fight bladder CANCER

EXEMPLAR
Roundtable Report

Building community consensus to ensure exceptional services for people affected by bladder cancer

January 2022

Acknowledgments

FIGHT BLADDER CANCER

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Exemplar Research Project Report:
Launch Roundtable Summary

Introduction

On 20 May 2021, Fight Bladder Cancer convened a roundtable discussion to launch our Exemplar Research Project report and build a community consensus on the report's recommendations.

Fight Bladder Cancer embarked on the ground-breaking Exemplar Research Project, 'striving for exceptional services for people living with bladder cancer' in 2017. The project explores the strengths and gaps in bladder cancer services across the UK and makes recommendations for improving experiences and outcomes for all bladder cancer patients. The report addresses inconsistencies in quality of care across different regions, identifies projected gaps in research and availability of services, and calls for urgent action centring on three priority areas:

- Putting in place an exemplar pathway for bladder cancer diagnosis, treatment and care
- Developing and growing the bladder cancer workforce
- Improving patient support and involvement in care

The roundtable opened with speakers presenting the report's findings and recommendations, contextualised by their own experiences as healthcare professionals (HCPs), patients or carers, followed by a broader discussion and Q&A session. After each session, participants had the opportunity to provide input on which recommendations and action items they would want to see prioritised through a series of polls. The results of the polls, along with the valuable insights shared by participants, will guide Fight Bladder Cancer's next steps and advocacy to bring about the objectives set forth in the report.

The discussion was chaired by Fight Bladder Cancer Chief Executive, Dr Lydia Makaroff, with participants hearing from the following speakers:

The need for an exemplar patient and carer experience:
- Dorothy Markham, Chair of the Fight Bladder Cancer Scottish Steering Group and bladder cancer patient

Putting in place an exemplar pathway:
- Dr Johnstone Shaw FRCGP FRCOG, retired GP and bladder cancer patient
- Mr Hugh Mostafid, Consultant Urologist, Royal Surrey Country Hospital

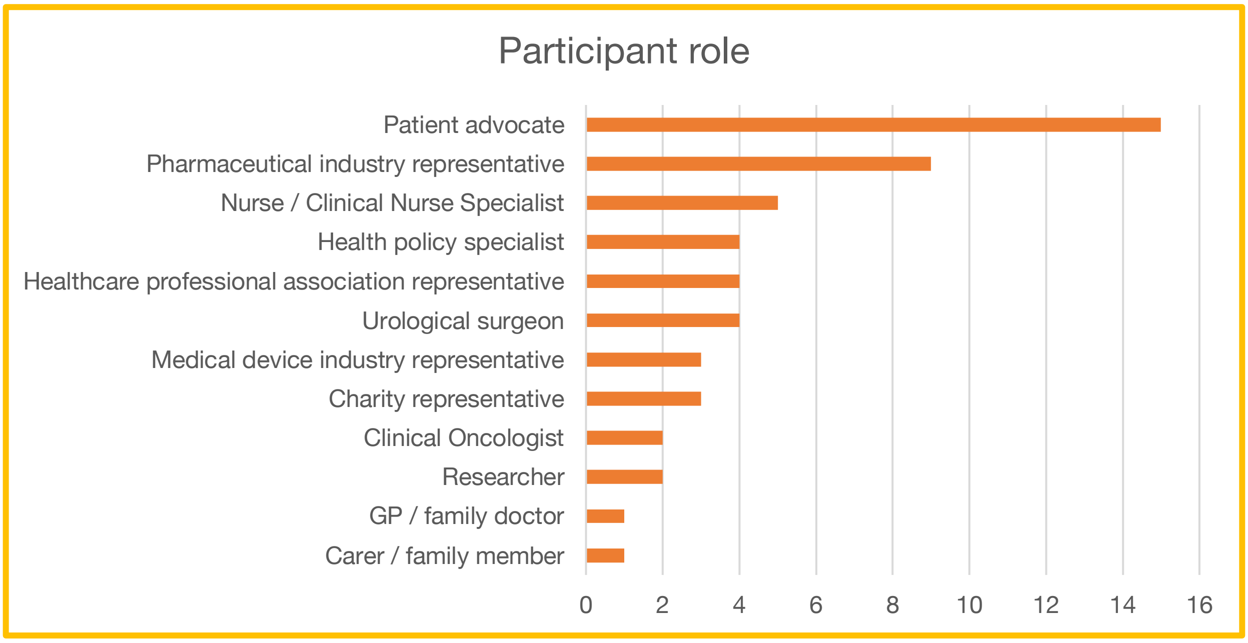
Developing and growing the bladder cancer workforce:
- Julia Taylor MBE, Macmillan Urology Clinical Nurse Specialist, Clinical Governance lead (Urology), Salford Royal NHS Foundation Trust, and Past President of the British Association of Urological Nurses (BAUN)
- Heather James, Urology Oncology Clinical Nurse Specialist, Betsi Cadwaladr University Health Board

Improving patient support and involvement in care
- Noamh Gallagher, Fight Bladder Cancer Patient Representative
- Tracy Staskevich, Cancer carer and Co-founder, Fight Bladder Cancer

Summary of the roundtable

Participants

The virtual roundtable welcomed 53 participants from nations including England, Scotland, Wales, Northern Ireland, Ireland, Belgium, the Netherlands, Canada, and the USA. Their roles included patient and carer advocates, nurses, urological surgeons, clinical oncologists, GPs, healthcare association representatives, charity representatives, health policy specialists, researchers, and medical industry representatives.



