



Bristol-Myers Squibb

Addressing Challenges in Bladder Cancer

Expert Roundtable Report



This report has been produced and funded by Bristol-Myers Squibb (BMS) and draws on the bladder cancer expert roundtable discussion that took place on 23rd May 2017; initiated and organised by BMS.
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Foreword

Although bladder cancer is the tenth most common cancer in the UK, it has long been under-prioritised and overlooked relative to the impact it has on patients. A wide range of challenges face those with the disease, including delayed diagnosis, a lack of awareness of symptoms among GPs and a protracted and complex pathway for patients to navigate. This report explores these issues, and puts forward a number of recommendations for how to address some of these concerns based on the first-hand experience of patients, clinicians and clinical nurse specialists.

There is also regional variation in the quality of services available to patients. In Dudley, the town I grew up in and have represented in Parliament since 2005, the mortality rate for men is 19.6 per 100,000, compared to 15 per 100,000 nationally.¹ This is considered significantly worse than average by the National Cancer Intelligence Network. Greater public awareness, earlier diagnosis and improved investment in bladder cancer could help to reduce such variation by improving the situation across the country.

Bladder cancer places an immense burden both on patients and their families. Incremental improvements, such as those included in the recommendations of this report, could contribute to a better experience for patients from diagnosis and through their treatment.

This report draws on the expertise of patient group representatives, doctors and nurses who contributed to a roundtable discussion on the challenges facing people with bladder cancer. I would like to thank them for their time and valuable insight. I fully support the recommendations proposed in this document and I will advocate for their implementation, and seek to encourage others to do so, throughout this Parliament.

Bladder cancer is a disease which few people talk about and fewer understand. It is my hope that this report is the first step along a path that will improve the lives of bladder cancer patients and their families.



Ian Austin MP
Member of Parliament for Dudley
North and Parliamentary
Bladder Cancer Champion



Bladder Cancer: The Challenge

Although survival rates for bladder cancer have improved in recent years, in comparison to other cancer types such as bowel, prostate and breast, five and ten-year survival rates remain low.² As such, there is an urgent need for earlier diagnosis in order to improve outcomes.^{3,4} As this report shows, patterns of delayed diagnosis and low GP awareness are a particular issue affecting survival. Furthermore, the need to speed up diagnosis is an especially urgent issue for women, among whom survival outcomes are significantly worse. This is, in part, due to the persistent conflation at primary care level of bladder cancer symptoms with those of urinary tract infections.

It is widely acknowledged that bladder cancer patients face a number of challenges once diagnosed with the disease.⁵ This includes a complex, prolonged care pathway and high recurrence rates that frequently require intensive surveillance over the lifetime of the patient. Indeed, bladder cancer has the highest recurrence rate of any known cancer,⁵ ranging from 30% to 70%, with rates of progression as high as 10% to 30% for high-risk tumours.⁶ Together with the physical and psychological effects of radical cystectomy surgery to remove the bladder (which is a mainstay of treatment for higher risk forms of the disease), bladder cancer has an often significant and lasting impact on patient quality of life.⁷ There is also a significant lack of investment in bladder cancer research and a stark absence of treatment developments over many decades, leaving patients – particularly those with more advanced forms of the cancer – with a paucity of options.⁵

These challenges make bladder cancer, often referred to as the ‘Cinderella’ of cancers, a topic of policy discussion warranting urgent attention. This report explores some of the issues facing patients and health professionals and makes a number of recommendations on how challenges in bladder cancer can be addressed.

The content and recommendations outlined in this report are based on discussions held during a roundtable. The meeting brought together a broad range of experts – including clinicians, clinical nurse specialists and health charity representatives – to discuss some of the current issues facing patients and health professionals along the bladder cancer care pathway. A full list of expert roundtable contributors is included as an appendix to the report. Both the report and roundtable have been initiated, organised and sponsored by Bristol-Myers Squibb (BMS), with the roundtable chaired by Dr Hugh Mostafid, Consultant Urologist.



“Bladder cancer is the one cancer where survival has actually worsened in the past few decades. Whilst there are fewer cases than there were twenty years ago, the same number of people are dying. This sits in contrast to other cancers, for which survival has improved dramatically in the same timeframe.”

Dr Hugh Mostafid

Consultant Urologist at the Royal Surrey County Hospital, Guildford



“The NICE guidelines are now available and written down clearly, and yet there still seems to be incredible heterogeneity and complacency with regards to this disease.”

