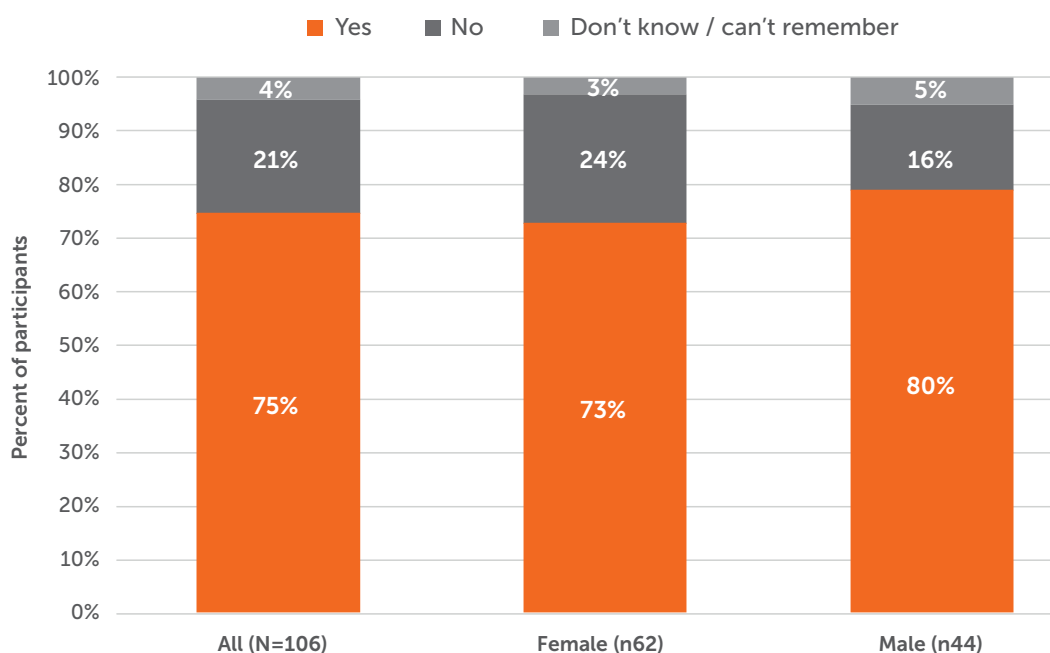
## ACCESS TO CLINICAL NURSE SPECIALISTS

Many interviewees reported that Clinical Nurse Specialists were a vital support to them through their patient journey.

**However, not everyone affected by bladder cancer we interviewed had access to a bladder cancer Clinical Nurse Specialist.**

While the majority (75%) of the 106 bladder cancer patients who completed the online survey were given the name of a Clinical Nurse Specialist to support them, 21% were not.

### Were you given the name of a Clinical Nurse Specialist who would support you through your treatment? (N=106)



**Figure 11.** 1 in 4 bladder cancer patients surveyed reported that they were not given, didn't know, or couldn't remember the name of their Clinical Nurse Specialist.

Women were more likely to report that they had not been provided with the name of a Clinical Nurse Specialist (24% women, 16% men).

Similarly, some also reported that although the centre they access does have Clinical Nurse Specialists they could contact, this process was not easy. Some interviewees reported a lack of availability or difficulties contacting their Clinical Nurse Specialist over the phone. Several said they had not had much contact with their Clinical Nurse Specialist.

'I know everybody says your Clinical Nurse Specialist really wants to hear from you and that's what they're there for. But you do feel a bit like a pain when you ring. Because I did get that impression, that they were really busy. It was just a hospital card with the names and numbers on. And we never saw the same one twice. I think, another thing is when you ring you have to leave a voice mail. But if that phone went through to a receptionist or just a real live person, it might make it feel a bit more personal. Yeah. So I think if you were just assigned one Clinical Nurse Specialist instead of being given, like, a group.'

Lisa, Carer, 45–54, Yorkshire and the Humber

During our interviews, Clinical Nurse Specialists reported changes to their role in response to their departments changing the way a service was delivered. Some reported that they are expected to cover wider geographical areas and travel between multiple centres to provide services.

Anecdotally, in one region, one Clinical Nurse Specialist is responsible for up to 100 community-based patients. This workload has to be managed alongside handling frequent phone calls from patients and their carers, as well as managing appointments, letters and other administrative tasks. Most participants reported a substantial disparity compared to colleagues in prostate, and other urology services, in terms of resources and time to make a phone call and follow up with individual patients.

Clinical Nurse Specialists recognised that there is an ageing population of senior nurses and when they retire there will be a bigger workforce gap. They thought that the poor understanding of what Clinical Nurse Specialists "do", with a broad variety of job titles covering the activities we associate with a Clinical Nurse Specialist, contributes to fewer junior nurses becoming Clinical Nurse Specialists and underinvestment in the roles generally.

## CLINICAL NURSE SPECIALIST TRAINING

Most health care professionals felt strongly that for Clinical Nurse Specialists to become increasingly specialised and provide quality care for bladder cancer, they needed more frequent training, but stated that opportunities to receive additional training remain limited. Several Clinical Nurse Specialists highlighted their need to get access to bladder cancer experts or specialists for training and ongoing role development. They stressed these opportunities were very rare and asked if voluntary sector organisations such as Fight Bladder Cancer could do anything to facilitate them.