Their organisations included:

- Action Bladder Cancer UK
- British Association of Urological Nurses
- British Uro-oncology Group
- Royal College of Radiologists
- British Association of Urological Surgeons
- Compassion in Dying
- European Association of Urology
- Fight Bladder Cancer
- The Urology Foundation
- Urostomy Association
- World Bladder Cancer Patient Coalition
- University of Warwick

The following trusts and boards were represented:

- Barts Health NHS Trust
- Betsi Cadwaladr University Health Board
- Guy's and St Thomas' NHS Foundation Trust
- Liverpool University Hospitals NHS Foundation Trust
- North West Anglia NHS Foundation Trust
- Royal Devon and Exeter NHS Foundation Trust
- Royal Marsden NHS Foundation Trust
- Salford Royal NHS Foundation Trust
- Swansea Bay University Health Board
- University College London Hospitals NHS Foundation Trust

Introductory Session

Dorothy Markham, Chair of the Fight Bladder Cancer Scottish Steering Group and bladder cancer patient, used the context of her own experiences to highlight the need for an Exemplar patient and carer experience.

> *"There have been days when it's been OK, and days when it's not been OK, days when the service has been good and days when the service has been terrible"*

Dorothy's bladder cancer journey demonstrates the delays and difficulties in accessing diagnosis, care and support that people with bladder cancer can experience. Originally sent away from the GP with antibiotics, Dorothy asked for a second opinion but was told she would have to wait months. Knowing that she couldn't wait that long, she decided to see a private consultant, which eventually led to her being diagnosed with muscle invasive bladder cancer. Further difficulties arose for Dorothy when the wound from her bladder removal surgery became infected, and she found herself in hospital with nurses who knew very little about bladder cancer. She felt she had to direct them.

> *"Everywhere I went I looked for information on bladder cancer, but everywhere I went I couldn't find any"*

Dorothy's journey, including the service she received and the lack of information available to her, inspired her to play a part in promoting awareness of bladder cancer and advocating for policy change to improve the lives of those affected. Dorothy discussed some of the recent work she has supported, including securing a motion supported by 35 MSPs in the Scottish Parliament, and highlighted the importance of the third sector in improving patient outcomes and experiences. She highlighted how the Fight Bladder Cancer Exemplar Project provides an opportunity to create a clear pathway where everyone experiences a quality patient journey, gets a choice and knows what to expect, regardless of income, location or demographic.

Session 1: Putting in place an Exemplar pathway

Summary of key findings:

- Bladder cancer is one of the few major cancers without a standardised pathway
- There are large inequalities and variations across regions in treatment times, Clinical Nurse Specialist support, and access to clinical trials
- Women in particular experience long delays in initial diagnosis with recurrent urinary tract infection (UTI) symptoms
- There are fragmented services and long waiting lists for diagnosis and treatment
- Overwhelmingly HCPs felt that trans urethral resection of bladder tumour (TURBT) must be reclassified from intervention to diagnostic test across the UK
- There is a lack of continuity of service due to a lack of resources, disorganisation of services and poor communication
- There is a lack of needs assessments to ensure that patients have support to manage at home

In the first session, *Putting in place an Exemplar pathway*, Dr Johnstone Shaw, retired GP and bladder cancer patient, and Mr Hugh Mostafid, Consultant Urologist, drew on their experiences as clinicians (and in Dr Shaw's case, also as a patient) to identify the key challenges and inconsistencies in bladder cancer care delivery across the UK.

Dr Johnstone Shaw worked as a GP for 35 years near Edinburgh. Upon retirement in 2019 he quickly became ill with bladder cancer, eventually needing a radical cystoprostatectomy. Informed by his many years serving as a GP, Dr Shaw highlighted the challenges primary care doctors face in recognising and referring possible bladder cancer symptoms. He advocated for reform of national and local referral guidance to create a standardised pathway from primary to secondary care for all patients, regardless of age or sex.

Referral to a specialist

GPs face difficulties when deciding whether to refer patients with possible bladder cancer symptoms for further testing. For example, haematuria (blood in pee) is a symptom of bladder cancer, but the chances of it signifying cancer and not a urinary tract infection (UTI) is quite rare, which creates difficulties for GPs deciding when to refer patients.

> *"One in four patients present in a slightly atypical manner"*
> Hugh Mostafid

> *"It was easy as a 65-year-old GP, when I developed blood in my urine (or haematuria) to identify [it as symptom of bladder cancer] and get myself diagnosed by my GP and referred on… But as the report very well points out, there is good evidence that women of all ages with recurrent UTIs are experiencing great difficulties getting their symptoms across and there are massive delays in diagnosis"*

Current national guidelines complicate this further, as patients with differing ages and sexes are recommended for referral depending on presentation of different symptoms. This particularly impacts women and people aged under 60. Dr Shaw shared that in his experience; women of all ages with recurrent UTIs had difficulties and long delays in getting referred and diagnosed, and that younger patients with persistent blood in their urine and repeated UTIs were not referred because of the current guidelines.