Dr Simon Crabb

Associate Professor in Medical Oncology,
University of Southampton NHS
Foundation Trust



Recommendations

The recommendations below have been ordered according to priority, as agreed by the expert roundtable participants.



1. Reforming the TURBT waiting time target:

- a. In order to reduce delays in referral on to treatment for patients post-TURBT, thereby enhancing patient experience of NHS care and improving survival prospects, the initial transurethral resection of the bladder tumour (TURBT) should be reclassified as a diagnostic staging procedure.
- b. As the clock currently stops after a patient has undergone a TURBT, waiting time standards for the disease should be revised so as to ensure that the 31-day rule for referral on to treatment still holds following a TURBT procedure. Healthcare professionals should ensure that any new event of ongoing treatment for bladder cancer is closed, with a new target for subsequent treatment opened.

2. Increasing research investment in bladder cancer:

To improve the treatments available to people with bladder cancer, optimise medicines usage, and to develop new diagnostics for primary care, greater research investment should be channelled into the area.

3. More cost-effective, simplified diagnostic tests should be developed for use in primary care services,

to allow for large scale targeting of high risk groups and to drastically reduce the current requirement for invasive testing and investigation procedures in secondary care.

4. Patients should be signposted more routinely to high quality sources of information and support. This should include:

- a. **A clearly mapped out patient pathway for bladder cancer, made widely available to patients** to enable them to keep track of the next steps required for high quality treatment and care and to hold their healthcare professionals to account. .

5. To allow progress to be tracked and areas requiring improvement to be identified, **the National Cancer Patient Experience Survey should be revised to capture more detail on the specific experiences of bladder cancer patients.**

Attendees called for the survey to:

- a. Report separately on the specific perspectives of bladder cancer patients, and of other urological cancer patients, in order to measure their experiences and track progress.
- b. Collate perspectives from all patients, not just in-patients as is currently the case, so that a fully representative sample of people with bladder cancer is included.
- c. Report on the numbers of clinical nurse specialists available to patients with urological cancers and to bladder cancer patients specifically.

6. **A greater number of clinical nurse specialists (CNS) should be made available to urology teams, with more CNSs also trained to specialise in bladder cancer.**

As first steps to drive progress:

- a. CNS numbers should be reported on within the National Cancer Patient Experience Survey.
- b. A comprehensive study should be carried out of nurses working with bladder cancer patients; exploring nurse titles, roles and workload.

7. **E-learning tools and other educational methods should be developed to help GPs better understand the variety of symptoms that bladder cancer patients can present with,**

and to encourage women presenting with recurrent or persistent UTIs to be viewed by GPs as a high risk group requiring further investigation.

8. **Public awareness campaigns to drive earlier diagnosis in bladder cancer:**

- a. New campaigns should be developed focusing specifically on raising womens' awareness of the symptoms of bladder cancer and aiming to spell out the links with recurrent or persistent UTIs and symptoms commonly associated with cystitis. Policy should focus on empowering women to question their doctor and to say "don't assume I have a UTI".
- b. Novel methods should be employed to refresh public awareness campaigns targeted at older men who are at greatest risk of bladder cancer.

Achieving earlier diagnosis in bladder cancer

Achieving early diagnosis of bladder cancer is widely regarded as being critical to improving survival rates.⁵ When diagnosed at its earliest stage more than 8 in 10 people with the disease will survive for five years or more. Around 1 in 10 people survive for five years or more when diagnosed at the latest stage.⁸

To encourage earlier diagnosis, experts at the roundtable were clear that public awareness must be raised so that more people recognise signs of the disease (such as haematuria [blood in urine]) and present to their GP. It was also emphasised that the public should be taught to challenge their healthcare professionals to undertake a test when symptoms persist. While public awareness initiatives have been run in the past, such as the Blood in Pee campaign led by Public Health England,⁹ attendees called for efforts to refresh and revise such public campaigns. In particular, it was argued that more innovative methods should be used to target those at greatest risk, including by aiming campaigns at the wives and daughters of men over the age of 60 who are at most serious risk but who may not be as likely to seek help for symptoms.¹⁰