Most Clinical Nurse Specialists reported that the British Association of Urological Nurses (BAUN) conference was the largest and most substantial annual event applicable to their roles. Training sessions were often only available at weekends which many staff found too challenging to fit in with their busy working and home lives. Several Clinical Nurse Specialists reported that they organised their own 'Bladder Cancer CNS' (Clinical Nurse Specialist) group to keep up with current developments in their speciality. At these group meetings, speakers were invited and learning opportunities to remain up to date with the latest thinking were made available. However, these meetings were always organised out of standard shift time requiring the staff to invest their own free time to attend.

## PATIENT CASE STUDY

### DEREK

Like so many other people I looked forward to retiring at 70 and having time to carry on my hobbies. That turned out to be somewhat complacent. In summer 2014, I noticed blood in my urine. At the time I thought I would just monitor the situation, but the blood returned intermittently.

My GP arranged an appointment at the [Hospital] the following week for a flexible cystoscopy. I then had an appointment to see the urologist, who explained what the problem was. It was clear to him that we did not fully understand everything he was telling us, so he asked if we would like to see a Macmillan nurse, to which we agreed.

The Macmillan nurse explained my situation with the aid of an excellent booklet. I then had an appointment to see the oncologist at the [Hospital] where I was told I had Grade 3 aggressive bladder cancer. We went through the choices of the treatments involved and I was recommended to go and see the surgeon at [Hospital] to discuss his views and see the right way forward for me. I decided on chemotherapy and radiotherapy.



Throughout the chemotherapy, although at times it was gruelling, there were sufficient drugs to help combat side effects, plus the chemo nurses were always there at the end of the phone line with help and reassurance 24 hours a day. The staff at the [Hospital] where I was treated were very welcoming and easy to talk to. They always explained everything that was going to happen and took good care of me. After treatment, I looked forward to coffee and cakes and a chat with volunteers at the cafe.

I would like to thank [my consultant], for her excellent diagnosis and treatment, and her entire team for the way I was looked after; I could not have wished for anything better. I believe my treatment saved my life.



# OUR RECOMMENDATIONS:

## DEVELOPING AND GROWING THE BLADDER CANCER WORKFORCE

Based on these research findings we recommend that health systems across the UK grow and develop the bladder cancer workforce. This includes ensuring that the whole bladder cancer workforce is sustainable now and in the future, with Clinical Nurse Specialists, in particular, supported to deliver comprehensive and high-quality holistic care to people affected by bladder cancer and their families.

### WHAT WE CAN DO NOW:

- The NHS, Health Education England, NHS Deaneries in the devolved nations, and the bladder cancer community should work in partnership to map the current Clinical Nurse Specialist workforce and determine the optimal number of bladder cancer Clinical Nurse Specialists required to meet current and future patient need
- National NHS teams, Health Education England and NHS Deaneries in the devolved nations should work in partnership with local NHS organisations and the bladder cancer voluntary sector to ensure all urology Clinical Nurse Specialists have ongoing access to training and exposure to bladder cancer specialists to support learning and development
- National and local NHS leaders should be called upon to support the reduction of variances in training provision for Clinical Nurse Specialists, including by identifying educational gaps and allocating funding to fill them

- Local and national NHS leaders should champion and amplify existing training, including British Association of Urological Nurses training, for Clinical Nurse Specialists to ensure all members of staff are aware of the opportunities already available and have equitable access to learning and development

### AREAS FOR FURTHER RESEARCH AND EXPLORATION:

- The bladder cancer community and national policymakers should invest in opportunities to grow the workforce of health care professionals specialising in bladder cancer, with a particular focus on Clinical Nurse Specialists
- The value of expanding nursing roles focused on patients in the community should be considered, particularly given the need to provide bladder cancer patients with ongoing support post-cystectomy with stoma management
- Health Education England, NHS Deaneries in the devolved nations and NHS leaders should recognise the importance of different specialisms within urology Clinical Nurse Specialists and ensure that all major centres have a lead bladder cancer Clinical Nurse Specialist
- The bladder cancer community and national policy makers should ensure that the bladder cancer workforce is growing at a rate to cope with additional demand generated by improvements in the service pathway, such as increased UTI referrals from primary care



# RESEARCH FINDINGS

## 3 IMPROVING AWARENESS, SUPPORT AND INVOLVEMENT IN CARE ACROSS THE PATHWAY

### KEY FINDINGS

- Interviewees highlighted the substantial physical and psychological impact bladder cancer can have on the everyday lives, friendships and relationships of people with bladder cancer, as well as their carers and families
- Several people affected by bladder cancer reported that they lacked information and did not have the opportunity to explore their options with the clinicians managing their treatment and care. They felt this may have had a substantial impact on their long-term health outcomes, especially if it meant they had not received the most suitable treatment
- Health care professionals, patients and family members emphasised the importance of access to information and support services, and connection with others who have experience of bladder cancer for practical advice and reassurance to help them cope
- Many patients and family members stated that they would have benefited from earlier access to support services. Barriers to access included a lack of awareness and absence of signposting by health care professionals
- Women affected by bladder cancer reported less involvement and less signposting to support services than men
- Health care professionals identified the 'first diagnosis of bladder cancer' as a key time in which patients and their families experience initial trauma and anxiety, and need support and information quickly. However, they reported that limited time and resources impacted their ability to provide the support they ideally would want to give. Only some health care professionals reported providing information leaflets or signposting to support services
- Other barriers to patients and family members receiving support included: feeling that support services were not suitable for them, difficulties asking for help, and feeling uncomfortable in support group settings. This suggests that there may be a need for a variety of support options and approaches
- People who had been diagnosed with bladder cancer and their carers stated that there is not enough targeted support and information for the carers and family members supporting bladder cancer patients
- People affected by bladder cancer and health care professionals emphasised the lack of existing awareness of bladder cancer and called for Fight Bladder Cancer to work to improve awareness of bladder cancer and the support services available. Several patients stated that they had not heard of bladder cancer before they were diagnosed and indicated that general health care professionals have a lack of awareness of bladder cancer
- In addition to the strain that COVID-19 has placed on individual's lives and access to health and care services, the shutdown of in-person support services also impacted the support available to people affected by bladder cancer, particularly if they were not able to access online services