The guidelines state that a monitoring strategy should be used for these patients who are not referred, but it was stressed in the discussion that they are not explicit about when and how to do this, and that there is no clear mechanism for calling patients back into primary care. Dr Shaw noted that guidelines should consider listening to patients for cancer alarm bells.

What we can do now: referral

- Through the Women's Health strategy for England, the Government should commit to reviewing women's experiences of cancer care and areas of cancer where women are experiencing poorer outcomes, and the reasons behind this (for example difficulties obtaining referral)
- The Be Clear on Cancer team within Public Health England (PHE) should re-launch the Blood in Pee campaign
- National referral guidelines should be reviewed by the responsible bodies across the UK to ensure:
- Urgent cancer referral (Two Week Wait) for people of all ages (instead of 45 years and over) who have visible haematuria [blood in pee] that persists or recurs
- Non-urgent referral in people of all ages and genders with recurrent or persistent unexplained urinary tract infection
- 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'

Mr Hugh Mostafid, Consultant Urologist, spoke alongside Dr Johnstone Shaw and gave his clinical perspective on the bladder cancer pathway. He spoke of his concerns surrounding the lack of consistency of care in bladder cancer services, the need for "one-stop-shop" diagnosis clinics, and the importance of reclassification of TURBT.

Bladder cancer is one of the few major cancers without a standardised pathway

> *"One of the things that really strikes me is that for many other cancers, let's take for example breast or colorectal cancer, wherever you go in the country the pathway is pretty much the same. Bladder cancer is really yet to catch up with that"*
>
> Mr. Hugh Mostafid

Participants heard how inconsistencies in bladder cancer care and services start at the very beginning of a patient's journey, with monitoring and referral, and continue through diagnosis and treatment. The speakers highlighted two areas where change is needed to move towards a UK wide standardised bladder cancer pathway.

First was the role of TURBT and the need for it to be uniformly reclassified as a diagnostic procedure across the UK. It was noted that whilst the guidance has recently been changed in England, there is still more work to be done to support the implementation of the new guidance in England and push for the change in the devolved nations.

Secondly, the way that patients are investigated once they are referred can often be inefficient and cause unnecessary delays and stress for patients, unnecessary loss of life and poor outcomes. Findings showed that patients overwhelmingly prefer to have all their investigations done in one visit to a hospital rather than returning for separate scans, tests and follow-ups. It was agreed that the implementation of one-stop-shop diagnostic clinics across the country would reduce patient stress and anxiety, as well as deliver a faster diagnosis.

> *"It would be much better for [patients] to come in and have a one-stop investigation; as logical as that may seem, it's still not consistent across the country"*
>
> Mr. Hugh Mostafid

Looking ahead:

- As a matter of urgency, NHS England (with the support of Fight Bladder Cancer) should convene a Bladder Clinical Expert Group to define what an optimal pathway for bladder cancer should look like in England and across the UK, prioritising rapid referrals, assessment, diagnosis and treatment, as well as ensuring smooth data transfers between different stages of the pathway. The group should be clinically led, with representation from patients, commissioners and other stakeholders in the bladder cancer pathway
- The group should have the necessary funding to commission an academic cost/benefit analysis of current bladder cancer services and possible pathway improvements
- All bladder cancer patients should have access to rapid diagnostic programmes. The model of a one-stop-shop in breast cancer should be applied to bladder cancer. The NHS should publish an evaluation of existing haematuria rapid diagnostic clinics

What we can do now: diagnosis

- Across the UK, reclassification of TURBT as a diagnostic procedure must be prioritised
- In England, the recent reclassification must be consistently implemented by NHS trusts. NHS England should ensure that the updated guidelines are being used consistently in monitoring 62-day waiting time performance
- Cancer Alliances should evaluate and publish evidence on the incidence of haematuria to establish its efficacy as a bladder cancer diagnostic tool
- Every clinician involved in possibly breaking bad news to a patient should be trained in how to deliver it
- Everyone with suspected and confirmed bladder cancer should be supported to return to healthcare services following the COVID-19 pandemic