Driving up public awareness about the causes, as well as the symptoms, was also thought to be important in order to encourage more of those at greatest risk to come forward to their GP. Despite the fact that it represents the second most common tobacco-related cancer after lung cancer (with smoking linked to an estimated 37% of all cases)^{11, 3} participants noted a very low level of awareness among patients about the fact that smoking is a significant cause. One suggested method for raising awareness about the association with smoking was for NHS smoking cessation services to more explicitly list and discuss bladder cancer as a major risk.^{11, 3}

As well as raising public awareness about causes and symptoms, efforts to better educate GPs about bladder cancer were considered to be vital in order to increase testing and drive more referrals to secondary care. Experts highlighted that few GPs are cognisant of the variety of symptoms associated with the disease, with many being aware of the symptom of haematuria but not others (such as frequency or urgency in passing urine).¹² A low-cost risk assessment tool for GPs and an e-learning module on bladder cancer were suggested as solutions to this problem. There are also clear opportunities for progress to be made if more GPs are encouraged to refer potential bladder cancer patients with unclear symptoms to the multi-disciplinary Rapid Diagnostic and Assessment Centres being established by NHS England across the country.¹³

The testing and diagnosis stage for bladder cancer commonly involves testing a urine sample for cancer cells and usually requires patients to undergo several laboratory tests and an invasive procedure. There is currently no screening programme for the disease^{14, 3} and patients are usually diagnosed when presenting with symptoms (most commonly with haematuria) at either their GP surgery (27%) or in the emergency department (18%).¹⁵ The complex range of procedures and tests required even at this earliest stage of the bladder cancer pathway is one factor contributing to the high economic burden that the disease places on the NHS. Correspondingly, bladder cancer is considered to be the most expensive cancer to treat per person.¹⁶

These high costs were an important issue raised by roundtable participants. Calls were made for a test to be developed – over and above a urine dipstick test for non-visible haematuria – to check for bladder cancer more simply and cost-effectively within primary care. To avoid delays incurred by sending patients to hospital for tests, experts called for GPs to be provided with a simple – even if imperfect – test that would allow for more targeted, widespread testing of high risk groups. One option proposed was for an enhanced ‘well man’ check to be rolled out that would look at the patient holistically and include a simple form of screening for bladder cancer as well as a dipstick test. It was suggested that this could allow for the development of an equivalent in bladder cancer to the prostate-specific antigen test (PSA).



“Men get a late diagnosis for bladder cancer because they don’t go to the doctors with their symptoms, and women frequently get late diagnosis because their symptoms are mistaken for something else. It’s about making sure these people are not missed: We need to look out intelligently for the real risk factors, and educate GPs on the nuance of these.”

Andrew Winterbottom

Bladder Cancer Patient and Founder
& Director of Fight Bladder Cancer

Closing the gender survival gap: Delayed diagnosis in women

A significant issue raised during the roundtable was while bladder cancer is more common among men, women experience notably worse survival rates and are more likely to present at the most advanced stage of disease.¹⁷ While other causes such as tumour biology and sex hormones could play a part, this gender difference is also connected to widespread delays in diagnosis for women at primary care level.¹⁷ Recent data from the Office for National Statistics (ONS) shows that bladder cancer has the largest gender difference for one-year survival out of all cancers, with 78.0% of men expected to survive at least one year, compared with 66.9% of women.¹⁸ For five-year survival too, there is a 11 percentage point difference between men (58%) and women (47%).¹⁹ Diagnosis on emergency presentation – where survival is significantly lower than other routes – is also more common among women, with a 24% emergency diagnosis rate for bladder cancer compared with 16% for men.²⁰

With the most common symptoms of bladder cancer being blood in urine and frequency, urgency or pain on passing urine,¹² a major factor contributing to the gender survival gap is frequent conflation of bladder cancer symptoms with those of urinary tract infections (UTIs), or sometimes cystitis symptoms.⁴ This was identified by our experts as a significant problem that must be addressed in order to improve survival outcomes. With UTIs being very common among women, a lack of GP and public awareness about the risks has led to a situation whereby women displaying the symptoms of bladder cancer are too frequently misdiagnosed; causing delays to treatment and heightening the chance that they present to emergency services with a later stage of the disease.

Attendees called for a public awareness campaign to be developed that is focused specifically on enhancing women's knowledge about the symptoms of bladder cancer, empowering and encouraging them to question their doctor about whether their UTI diagnosis might in fact be bladder cancer.