## INVOLVEMENT IN TREATMENT AND CARE

For people with bladder cancer, there are important decisions regarding treatment options. Significant treatment decisions for bladder cancer patients can include the decision between immunotherapy directly to the bladder (such as BCG), chemotherapy, radiotherapy, full or partial bladder removal (RC – radical cystectomy) and, in the case of bladder removal, the type of operation and whether to have a stoma or neo-bladder. Treatment decisions have implications for long term survival and health outcomes. In particular, the decision to undergo a bladder removal has the potential to have profound life-changing impacts on a patient's future life and lifestyle and that of their family.

**Given the life-changing implications of treatment decisions, it is crucial that patients are fully involved in the decision-making process for their treatment.**

54% of the 106 patients who completed the online survey reported that they were as involved as they wanted to be in the decisions made about their treatment and care. However, 14% reported that they were not and women were more likely to report that they were not as involved as they would have liked (21% women, 5% men).

Health care professionals we interviewed highlighted the importance of involving patients in the treatment decision-making process. Some people affected by bladder cancer reported good relationships and communication with the health care professionals treating them. They said they did feel involved in decisions around their own treatment and care, and were supported in making an informed choice:

'It was discussed. My questions were answered. Yes, I felt involved. It was helpful that the Consultant actually had this app on his mobile phone and put in all the figures and said 'Right. If you have BCG, this is the potential for a relapse. If you don't have it, this is the potential.' Actual figures, that was helpful... It's something very concrete that you can say 'Okay. That's the right decision to make.'

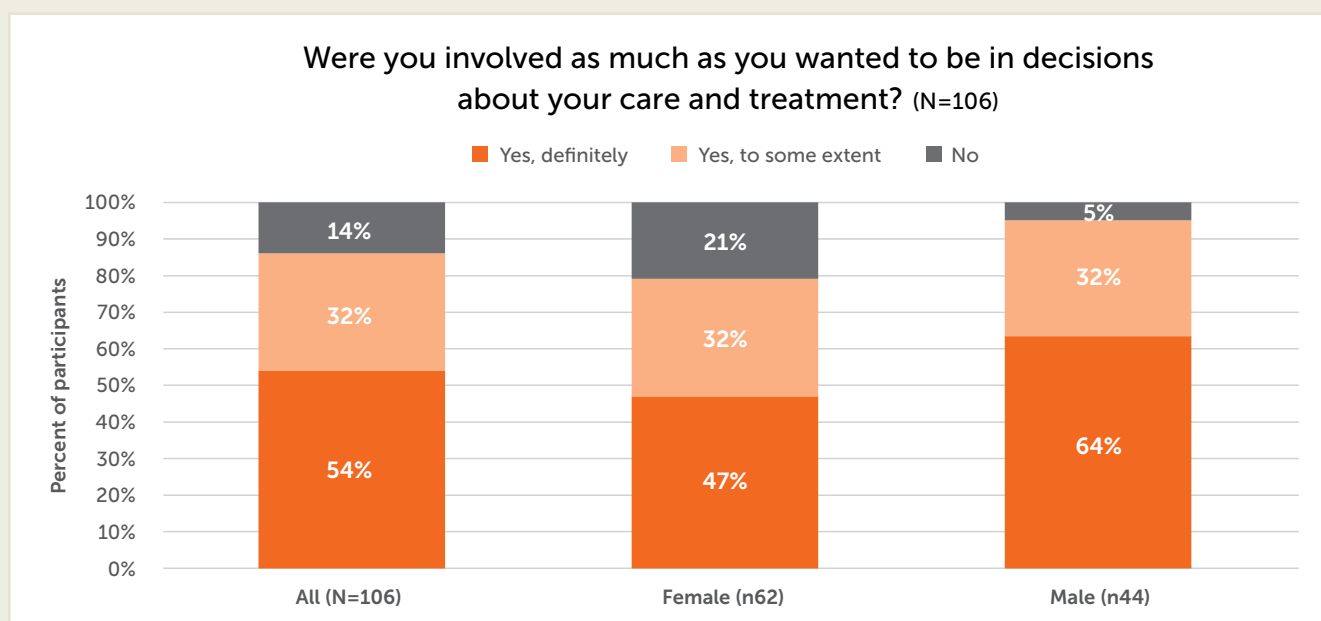
**Sarah, Patient, Aged 65–74, South East England**

'You see them all before the op and they explain what they're going to do, even the Anaesthetist came round and explained what he was going to do. And then he came round after, to see how you are, as well. They explained it, what happened, giving me an option of what kind of operation I wanted.'