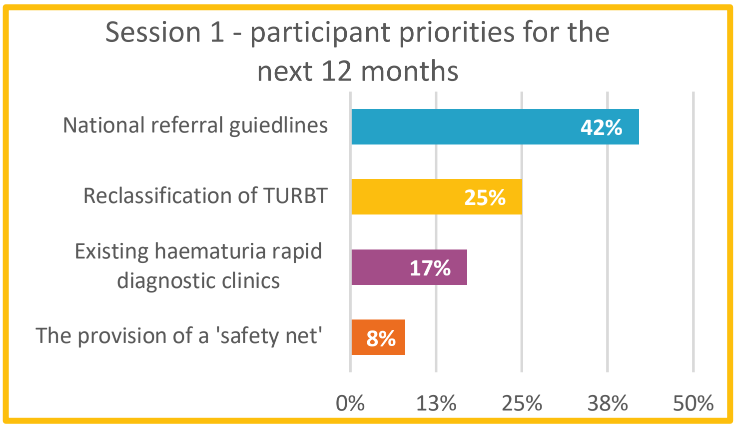
Breaking bad news

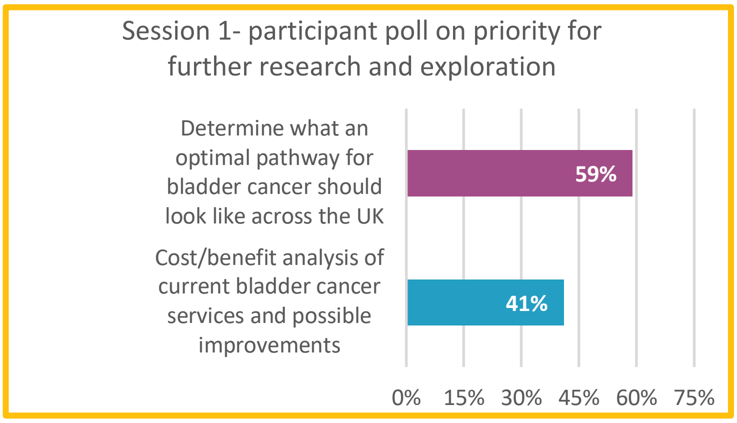
As a part of standardised one-stop-shop diagnostic clinics, the speakers also emphasised the importance of effective and empathetic communication of diagnosis and treatment plans. It was agreed that the delivery of bad news in particular should be handled by a member of the bladder cancer team, and preferably with a Clinical Nurse Specialist present. Dr Shaw shared the negative aspects of his own experience and stressed the need for health services to establish best practice when delivering bad news to patients.

Participants' priority actions

Participants identified reviewing the NICE bladder cancer referral guidelines and the Scottish Referral Guidelines for Suspected Cancer as the key priority for the next 12 months. Also considered important was the reclassification of TURBT across the UK and the review of existing haematuria and rapid diagnostic clinics.

Fight Bladder Cancer will lead the bladder cancer community in approaching national policy makers, NHS managers and clinical, innovation and system leaders to push for the implementation of these recommendations as a priority in the next year. We will also seek to work with NHS England to convene a steering group of bladder cancer experts that will drive a national conversation on the optimal bladder cancer pathway for the whole of the UK.





Session 2: Developing & growing the bladder cancer workforce

In the second session, *Developing and growing the bladder cancer workforce,* participants heard from Julia Taylor MBE, Macmillan Urology Clinical Nurse Specialist and Past President of BAUN, and Heather James, Urology Clinical Nurse Specialist. They described the challenges hospitals face in providing patients with access to Clinical Nurse Specialists.

Summary of key findings

- Health care professionals, particularly Clinical Nurse Specialists, are crucial to patient experience. However, not every bladder cancer patient has access to a Clinical Nurse Specialist
- A lack of a Clinical Nurse Specialist can result in uncertainty around appointments, cancellations and test results, which causes real concerns for patients and carers
- Clinical Nurse Specialists reported issues relating to high caseloads and low resources with some expected to cover wide geographical areas
- There is an ageing population of Senior Clinical Nurse Specialists and a poor understanding of what Clinical Nurse Specialists 'do 'amongst decisionmakers. This lack of clarity contributes to fewer Junior Nurses being encouraged to train as Clinical Nurse Specialists
- Workforce planning issues and the impending retirement of the majority of Clinical Nurse Specialists will further amplify these issues
- There is no clear current picture on Clinical Nurse Specialists coverage of bladder cancer
- There is a lack of an educational framework and access to support for on-going training

Heather James is a Urology Clinical Nurse Specialist based in North Wales at the Betsi Cadwaladr University Health Board. Using the context of her experiences as a urology Clinical Nurse Specialist at a smaller general hospital, Heather spoke about the importance of bladder cancer Clinical Nurse Specialists and the need for parity in provision across the country, including patient access to Clinical Nurse Specialists and Clinical Nurse Specialists' access to training.

Understanding the role and importance of a Clinical Nurse Specialist

> *"The four elements that Clinical Nurse Specialists need to have at the heart of their practice: leadership, education, audit and research"*
>
> Julia Taylor

The key components of the Clinical Nurse Specialist role include leadership, education and research, as well as well as patient-centred elements such as nurse-led clinics and holistic needs assessments. Due to the complexities of the bladder cancer care pathway, the difficult and life-changing decisions that can be involved, and the often long and anxiety-inducing waits between diagnosis and treatment, Clinical Nurse Specialists are crucial for bladder cancer patients. They are critical to building relationships with patients and their families, understanding how best to communicate with them, and, importantly, supporting their holistic needs. Referencing a survey she conducted, Heather noted that patients feel the most stressed between the time they attend the rapid access clinic and receiving the results of their TURBT. This demonstrates the value of patients being able to access a Clinical Nurse Specialist at the very start of a bladder cancer journey, not just post-diagnosis.