"Those who are really suffering from delayed diagnosis are those suffering from UTIs and for whom it is already too late once they have finally been referred. We should turn our attention to addressing this."

Dr Hugh Mostafid

Consultant Urologist at the Royal Surrey County Hospital, Guildford





RECOMMENDATIONS

- **Public awareness campaigns to drive earlier diagnosis in bladder cancer:**
 - a. New campaigns should be developed that focus specifically on raising women's awareness of the symptoms of bladder cancer and aim to spell out the links with recurrent UTIs. Policy should focus on empowering women to question their doctor and to say "don't assume I have a UTI".
 - b. Novel methods should be employed to refresh public awareness campaigns targeted at the older men at greatest risk of bladder cancer.
- **E-learning tools and other educational methods should be developed to ensure that GPs better understand the variety of symptoms that bladder cancer patients can present with**, and to encourage women presenting with recurrent or persistent UTIs to be viewed by GPs as a high risk group requiring further investigation.
- **More cost-effective, simplified diagnostic tests should be developed for use in primary care services**, to allow for large scale targeting of high risk groups and to remove the current requirement for invasive testing and investigation procedures in secondary care.

PATIENT CASE STUDY

(Female, aged 26 when diagnosed in 2016. Case study provided by Action Bladder Cancer UK)

No one really talks about bladder cancer. Many people don't know the signs or symptoms, and when I watch TV programmes on how to look out for cancer symptoms, bladder cancer is never mentioned - and as someone who has experienced the diagnosis first hand, this is really worrying. When I was pregnant with Zara, I had recurring urinary tract infections along with some pain, and even after several courses of antibiotics they kept returning. I asked my GP and midwife if this was normal and their response was "some pregnant women are just unlucky". I accepted this but something still didn't sit right with me. A few weeks later during a cardiac ultrasound (suspected abnormality with Zara's heart which turned out to be a simple murmur) the consultant noticed a small growth inside my bladder which she said needed investigated. She assumed just a polyp or stone, which made so much sense due to all the infections I'd been getting! The same week I was admitted for a cystoscopy and biopsy. Even during this procedure, the consultant said it didn't look suspicious and was unlikely to be anything to worry about.

While I waited for biopsy results, health professionals would tell me "don't worry, it will be fine...you're too young for bladder cancer." But for some reason I couldn't get it out of my head.

What if I had cancer? I was pregnant! Could it reach my unborn baby? Would this harm her? Would I need chemotherapy? Would me and my baby be okay? Within a week or so, I was asked to attend a consultation with my Consultant Urologist, who is also a specialist in bladder cancer. He was, and still is, amazing. He explained I had a high grade, fast growing cancer and we needed to get it out, so I was booked in for surgery as soon as it was safe to do so.

Being pregnant I had to have several steroid injections before surgery to make sure Zara's lungs were strong enough, should she decide to make an early appearance... I prayed she was going to be okay. I was 27 weeks pregnant when my consultant removed 2 small tumours from the inside lining of my bladder wall. The operation was a success! Due to being pregnant it wasn't safe to have any additional chemotherapy or chemicals into my bladder, this is likely to happen in the future. I was so lucky it was caught early enough. If it wasn't for my pregnancy, they wouldn't have had any reason to do a scan, and it may have been a completely different story today! Unfortunately, my cancer has a high chance of returning, but I am lucky enough to have close contact with my consultant and his team, and I have check-ups every 3 months due to the risk of recurrence.

Patient experiences and quality of life

People with bladder cancer, especially those with more advanced forms, experience a significant and wide-ranging impact on their quality of life.⁷ This can be viewed as more pronounced than the quality of life impact for patients with many other cancers. The National Institute for Health and Care Excellence (NICE) has recognised this in its guidelines on bladder cancer, which state: “the involvement of the urogenital tract and the nature of the treatments give this cancer a strong psychological impact, in addition to the physical impact of the disease and its treatments, which is often profound.”¹⁰ The NICE guidelines also emphasise there is “evidence that the patient experience for people with bladder cancer is worse than for people with other cancers”.¹⁰

With bladder cancer’s complex and lengthy treatment and care pathway, patients frequently experience significant delays and uncertainty at every stage, and can feel that they are constantly waiting for their next appointment, test result or treatment with little support available. Roundtable participants described the patient journey for the disease as often being a lonely one, with a sense that people are left ‘alone in the waiting room’ throughout this time. In particular, attendees raised concerns that, despite bladder cancer patients’ profound quality of life impact and difficult treatment decisions, many are not signposted to the relevant information or sources of support once diagnosed; an issue that requires urgent attention. For example, participants told of how patients accessing support groups are frequently unaware of the type of bladder cancer they have or how far their disease has progressed.