**Ralph, Patient, Aged 55–64, Yorkshire and The Humber**

However, other interviewees reported a lack of information and involvement in their treatment and care which they felt may have a substantial impact on their long term health outcomes.

**Figure 12.** 14% of patients (21% of women and 5% of men) said they were not as involved in treatment decisions as they would have liked.





'Had I had a proper consultation and had the possibilities explained to me then I think I might have gone for bladder removal, because I'm that type of person. I don't want to risk anything. He said to me, which absolutely gobsmacked me 'I don't know why you didn't go for an RC with your level.' And I just looked at him, I couldn't believe what he was saying, because he was the very one that had rung me and said 'You've got CIS, you're having BCG.' So, yes, I was gobsmacked, I didn't know what to say to him, to be honest.'

Diana, Patient Aged 55–64, South West

'I know it's spreading and I know there's no cure. I do sometimes question whether, in the early days, there might have been a window when that cure could have taken place. I think they should have said more about removing the bladder to get rid of the cancer and the benefits or not benefits for doing that... I don't remember them being involved, it was me calling them, really, and every time I went in for an appointment.'

Larry, Patient, Aged 55–64, South East

## ACCESS TO INFORMATION AND SUPPORT SERVICES

**People affected by bladder cancer emphasised the importance of support services, including the Fight Bladder Cancer support forum.**

'The most useful thing I think has been the support from the 'Fight Bladder Cancer' support group. At least you can see from that that other people are having the same issues and so I know... no matter how horrible it feels like at the time, it is just a normal side effect that everybody seems to be getting.'

Aaron, Aged 45–54, South West

**Peer support and the opportunity to talk to someone who has been through a similar experience to them was highlighted as a key service for people affected by bladder cancer – for emotional support, practical advice and general support when navigating important and potentially life-changing treatment decisions.**

'That was my worst day, the realisation that I was going to have a urinary bag and a stoma bag and things were going to change dramatically for me. So she put me in touch with the voluntary organisation, the Urostomy Association, and I went and I visited a girl who had a stoma bag. And she was very reassuring and definitely, it was very worthwhile to go to visit her. She was the first person that [I] spoke to, and I found it very helpful. Most of the people I spoke to were medical and weren't interested in my mental needs or how I was feeling.'

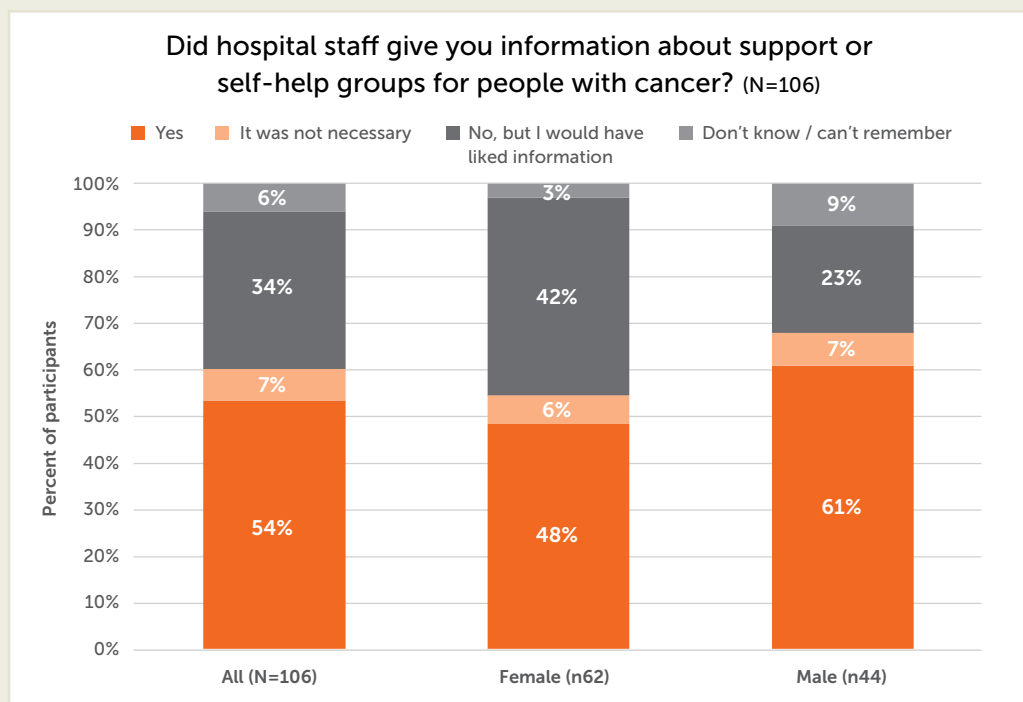
Melissa, Patient, Aged 55–64, Northern Ireland



Health care professionals identified the initial trauma and anxiety patients, and their families experience at 'first diagnosis' and the need to have their questions answered quickly. Clinical Nurse Specialists reported that they would usually receive a flurry of questions immediately following a new diagnosis; about treatment options, their risks and benefits.

Some people affected by bladder cancer reported receiving support from health care professionals, particularly Clinical Nurse Specialists, as well as signposting to external support services and information resources.

**Figure 13.** Nearly half of all bladder cancer patients surveyed stated that they were not given information about support groups or self-help groups.