The capabilities required to be a Clinical Nurse Specialist and deliver the crucial components of their role are poorly understood and applied in different ways across the country. It was highlighted that, for Clinical Nurse Specialists to perform their roles effectively, the team around them, including administrative staff and cancer navigators, needs to be bolstered. By understanding the roles, remits and capabilities of the whole team it will then be possible to plan, develop and grow the bladder cancer workforce in a way that benefits patients the most.

Both Heather and Julia noted that during the COVID-19 pandemic, the importance of their role became even more apparent. With many bladder cancer Clinical Nurse Specialists redeployed, bladder cancer patients had no one to advocate for them in the system in many parts of the country. For Clinical Nurse Specialists not redeployed, the importance of maintaining relationships with patients throughout lockdown was emphasised.

> *"There is still a bit of a postcode lottery on whether patients get access to a Clinical Nurse Specialist"*
> Heather James

Need for equal access

Whilst it is recommended in national guidelines that everyone with bladder cancer should have access to a Clinical Nurse Specialist, in practice there are huge differences between different hospitals across the country. Though it was agreed there is an understandable difference in resources between tertiary centres and general hospitals, it was also noted that given the impact of Clinical Nurse Specialists on patient experience, accessing a Clinical Nurse Specialist should not be down to a postcode lottery.

There is also disparity in access to bladder cancer Clinical Nurse Specialists compared with Clinical Nurse Specialists specialising in other cancers. Whilst urology nurses support not just bladder cancer patients - but also renal, prostate and testicular cancer, as well as other non-cancer patients - breast cancer nurses (for example) are trained to work specifically with breast cancer patients. Despite this, the relative number of breast cancer Clinical Nurse Specialists is much higher. Anecdotally for example, one hospital has three breast cancer Clinical Nurse Specialists, but just one full-time and one part-time Clinical Nurse Specialist for all of urology. The lack of urology nurses was demonstrated through a past review of the prostate cancer specialist workforce, which showed that prostate cancer nurses made up only 2% of the UKs specialist nursing population. This is similar to the number of nurses for rare cancers, even though prostate cancer is the most common cancer in men.[1] It is likely that this shortage of staff is evident across urology, including bladder cancer.

The speakers emphasised the need to expand the urology and bladder cancer workforce to create parity across the country and better reflect the diversity of demands placed on urology Clinical Nurse Specialists. To achieve this, a greater understanding of the role and numbers of bladder cancer Clinical Nurse Specialists is needed.

Julia Taylor MBE began her career as a nurse over 20 years ago and was asked to set up specialist practice in urology at the Salford Royal NHS Foundation Trust. From the beginning, she recognised that there was an urgent need in bladder cancer, having witnessed patients who would have benefitted from having a Clinical Nurse Specialist to help them through their diagnosis. Julia highlighted the importance of understanding the roles and capabilities of Clinical Nurse Specialists and the importance of education in growing the bladder cancer workforce.

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[1] Prostate Cancer UK, About prostate cancer: facts and figures, accessed July 2021

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 needs
- Fight Bladder Cancer should conduct a workforce mapping exercise of Bladder Cancer Clinical Nurse Specialists in the UK and the Healthcare Quality Improvement Partnership and NHS Digital should work together to conduct a national bladder cancer audit
- Health Education England and NHS England should ensure that the cancer workforce strategy ensures sufficient Clinical Nurse Specialist capacity now and, in the future
- All urology Clinical Nurse Specialists should have ongoing access to training and exposure to bladder cancer specialists to support learning and development, funded through Health Education England and devolved NHS Deaneries training and education funding
- National and local NHS managers and system leaders should support the reduction of variances in training provision for Clinical Nurse Specialists to ensure both aspiring and current Clinical Nurse Specialists have equitable access to learning and development. This requires both adequate funding and championing of existing training provision (e.g. BAUN educational events), alongside the identification of educational gaps and ensuring that funding mechanisms are in place to support new educational programmes

Challenges for the urology and bladder cancer workforce

"From a nurse's point of view, it's such a varied specialism, with a variety of patients and variety of diagnoses within that umbrella of bladder cancer"

Heather James

The speakers noted the negative impact of the reduction in urology wards on the development and training of new urology nurses. Previously, nurses caring for bladder cancer patients on the urology ward would begin to build a specialism and receive access and coaching from existing bladder cancer or urology nurses. As day wards improve, the need for urology wards has decreased and they now tend to be shared with other specialities. Therefore, this route into bladder cancer and urology specialism is decreasing. This reduction in intake combined with an "ageing nursing population" further exacerbates the shortage of urology Clinical Nurse Specialists. Participants heard the results of a 2014 survey review of urology nurses, which found that in prostate cancer, 50% of nurses will have left their role by 2024, mostly due to retirement. It was agreed that these two challenges are cause for concern for the future of the urology Clinical Nurse Specialist community.

The importance of training and networking

As part of the discussion on the need for new bladder cancer nurse recruits, it was noted that bladder cancer is not seen as an attractive specialism for junior nurses. To combat this, investment will be needed to raise the profile of bladder cancer for nurses in training, by creating and encouraging networking opportunities and by building an educational framework that articulates the role and impact of a bladder cancer or urology Clinical Nurse Specialist.