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“Patients often do not have the information they need or the awareness to be empowered to know who to push for information.”

Hazel Pixley

National Secretary, Urostomy Association

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“Most bladder cancer patients sit there not knowing what good treatment is or what bad treatment is... It becomes a process of being in the waiting room: you’re waiting for check-ups and tests, waiting for results, waiting to hear when your next treatment will begin, waiting for progression and recurrence...and it’s often a lifetime relationship with this cancer.”

Andrew Winterbottom

Bladder Cancer Patient and Founder & Director of Fight Bladder Cancer



One solution proposed to assist patients in reaching life-changing treatment decisions was to make widely available an online patient decision aid covering the whole bladder cancer treatment journey. Attendees highlighted that an updated version of a decision aid relating specifically to high-risk non-muscle invasive bladder cancer treatment options had previously been developed by NHS England, with input from patient advocacy groups, but that the update had not been implemented and the online version of the PDA has subsequently been taken down and there is no intention to provide such online aids in the future. More recently, a short text version of the original (not updated) PDA, in pdf format only, has been made available through the NICE web portal - though without any obvious public awareness. Approaches have again been made to NHS England to encourage them to at least use the updated content for the short text version that is being used. Strong support was expressed among roundtable participants for a fully functional online decision aid covering the whole bladder cancer pathway to be made available once again for all patients across the country.

Given how confusing the pathway can be for patients, the absence of a care pathway for bladder cancer was highlighted as a major problem impacting on the patient experience. It was agreed that there was an urgent need for the care pathway to be mapped out more clearly. An easily accessible, simple outline of the bladder cancer journey, which lays out important steps and stages, was thought to be crucial in order to build patients' knowledge about what their care should look like and to enable them to adopt a more proactive approach in managing their care. While it was flagged that algorithms and maps had been developed by experts previously as part of guideline development groups, an overview of the patient pathway has never previously been released to patients in the public domain. One suggested option for dissemination of a 'gold standard' pathway map was for this to be included within the patient-held records currently being developed.

"Bladder cancer is a disease that is scary and bewildering from the outset. Part of the problem is that you don't know where you're going. As a bladder cancer patient, you have very little awareness about what is going to happen to you, never mind in what timescale...this is disempowering and it is partly because a pathway map has never been promoted or published."

Phil Kelly

Patient Advocate and Trustee, Action Bladder Cancer UK



Results of the National Cancer Patient Experience Survey (2015) also reveal notable areas where vast differences exist between the experience of urological cancer patients and the average person with cancer in England. These results are concerning in light of the significant quality of life impacts bladder cancer carries with it. For example, only 34.2% of those with urological cancers felt that they were given information about the impact that cancer could have on their day to day activities, compared to 53.6% of all cancer patients.²¹ Issues around lack of support are also evident, with the number of those with urological cancer who felt that they had a member of hospital staff with whom they could discuss their fears 8.8% lower than the average of all cancer patients.²¹ Furthermore, just 39.5% of those with urological tumours reported that hospital staff gave them any information about support groups, compared to 61.9% of all cancer patients.²¹

However, while the patient experience survey goes some way to indicating the level of dissatisfaction among patients with urological cancers, attendees were concerned that the full picture of bladder cancer patient experiences are obscured by the survey. As bladder cancer is included together with other urological cancers, the lack of specific information on the disease within the survey was identified as a significant barrier preventing improvements to the pathway; making it difficult to effectively monitor and address any particular areas of weakness, or to recognise areas of progress.



"The frustration with the national cancer patient experience survey is that bladder cancer is hidden within urological cancers, as a generic group. In fact, these cancers are very disparate in many ways, affecting different patient populations and with different pathways... Until we have some specific bladder cancer information it's hard to track the changes – we can't even see very easily if things are getting better or worse."