'When I saw the Consultant for the actual definitive diagnosis, I saw [Clinical Nurse Specialist] at the same time and she said, 'Don't look at the internet, just go on [Fight Bladder Cancer's] website. Which was brilliant advice, because the website is so easy to access and it was easy for me, for my kids to access it, my husband. It's just the language you use is just right, it was just right for me, anyway. But I also had loads of pamphlets and leaflets and [Clinical Nurse Specialist]'s telephone number. The advice was fine and my questions were answered and I've also had to contact [Clinical Nurse Specialist] for various issues in the last year and she's been great.'

**Sarah, Patient, Aged 65–74, South East**

However, while some stated that they were signposted to support services early by their medical team, several interviewees reported that they were not provided with information leaflets or signposted to support services. Many people affected by bladder cancer said they would have benefited from access to support services sooner.

'It would have been interesting to have met other people just to talk about things. I think, because it was only early stage, I've been very lucky and I've met people and chatted to people... but I've only met those people later on, since I've come across the charity, the Fight Club meetings.'

**Geoff, Patient, Aged 65–74, South East**

Over half of the 106 patients (54%) who completed the online survey stated that they were provided with information about support or self-help groups for people with cancer. However, over a third (34%) reported that they were not given this information and they would have liked information about support available. Women were more likely to report that they would have liked this information but it was not provided to them (42% women, 23% men).

Health care professionals reported that finding the time to provide the support they wanted to give was always a challenge. While some reported thriving on-site support services and groups for patients and their families, other centres did not have any on-site support. Only some reported that their centre gave their newly diagnosed patients information leaflets and a Clinical Nurse Specialist's contact details for follow up care and support.

Some people affected by bladder cancer reported barriers to accessing support services, including lack of awareness of what is available, not living near in-person support groups and services, and a lack of ability or willingness to access online support services. However, some people just did not think that certain services were suitable for them or they reported feeling uncomfortable in a support group setting.

Interviewees also highlighted that COVID-19 restrictions put a stop to in-person support for bladder cancer, which was particularly isolating for people unable to use digital support services.

Health care professionals reported that patients and carers ask for practical information on subjects such as: accessing financial support; what to do if they are no longer able to work; how to receive regular care at home. Generally, they reported that patients worry about 'the practical stuff': holiday insurance; returning to work; day-to-day living; and access to benefits. Several asked if Fight Bladder Cancer could help in providing these services.

People affected by bladder cancer reported gaps in specific information and support. This included a lack of information from health care professionals about what to expect and how to cope with treatment. Many reported that they would get this type of information from the Fight Bladder Cancer forum or other peer support, but felt it should be easily available for all patients going through diagnosis and treatment for bladder cancer.

'The [Clinical Nurse Specialists] are very good and they give you a pad when you leave, but they might have said 'We advise you to go into Boots and buy some pads and the size you need is X, Y, Z.' When you go into Boots, we men, we're not used to buying pads. At least if we were asked out to dinner, I could actually go out to dinner and I still had to go to the loo, it wasn't impossible and it was doable... That sort of thing would make you start to get depressed. You've got to lead as normal a life as possible.'

**Geoff, Patient, Aged 65–74, South East**

Several women who had undergone a bladder removal reported that while they were given information about the practicalities of living with a stoma, there was a lack of communication from health care professionals around their sexual life. This was also an issue they lacked the confidence to bring up themselves.

'That's something that has not been addressed at all.... I was talking to the Stoma Nurse and I said 'Remember you mentioned about the person that I could talk to about my sexual relationship?' She said 'You'd need to go through your GP and get referred to her.'... It hasn't been broached and it's embarrassing for me to talk about, as well. I just want to start off the conversation, that's the thing. It would have to be somebody medical who could look at my notes and see what was removed. I'm frightened to have sexual intercourse, I just don't want to, because I just don't want it to hurt me.'

**Melissa, Patient, Aged 55–64, Northern Ireland**

## TARGETED SUPPORT FOR CARERS AND FAMILY MEMBERS

People of all genders affected by bladder cancer reported that going through bladder cancer had impacted on their relationships with friends, family and particularly with their partners. Some highlighted the need for specific support for couples going through bladder cancer.

**Several people affected by bladder cancer felt that there was not enough targeted support for carers and family members who were supporting someone with bladder cancer.**

'It was very difficult for my parents to deal with it, and [my] relationship with [my] parents as a younger person with cancer. And, perhaps, the saddest aspect of being diagnosed with bladder cancer is that, at my age, [my] parents have to hold [my] hand and I think that changed my dad's life forever. Not a single person offered him any care or support as an essential older person, carer or a person with a child with bladder cancer.'

**Rick, Patient, Aged 45–54, London**

'I suddenly became the carer then because literally within a couple of days of the first chemo it was like a sledgehammer and [my partner] just got worse and then when she had the second chemo, the two hour one, I mean she could hardly walk bless her and you feel like you're a carer then. You need maximum attention which carries on really from then right through until a few months the other side of the RC, you know. I feel like I don't really need the support with everything [now] whereas I would have welcomed it in that stage between diagnosis and RC so maybe there could be some more information there.'

**Ivan, Carer, Aged 55–64, Wales**

Some interviewees felt support and information resources for carers and family members are needed to help reduce the pressure on patients of having to explain everything to their family and friends themselves.

'It [would] be an idea [if] people got like a family pack where it has resources in it that you could share with family members, you know, some leaflets and different bits of information without it [being] very much on the person [with bladder cancer]. Because for some people ignorance is bliss.'