It was noted that existing training (including through BAUN) must be strengthened by identifying the gaps, and funding greater development in those areas. The speakers highlighted the importance of access to high quality training for all Clinical Nurse Specialists, no matter where they are in the country or what hospital they work in, so that all patients can receive an equal standard of care.

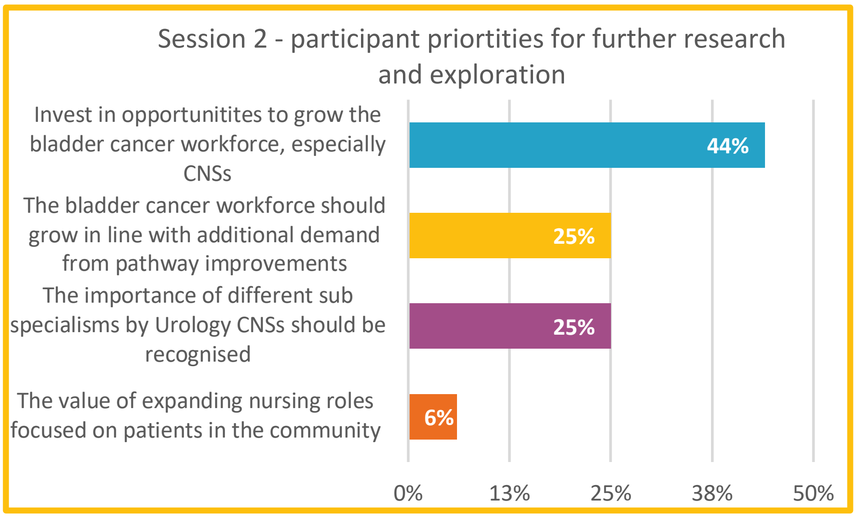
Looking ahead:

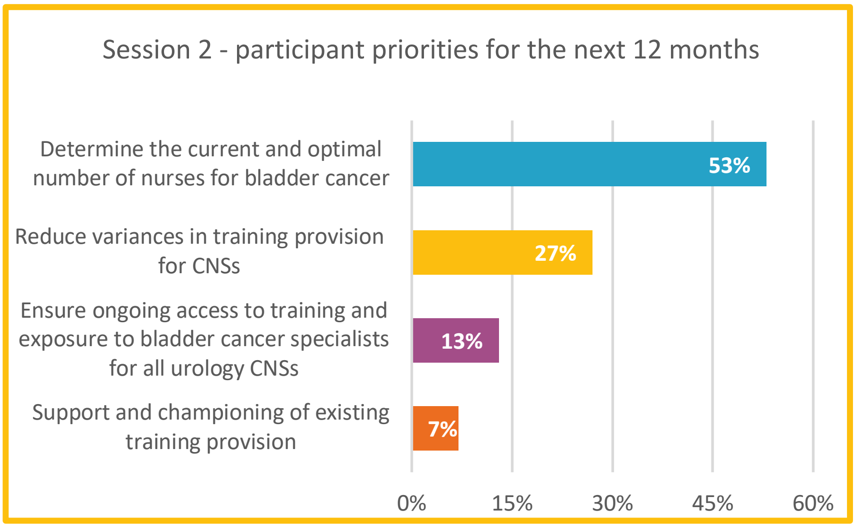
- The NHS and NHS England should invest in opportunities to grow the workforce of bladder cancer health care professionals, especially Clinical Nurse Specialists, in line with Cancer Workforce Strategy and the NHS People Plan
- Health Education England must expand nursing roles focused on patients in the community, particularly with stoma management
- NHS England deaneries in Scotland, Wales and Northern Ireland should ensure that patients with multiple comorbidities have a clear care coordinator and point of contact
- The importance of different sub-specialisms by Urology Clinical Nurse Specialists should be recognised, with all major centres having a lead bladder cancer Clinical Nurse Specialist
- The bladder cancer workforce should grow at a rate that is able to cope with additional demand generated by improvements in the service pathway. This will require additional funding for training and development

Participants' priority actions

Participants identified understanding the current number of nurses who work with bladder cancer patients as a top priority for the next 12 months, followed by determining what the optimal number of bladder cancer Clinical Nurse Specialist should be. Fight Bladder Cancer will work together with the bladder cancer community in the next 12 months to advocate for these recommendations with national NHS teams, Health Education England and NHS Deaneries in the devolved nations.

Investing in growing the bladder cancer workforce was also highlighted as a priority in the long-term. The recognition of sub-specialisms within urology and ensuring that the workforce grows at a rate to cope with any additional demand generated by improvements to the bladder cancer pathway were also of high importance. Fight Bladder Cancer will convene a working group to push these priorities forward with national policymakers.





Session 3: Improving patient support & involvement in care

In the final session of the event, *Improving patient support and involvement in care*, participants heard from Noamh Gallagher, Fight Bladder Cancer Patient Representative, and Tracy Staskevich, bladder cancer carer and Co-founder of Fight Bladder Cancer.