Phil Kelly

Patient Advocate and Trustee,
Action Bladder Cancer UK



RECOMMENDATIONS

- **A patient pathway map for bladder cancer should be made widely available to patients, their family and carers**, enabling them to keep track of the next steps required for high quality treatment and care and to question their healthcare professional.
- **Patients should be signposted more routinely to high quality sources of information and support**, to ensure they are no longer left alone in the waiting room.
- To allow progress to be tracked and areas requiring improvement to be identified, **the National Cancer Patient Experience Survey should be revised to capture more detail on the specific experiences of bladder cancer patients**. Attendees called for the survey to:
 - a. Report separately on the specific perspectives of bladder cancer patients, and of other urological cancer patients, in order to measure their experiences and track progress.
 - b. Collate perspectives from all patients, not just in-patients as is currently the case, so that a fully representative sample of people with bladder cancer is included.
 - c. Report on the numbers of clinical nurse specialists available to patients with urological cancers and to bladder cancer patients specifically.

The bladder cancer treatment landscape

"We are only just emerging from the 'dark ages' when it comes to treatment for bladder cancer, which has been starved of research into new treatments and approaches and as a result the options are crude and few for patients. The reality is that clinicians are often as uncertain as we are when it comes to treatment decisions...and we are still in a world of under and over-treatment."

Phil Kelly

Patient Advocate & Trustee, Action Bladder Cancer UK

In exploring the treatment landscape for bladder cancer, there was agreement that patients are still faced with a severe lack of options, with poor understanding even among clinicians about the comparative efficacy of the treatments that are available. This was attributed by participants to insufficient research funding over the long-term. These arguments echo those of many others operating in the space, such as the European Cancer Patients Coalition (ECPC), for which Fight Bladder Cancer and Action Bladder Cancer UK provide the European lead on bladder cancer. ECPC has argued that the lack of resource provision generally, including funding for research and reimbursement of new medicines, "does not reflect the high disease burden or societal cost" and has "resulted in few new treatment options being available to patients, delayed diagnosis and low survival rates".⁸ Roundtable participants cited the lack of new surgical devices for bladder cancer over many years as one example of the impact that insufficient funding has had and questioned the NHS decision not to recommend commissioning of the new 'robot' device that would have helped improve radical cystectomy surgery.

"Bladder cancer has long been disadvantaged because of a lack of new treatments coming through, and public awareness has suffered as a result...We hope with newer advances coming through, public awareness might be raised about the need to improve outcomes."

Janis Troup

British Uro-Oncology Group (BUG) Secretariat

When considering why bladder cancer has seen little progress in terms of survival outcomes when compared to many other cancers, attendees also highlighted a lack of NHS nurses specialising in the area as being a key factor preventing improvements. For example, colorectal cancer is increasing as a specialism in its own right and that prostate cancer specialist nurses are common, whereas bladder cancer specialist nurses are far more difficult to come by. Recognising the role played by clinical nurse specialists (CNS) in acting as a champion to support patients right along the pathway, experts called for more CNSs to be trained with a specific focus on bladder cancer. With urology nurse specialists among those with the greatest patient workload, participants also advocated measures to ensure a higher number of CNSs are made available to urology teams. Moreover, it was stressed that such changes should be brought about through real increases in the bladder CNS workforce rather than via a shuffling around of CNS titles. One solution proposed to encourage such a shift was for CNS levels to be reported in the National Patient Experience Survey, allowing for numbers to be tracked and compared with those for other cancers.



“We know that urology nurse specialists have got the heaviest patient workload. In comparison to gynaecology for example, we have about the same number of nurse specialists but around twice the number of patients. Not only should we be counting the numbers though, we should be looking at what they do: Urology nurses have their own caseloads in nurse-led clinics, where they do cystoscopies, diagnostic tests etc., as well as providing psychological support and being a champion for patients.”

Pauline Bagnall

Uro-Oncology Nurse Specialist at Northumbria Healthcare NHS Foundation Trust and Council Member, British Association of Urological Nurses

In addition to underscoring the importance of training more CNSs in the field and flagging the need to expand investment in bladder cancer to improve survival, roundtable participants were concerned that patients are still too frequently experiencing delays in referral on to treatment. Despite the release two years ago of NICE guidelines on bladder cancer,¹⁰ attendees observed that changes in practice as a result of the guidelines do not appear to have materialised, with many patients still not getting the therapy they need at the right time. A high-priority issue flagged by experts as a key cause of such delays relates to the lack of waiting time targets that are in place following the ‘TURBT’ procedure.