**Jessica, Family Member, Aged 35–44, Scotland**



## AWARENESS

Health care professionals and people affected by bladder cancer that we interviewed felt that bladder cancer needs its profile raised to improve awareness and resources for people affected by bladder cancer. Several interviewees stated that they think voluntary sector organisations such as Fight Bladder Cancer have a key role in raising awareness for bladder cancer.

'I'd never even heard of bladder cancer, which sounds like a stupid statement to make, because you can get cancer anywhere, but I didn't know of its existence back then. So, yes, I felt dreadfully alone at the start, thinking 'I'm the only person in the world that's got bladder cancer.' Little did I know how prevalent it was back then.'

Diana, Patient, Aged 55–64, South West

Many people affected by bladder cancer stated that they had not heard of bladder cancer before their diagnosis. Several interviewees who had experienced a delay in referral from their GP, or other negative interactions with general health care professionals, felt that there needed to be increased health care professional awareness and knowledge amongst health care professionals of the signs of bladder cancer, including in women and younger people.

Health care professionals we interviewed suggested that Fight Bladder Cancer leaflets should be placed in GP practices, haematuria clinics and other diagnostic centres.



## PATIENT CASE STUDY

### SUE

In 2013 I had been experiencing increasing urgency and frequency of weeing, and every now and then it could be painful with a tiny bit of blood on the loo paper. My doctor thought I had a bladder stone so I just carried on. In May 2014, however, I found that I was weeing blood. I knew that it wasn't a UTI. I went back to my GP, and I was sent for an urgent cystoscopy. Despite the fact that the word 'cancer' was lurking in the back of my mind, it was still a shock to see two small tumours on the screen. TURBT followed and the tumours were removed but they found Carcinoma In Situ (CIS).

It was during this process that I discovered Fight Bladder Cancer and joined the group. What a relief to find that I was not alone – there were others going through the same journey as I was and I could talk to them! Just before I started the BCG, I decided I was not going to let cancer beat me and that I would retire. I wanted to be there for my family.

I finished the six BCG treatments and in January 2015 went in for a biopsy. Sadly the BCG had made little impression on the CIS – not what I was hoping to hear. I discussed my options with

the team: radiotherapy or radical cystectomy (RC). Once again, Fight Bladder Cancer was such a help as so many have been faced with the same choice and shared their experiences. I opted for a radical cystectomy including a full hysterectomy, and I chose to have a stoma and bag.

I was on a fast track to recovery programme, being fit and healthy apart from the cancer, and apparently, I had a positive attitude! Life was good. I stayed in the Fight Bladder Cancer group as it is nice to be able to help others starting their journey. I also felt that a lot of members had become friends. I had the chance to meet some in person and four of us took part in a fundraising skydive with the Red Devils. A lot of group and family members had come to support us. I had vowed it was something I would never do but I'd done it. Would I do it again? Probably!

# OUR RECOMMENDATIONS:

## IMPROVING AWARENESS, SUPPORT AND INVOLVEMENT IN CARE ACROSS THE PATHWAY

Based on these findings, we recommend improving awareness, support and involvement in care across the bladder cancer pathway. This should include developing best-practice procedures and guidelines for communicating holistic and psychological support to patients, carers and family members, ensuring that patients are empowered to make informed decisions about their care.

### WHAT WE CAN DO NOW:

- The bladder cancer voluntary sector and local NHS organisations should ensure that all healthcare professionals working with people with suspected or confirmed bladder cancer are aware they can signpost to patient support services offered by the voluntary sector, with support service leaflets and/or posters placed in all GP practices, haematuria clinics and other diagnostic centres
- In line with NICE and NHS Scotland guidelines, health care professionals should ensure that patients are involved in all major treatment decisions with a full consultation where options are fully explored and explained, particularly those with consequences related to final outcomes, sex and lifestyle
- NHS organisations should be supported to fulfil the NICE recommendation to conduct annual surveys of bladder cancer patient satisfaction – particularly capturing whether patients were fully involved in treatment choices – with learnings actively shaping quality improvement across the country. The Scottish Intercollegiate Guidelines Network (SIGN) should consider developing similar guidelines for bladder cancer services in Scotland
- Results from the National Cancer Patient Experience Survey and the Cancer Quality of Life Survey should be made publicly available separately for bladder cancer, rather than having the results grouped with other urological cancers

### AREAS FOR FURTHER RESEARCH AND EXPLORATION:

- Fight Bladder Cancer will bring together key experts from the bladder cancer community to develop a best-practice procedure, and supporting guidelines, for communicating holistic and psychological support options to patients and empowering them to have an active role in making decisions about their treatment and care – including facilitating a better understanding of the consequences of treatments for sexual wellbeing and lifestyle, for both men and women
- Fight Bladder Cancer will bring together key experts from the bladder cancer community to develop a best-practice procedure, and supporting guidelines, of targeted support for the carers and family members of people living with bladder cancer



# Discussion

## URGENT NEED FOR CHANGE

There is an urgent need for improvements to services for people affected by bladder cancer. While some people do report a good experience this is largely due to the support of dedicated health care professionals who are desperate to provide the best care they can, but are increasingly understaffed and under-resourced, leading to fragmented services and long patient waiting times for treatment and care.