Summary of key findings:

- Bladder cancer can have a significant physical and psychological impact on patients, carers and their families
- Interviewees highlighted the importance of early access to peer support services. Access to support can be difficult and signposting varies widely between centres
- While some patients stated that they did feel involved and well supported in treatment decisions, some patients did not
- There is a lack of support for carers and family members of people affected by bladder cancer

Noamh is a paediatric nurse from Northern Ireland and was diagnosed with bladder cancer in May 2019, aged 47. Noamh's journey to diagnosis was not an easy one. Despite repeated trips to her GP for over a year with possible red-flag symptoms, she was only properly investigated after visiting A&E twice because of the pain she was in. It was here that she was able to be seen by a urology consultant who immediately took her to the urology unit and confirmed the presence of tumours. Noamh needed a complete hysterectomy.

Difficult decisions with life-long implications

A prominent theme from the discussion was the complexity of the bladder cancer pathway and the gravity of the decisions that must be made, which often have significant life-long implications. It was noted that these decisions come very early on in the process, often without time to gather and process information. The speakers agreed that there needs to be greater communication and patient involvement around the best course of treatment in conjunction with clear information on how those treatments will impact a patient's life, so that in a decision between bladder removal and lower-level treatments for a longer time, the ramifications of each option are fully understood.

> *" I memorised every poster in my GP surgery and there were none for bladder cancer"*
>
> Noamh Gallagher

> *"We need to encourage a wider discussion of what does that [treatment] mean for the rest of your life, how does that impact your job, your life, your family"*
>
> Tracy Staskevich

Lack of public awareness of bladder cancer

One of the reasons for the significant impact on patients and carers of bladder cancer is the lack of public awareness. Unlike, for example, breast cancer, those newly diagnosed with bladder cancer often do not know someone else who has already experienced this, or know what that pathway will mean for a patient. This in turn makes it very difficult for patients to communicate with friends and family who likely have no pre-existing knowledge of what the diagnosis means and what is to come.

Participants heard that not only are signposting and public awareness important for understanding the pathway and different treatments, but they also are key to helping people recognise their symptoms and refer themselves for investigation.

> *"Knowledge is power"*
>
> Tracy Staskevich

Tracy co-founded Fight Bladder Cancer with her husband Andrew 12 years ago, following his diagnosis of stage four bladder cancer. With very little information and support available at the time, Andrew and Tracy decided to start a local support group which eventually evolved into today's national charity. Tracy believes that without the correct knowledge as a patient or carer, you feel powerless. Therefore, one of the primary aims of Fight Bladder Cancer is to give patients and carers the knowledge and information they need.

Normalising taboo subjects

It is very important for patients and their families to be able to openly discuss the elements of bladder cancer that may be more difficult or embarrassing, including sex, pooing, concerns about travelling in a car, or whether you can go on an aeroplane.

Often people do not feel comfortable raising these with their medical team, so it is important that healthcare professionals make moves to normalise these conversations, allowing patients to speak more freely. It was suggested that by openly discussing difficult or awkward topics from the outset patients can gain a better understanding of the issues, are more likely to be happy with treatment decisions, and can be prepared for any impact on their day-to-day life those decisions might have. While some patient participants said they did not want to discuss end of life preferences, it was acknowledged that all patients should be presented with the option to discuss this openly with their medical team.

> *"We have to normalise these things and make sure we are talking about sex, death and toilets"*
>
> Tracy Staskevich

Peer-to-peer support

In conjunction with medical teams normalising these topics, both speakers highlighted the need for peer-to-peer support. Bladder cancer patients and carers can feel very isolated, making it critical to find people who they feel comfortable speaking with, through forums, connecting directly with other patients, or through speaking to their medical team.

Noamh shared how she provided direct peer-to-peer support to another patient following their diagnosis and reflected that she would have benefited from that herself when she went through diagnosis.

> *"Something that is often neglected by charities... is supporting the people who are supporting the patients"*
>
> Tracy Staskevich

The importance of carers

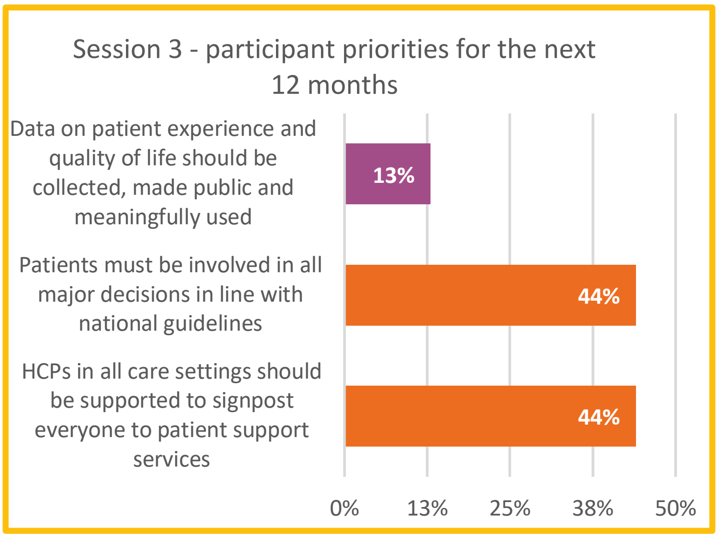
Finally, participants heard the importance of having support for carers through a bladder cancer journey. It was noted that often family and friends are the ones who feel like they must hold it all together and take care of the patients, but support services for them are too often overlooked.