Non-muscle invasive forms of bladder cancer are usually treated by endoscopic surveillance and telescopic removal of the tumour, known as transurethral resection of the bladder tumour (TURBT). TURBT, offered at diagnosis, is also used to obtain tissue and to record the size and number of tumours, and is often followed by chemotherapy (mitomycin C) or intravesical (BCG vaccine) immunotherapy directly into the bladder, with prolonged telescopic checking of the bladder, called cystoscopy, as follow-up.¹⁰ Those with non-muscle invasive bladder cancer that is deemed to be higher risk usually require another TURBT within 6 weeks to ensure that all the tumour has been removed and those with muscle-invasive disease require major surgery to remove the bladder, called a cystectomy, or radiotherapy.¹⁰ The TURBT is thus a crucial procedure required by clinicians to provide an accurate diagnosis of bladder cancer, and unusually it is regarded as both a diagnostic procedure and form of treatment.²²

Roundtable participants raised concerns about the fact that delays in referral on to treatment are commonplace for bladder cancer patients following this TURBT stage, carrying risks of progression into metastatic disease and causing patients and their families a high degree of anxiety. Whilst NHS waiting time performance measures are in place with the aim of avoiding such delays and ensuring high quality care for all cancer patients, the clock effectively stops for people with bladder cancer once they have received their first TURBT. According to current health policy, NHS healthcare professionals should see the 31-day target for cancer - which stipulates a maximum one month (31-day) wait from the date a decision to treat (DTT) is made to the first definitive treatment - as having been achieved once TURBT has been received. Attendees described this absence of targets following the TURBT stage as an unacceptable “anomaly” in the system, which means that delivering fast access to treatment for bladder cancer patients is often not a focus for many health professionals. The lack of targets following TURBT was identified by those at the roundtable as a key cause of the hold-ups often experienced by patients along the bladder cancer pathway. Roundtable discussions suggested that the issue could be addressed by re-classifying TURBT as a diagnostic procedure, and requiring the 31 target to apply after its completion.



“Too often we watch bladder cancer patients slide into metastatic disease progression in our care because of late presentation of disease and the delay in time to completion of staging tests and definitive radical treatment. If we changed the landscape by having tests introduced into primary care and targets for every time a bladder cancer patient needs a new treatment, we would impact on survival.”

Professor John Kelly

Consultant Urological Surgeon & Clinical Lead for Urology at University College London Hospital; Chair of The Urology Foundation Science and Education Committee



RECOMMENDATIONS

- **Increasing research investment in bladder cancer:** To improve the treatments available to people with bladder cancer, optimise medicines usage, and to develop new diagnostics for primary care, greater research investment should be channelled into the area.
- **A greater number of clinical nurse specialists should be made available to urology teams, with more CNSs also trained to specialise in bladder cancer specifically.** As a first step to drive progress, CNS numbers should be reported on within the National Cancer Patient Experience Survey.
- **Reforming the TURBT waiting time target:**
 - a. In order to reduce delays in referral on to treatment for patients post-TURBT, thereby enhancing patient experience of NHS care and improving survival prospects, the initial transurethral resection of the bladder tumour (TURBT) should be reclassified as a diagnostic staging procedure.
 - b. As the clock currently stops after a patient has undergone a TURBT, waiting time standards for the disease should be revised so as to ensure that the 31-day rule for referral on to treatment still holds following a TURBT procedure. Healthcare professionals should ensure that any new event of ongoing treatment for bladder cancer is closed, with a new target for subsequent treatment opened.

Concluding Remarks

While it is clear that there are many significant issues that need to be addressed in the treatment of bladder cancer in the UK, the roundtable was able to highlight specific areas for action that could have a positive impact on outcomes. With focus and leadership, bladder cancer could successfully shed its reputation as a 'Cinderella' disease and patients may begin to feel less 'alone in the waiting room'.

Roundtable participants agreed that charities, clinicians, professional association representatives and industry must come together to address the challenge of bladder cancer, with attention needing to be focused in order to gain the best results in improving outcomes for people with the disease.

The production of this report and recommendations is merely a first step in improving the lives of people with bladder cancer. It will be incumbent on the roundtable participants, clinicians, campaigners, policy makers and pharmaceutical companies to act on the recommendations in this report and, in doing so, address many of the challenges faced by people with bladder cancer.



Roundtable Contributors

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Phil Kelly

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