**Patient experience varies too much between centres. We need to work towards a high quality standardised pathway for bladder cancer patients that prioritises faster diagnosis and treatment, facilitates better support and information for patients and their families and enables services to be reviewed based on patient-reported outcomes.**

While most of these priorities are present in the NICE 2015 *Bladder cancer: diagnosis and management* guidelines, there is a need for critical review to assess how these guidelines can be implemented more effectively.

We know awareness of, and resources for, bladder cancer are low compared to other common cancers. Interviewees stated that they had not heard of bladder cancer before they were diagnosed and indicated that general health care professionals in primary care have a lack of awareness of bladder cancer, which can delay their diagnosis.

## GENDER DISPARITY IN BLADDER CANCER DIAGNOSIS

Women with repeated urinary tract infection (UTI) symptoms, in particular, experience long delays in referral from primary care for diagnostic tests (Burge & Kockelbergh, 2016) (Lyratzopoulos, Abel, McPhail, Neal, & Rubin, 2013), and are much less likely to receive a timely diagnosis (Zhou, et al., 2021). Women with bladder cancer also have worse outcomes compared to men. Women tend to present at an advanced stage, experience

differences in quality of life following treatment, and suffer worse cancer-specific mortality (Hart, Woods, & Quek, 2019). The first-hand accounts we have collected show the great impact this has on women and their families. Women reported experiencing months and sometimes years of psychological and physical distress due to long periods of unexplained symptoms, as well as the potential for poorer long term outcomes due to the delay in receiving their bladder cancer diagnosis and treatment.

The current NICE *Urological cancers – recognition and referral* guidelines only recommend that people with recurrent or persistent unexplained UTIs be considered for a non-urgent referral for bladder cancer if they are aged 60 years and over, and that people with visible haematuria that persists or recurs after successful treatment of UTIs be considered for urgent referral for bladder cancer if they are aged 45 years and over. It is vital that the current NICE referral guidelines for suspected urological cancer are reviewed to ensure people affected by bladder cancer in the UK are diagnosed and treated quickly regardless of their age or gender.

## THE IMPORTANT ROLE OF CLINICAL NURSE SPECIALISTS FOR BLADDER CANCER PATIENT EXPERIENCE

Our findings support the existing evidence that Clinical Nurse Specialists are particularly vital to patient experience (National Collaborating Centre for Cancer, 2015). They act as care navigators, supporting and providing information to patients and their families, as well as assessing need and signposting to support services. However, despite the NICE guideline that every patient should receive the name and contact details of a Clinical Nurse Specialist, not every patient reported that they had access to a Clinical Nurse Specialist.

**Clinical Nurse Specialists are in urgent need of more support and resources to provide specialist care to bladder cancer patients.**



## Information and support for people with bladder cancer

Offer clinical nurse specialist support to people with bladder cancer and give them the clinical nurse specialist's contact details.

Ensure that the clinical nurse specialist:

- acts as the key worker to address the person's information and care needs
- has experience and training in bladder cancer care.

**Figure 14.** The National Institute for Health and Care Excellence recommends everyone with bladder cancer is offered clinical nurse specialist support (National Institute for Health and Care Excellence, 2015, p. 11).

Interviewees called for more access to specialist training in bladder cancer, and work is needed to map the existing resources and develop the bladder cancer workforce based on need to improve continuity of care and support for bladder cancer patients.

## RECLASSIFICATION OF TURBT

According to health care professionals we interviewed, the reclassification of the TURBT from treatment to a diagnostic test is a key opportunity to improve the accountability for timely bladder cancer treatment across the UK. While this policy change has been implemented in England as of September 2020, this is not yet the case in Wales, Scotland and Northern Ireland. So far, it is unclear the extent to which this policy change has affected practice within NHS trusts in England.

## PATIENT INVOLVEMENT IN TREATMENT DECISIONS

Our findings further emphasise the need to improve patient engagement in decisions regarding their treatment and care. Bladder cancer patients are often not actively engaged in the treatment decision-making process and rely on their clinician's expertise. This can result in patients not adequately exploring the consequences of decisions about their care (Edmondson, 2017; Turabi, 2013). While health care professionals highlighted the importance of involving patients in treatment decisions, some people affected by bladder cancer reported that they lacked information and did not have the opportunity to explore their options with their health care team.

They felt this may have had a substantial impact on their long-term health outcomes, particularly if they were considering bladder removal (radical cystectomy). The draft 2020 NICE *Shared decision*

*making* guidelines (National Institute for Health and Care Excellence, 2020) emphasise the importance of patient-centred care and patient involvement in decisions, including making sure the full range of management options are available. Work is needed to ensure these recommendations are implemented effectively.

### Three-talk model

The three-talk model is a practical model of how to do shared decision making that is based on following choice, option and decision talk stages during the consultation.

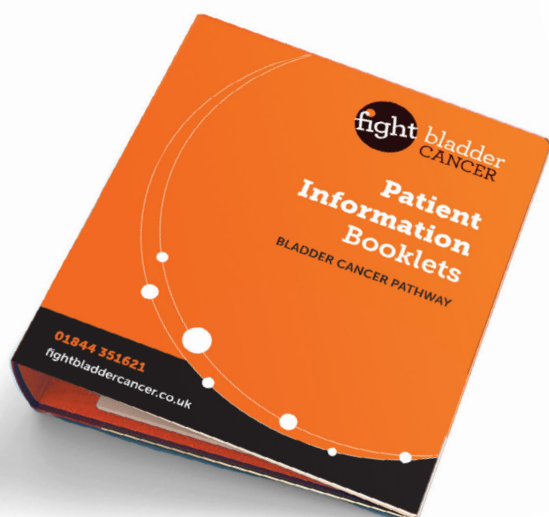
The model has 3 steps:

- introducing choice
- describing options, often by integrating the use of patient decision support
- helping people explore their preferences and make decisions.