What we can do now:

- Healthcare professionals in all care settings should be supported to signpost everyone with suspected or confirmed bladder cancer to patient support services
- NHS patient resources must include written references to patient support services
- Fight Bladder Cancer can work with healthcare professionals to supply patients with patient information materials
- Patients must be involved in all major treatment decisions in line with national guidelines – particularly those with consequences related to final outcomes, sex and lifestyle
- The NHS recommendations on implementing personalised stratified follow-up (PSFU) pathways tailored to individual needs should be included in the bladder cancer pathway
- Data on patient experience and quality of life should be collected, made public and meaningfully used in quality improvement – at the local and national levels
- NHS England, NHS Improvement, Picker, and IQVIA should ensure that the results from the National Cancer Patient Experience Survey and the Cancer Quality of Life Survey are made publicly available separately for bladder cancer, rather than having the results grouped with other urological cancers

Participants' priority actions

In line with the roundtable participants' priorities for the next 12 months, Fight Bladder Cancer will work with the bladder cancer community, NHS organisations across the UK and NICE to ensure that guidelines on patient involvement in decision-making are being upheld. Whilst also working to ensure that healthcare professionals in all settings are signposting anyone with suspected or confirmed bladder cancer to patient support services.



Looking ahead:

- Fight Bladder Cancer will bring together key experts from the bladder cancer community to develop best-practice procedures and supporting guidelines for communicating holistic and psychological support options to patients
- Fight Bladder Cancer will bring the bladder cancer community together to discuss ways to provide support for the carers and family members of people living with bladder cancer
- NHS England must do more to improve psychosocial support for people affected by cancer, building on the NHS Long Term Plan commitment that *"every person diagnosed with cancer will have access to personalised care, including needs assessment, a care plan and health and wellbeing information and support"*

Next Steps

The launch of the Exemplar Research Project brought the bladder cancer community together and built much needed consensus on UK-wide priorities for policy actions to improve bladder cancer care, as shown in the report's recommendations.

Having now built national and regional consensus, Fight Bladder Cancer will, together with the wider bladder cancer community, engage with national and regional NHS managers and clinical, innovation and system leaders to drive action on implementing the report's recommendations. Through our continued advocacy for action, Fight Bladder Cancer hopes to help the NHS move towards an exemplar bladder cancer pathway and transform the lives of the 20,700 people diagnosed with bladder cancer in the UK every year.

Fight Bladder Cancer is committed to dedicating significant resources to bring change within each of the Exemplar priority areas in the years to come. If you would like to get involved, please visit: www.fightbladdercancer.co.uk/exemplar.

Some of the Fight Bladder Cancer team, from left to right:
Lydia Makaroff, Anne MacDowell, Amy Jacob, Sana Gilfillan, Melanie Costin.

Participant Feedback

Thank you for an excellent meeting. I hope that we can work together on some future projects, as there is a lot of overlap on some of the research to be done.

Hazel Pixley
Chief Executive Officer, Urostomy Association

I would like to thank the Fight Bladder Cancer for organising such an insightful, patient centred meeting. We know that there continues to be much work to do to improve all aspects of bladder cancer care. This meeting, as well as the report, will act as the impetus to ensure we maintain the patient perspective at the centre of future drives to improvement. I look forward to working with Fight Bladder Cancer in the future, striving to achieve this common goal.

Dr Mohini Varughese
Royal College of Radiology

Thank you and all the panellists for running such an excellent and informative seminar. The report is comprehensive with some clear recommendations and actions, and I look forward to working together to try and realise them. Congratulations on a great event and report!

Louise de Winter
Chief Executive, The Urology Foundation

Excellent event and report identifying a path forward to exceptional bladder cancer care services for patients in the United Kingdom drawing from the experiences of the very people affected by bladder cancer. I congratulate our member Fight Bladder Cancer on the launch of the report and feel confident that the insights will not only have an impact in the UK, but inspire an exemplary pathway for the diagnosis, treatment, and care of bladder cancer around the world.

Alex Filicevas
Executive Director, World Bladder Cancer Patient Coalition

Congratulations to Fight Bladder Cancer on launching the Exemplar Report and for an excellent webinar. I thought the speakers were extremely informed and honest, and the patients´ ’perspective about "sex, death and toilets” needs to be understood by clinicians. The information and multidisciplinary pathways outlined in the Exemplar Report merit further discussion among the members of the European Association of Urology Patient Advocacy Group.

Eamonn Rogers
Chairman, European Association of Urology Patient Information

We are grateful to Astellas, Bristol Myers Squibb, the Merck-Pfizer Alliance, MSD and Roche for their support in covering the costs associated with the Exemplar Project, and to Arquer Diagnostics for funding the online survey conducted by Brainsell. Editorial control of all materials has been retained by Fight Bladder Cancer.

Fight Bladder Cancer *is a registered charity in England and Wales (1157763)*