**Figure 15.** The National Institute for Health and Care Excellence's draft *Shared decision making* guidelines recommends the "three-talk" model of shared decision making (National Institute for Health and Care Excellence, 2020, p. 14).

## NEED FOR BLADDER CANCER SUPPORT SERVICES

Interviewees highlighted the substantial physical and psychological impact bladder cancer can have on their mental health, everyday lives and relationships. The NICE 2015 guidelines recommend the use of a holistic needs assessment to identify an individualised package of information support for people with bladder cancer. Our findings indicate that women affected by bladder cancer report worse experiences of care, less involvement and less signposting to support services than men.



Some women we spoke to felt they had not received enough information or communication around their treatment options and what it would mean for their future lifestyle and sex life.

One striking finding from this study is the extent to which peer support is important for people affected by bladder cancer and their families. Both people who had been diagnosed with bladder cancer and their carers and family members emphasised the impact bladder cancer has had on their personal relationships and informal carers' emotional wellbeing, highlighting that there is not enough targeted support and information for the carers and family members supporting bladder cancer patients.

**People affected by bladder cancer need access to information and support services to talk to people who have experience of bladder cancer.**

Through online forums, support groups and peer mentoring, patients can access practical advice and reassurance to help them cope with the burden of diagnosis and treatment. This can also support patients to make important treatment decisions. People who are considering having their bladder removed want to talk to people who have had a similar surgery. However, there were barriers to interviewees accessing support services, including lack of awareness and signposting by health care professionals despite the focus on support within the NICE 2015 *Bladder cancer: diagnosis and management* guidelines. This meant some patients could not receive the support and advice they needed at key points such as first diagnosis or when making important treatment decisions.

## Information and support for people with bladder cancer

- Use a holistic needs assessment to identify an individualised package of information and support for people with bladder cancer and, if they wish, their partners, families or carers, at key points in their care such as:
  - when they are first diagnosed
  - after they have had their first treatment
  - if their bladder cancer recurs or progresses
  - if their treatment is changed
  - if palliative or end of life care is being discussed.

**Figure 16.** The National Institute for Health and Care Excellence has identified the use of a holistic needs assessment as a priority for implementation (National Institute for Health and Care Excellence, 2015).

## LIMITATIONS

There are limitations to the research carried out as part of the Exemplar project. More women than men affected by bladder cancer took part in interviews and the online survey, which does not reflect the fact that men are more likely to be diagnosed with bladder cancer. The sample of survey respondents and interviewees were self-selected and recruited through the Fight Bladder Cancer network, so were likely to be more inclined to access and value support services. While efforts were made to include more participants from the devolved nations and more non-white participants, the sample is skewed with more white participants and participants based in England.

## IMPACT OF COVID-19

The COVID-19 pandemic has put exceptional pressure on health care, affecting the treatment and care of people around the world. Emerging studies have recognised the impact COVID-19 has had on the services for people affected by bladder cancer. Nearly half of patients reported being affected by delays, postponements and cancellations of their treatment and follow up during COVID-19 (Spencer-Bowdage, et al., 2021).

**Cancer patient distress, isolation, and financial hardship have increased markedly in 2020, and patient organisations are key to helping the cancer community recover from the devastating impact of the COVID-19 pandemic**

(Global Cancer Coalitions Network, 2021)

Many of our qualitative interviews with people affected by bladder cancer took place during the COVID-19 pandemic. Interviewees reported that while services were not perfect before COVID-19, the pandemic had affected the continuity and wait times of their follow up tests and treatment. With in-person support services shut down, some people affected by bladder cancer do not have the support they need, particularly if they are not able to access online services. We must ensure that everyone affected by bladder cancer can access diagnosis, treatment and support, both for the remainder of the pandemic and beyond.

# Conclusions

Services for people affected by bladder cancer need urgent investment and intervention to secure the high quality diagnosis, treatment, care and support that patients need, and deserve. Often grouped with other urological cancers, bladder cancer – the fifth most common in the UK – faces a concerning absence of dedicated national focus, specialised workforce, and targeted support services focusing on the holistic wellbeing and mental health of those affected. Predictably, this has left patients with a ‘post code lottery’ of services between different centres. The result is unacceptable variations in service experience and outcomes.

To overcome this, we need to work to implement a high-quality standardised patient pathway for bladder cancer, which is made widely available to patients, with a focus on improving initial referral from primary care, continuity of care, access to skilled Clinical Nurse Specialists, patient involvement in treatment decisions and signposting to support services. As COVID-19 eases in the UK, particular effort is needed to bridge the gap between health, mental health, community and support services to improve bladder cancer-specific support and to develop targeted support for people with bladder cancer as well as their carers, partners and family members.

In 2021, the NHS is undergoing a period of recovery and reform. For bladder cancer services, the opportunity for a concerted period of service transformation and improvement is clear. Fight Bladder Cancer stands ready to work with the wider bladder cancer community, as well as local and national NHS leaders, to ensure bladder cancer services in the UK deliver the highest possible quality services for everyone affected by bladder cancer.





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