BLADDER CANCER – the current landscape and the key issues

This paper puts the spotlight on the current landscape for those with bladder cancer, some of the key issues around diagnosis and treatment, and looks at actions which may help to improve outcomes for patients.

Some Facts about Bladder Cancer

Bladder cancer is not a rare cancer – although it has the profile, awareness and research investment of a less common disease.

Over 21,000 people are diagnosed each year in the UK - Bladder cancer is one of the 10 most common cancers – this figure includes the earliest stage cases of non-muscle invasive bladder cancer (defined in histology with Ta or carcinoma in situ).

75% of bladder cancer patients are male; however women have poorer outcomes.

It is one of the few cancers where outcomes have worsened over time.

Mortality rates are high:

- 5 year survival for women has decreased from 43% to 41% since 2012.
- 5 year survival for men has decreased from 58% to 56% in the same period.

Emergency admission: A significantly high proportion of bladder cancer patients are diagnosed upon an emergency admission when compared to other cancers (c24% of women, c17% of men).

Referrals: 41% of bladder cancer patients do not get referred by their GPs using the urgent referral pathway.

There is a high risk of recurrence - Bladder cancer has the highest recurrence rate of any known cancer, ranging from 30% to 70% . The high recurrence rate means a patient may often have repeat treatments and surgical procedures.

There is a high rate of progression to more advanced disease - with rates of progression as high as 10% to 30% for high-risk tumours.

Living with Surveillance: Due to the high risk of recurrence, many patients will have to live with the anxiety of long term surveillance, which will often involve invasive procedures for testing.

Treatments: Treatment pathways can be long and often complex.

There are few available treatment options

No curative treatment: Over 50% of those patients with non-metastatic Muscle Invasive Bladder Cancer do not receive curative intent treatment.

Lack of new treatments: Until very recently, there have been no new treatments for bladder cancer for nearly 40 years.

NICE Guideline: the first Guideline for diagnosis and management of bladder cancer was published in February 2015. It has not been updated since then.

Variances: There are wide variances in care across the UK

Audit: There has been no national Audit for Bladder Cancer, as there has been for other common cancers.

There is a very low level of UK research investment – less than 1%.

Expensive: Bladder cancer is one of the most expensive cancers to treat.

SUMMARY OF THE CURRENT LANDSCAPE FOR BLADDER CANCER

Bladder cancer has an issue of poor awareness. Amongst the general public there is very little awareness of what symptoms to look out for and many patients say the first they heard of bladder cancer was upon their own diagnosis.

ABC UK is often told by bladder cancer patients and their families that they are angry, feel overlooked, and question why such a serious and common condition is so neglected – bladder cancer has not performed well in the annual National Cancer Patient Experience Surveys since they started. Patients tell us they find it difficult to get information about their condition, sometimes have trouble accessing best treatment or services, and are shocked by the lack of treatment choices and sources of support available to them and their families. There is a need for better understanding by health professionals, and little understanding of the key issues amongst decision makers – whether within health service provision and commissioning or within government.

If bladder cancer was given the investment and attention demanded by incidence and prevalence, we feel strongly that improvements in outcomes (and streamlining of treatment pathways and related expense) could emulate that of other cancers.

Bladder cancer is therefore common, expensive to treat, has experienced little improvement in outcomes, has a persistent pattern of poor experiences for patients across the UK and significant challenges for both patients and health professionals – bladder cancer is a forgotten or 'Cinderella' cancer. Recent developments in treatments are hopeful, but so much more needs to be done. These facts are what drive our work at Action Bladder Cancer UK.

We want to change this and turn the spotlight on bladder cancer – for it to receive the urgent attention it requires and for bladder cancer to be recognised as a common cancer, with poor outcomes, and receive the acknowledgement, level of public awareness, improvements in treatments and medical research investment which it merits - and which those with bladder cancer deserve.

We want bladder cancer patients to have a voice - and the support and care that they, and their families, need.

What are the key issues?

Late Diagnosis

Bladder cancer is often diagnosed late – when the cancer has already started to move through the walls of the bladder. This leads to the prospect of poorer outcomes for patients.

Why is this?

A combination of reasons might lead to a later referral for investigation - a lack of symptoms awareness, a hesitancy in seeking medical advice, low GP knowledge about bladder cancer and awareness of when to refer for further examination, and a lack of accurate and widely available testing for use at an early stage.

There is a necessity for better understanding within **primary care**. There is no national screening programme for bladder cancer – the lack of research investment means there is as yet no reliable test which could be used on a wide scale or within primary care.

Later diagnosis means the prospect of a worse outcome for the person concerned, it can affect (and limit) treatment options, and mean a worse quality of life for the patient. Late diagnosis of bladder cancer impacts significantly on survival - early detection saves lives.

- Survival strongly linked to stage at diagnosis
- 5 year survival if diagnosed at stage 1 = 80%
- Drops to around 20% if diagnosed at stage 4
- Outcome often less favourable in women: More likely diagnosed at a later stage

There is an urgent need for earlier diagnosis and a better awareness, and understanding, of bladder cancer both in the public and by health professionals and decision makers.

ABC UK GP Learning Module & other primary care resources:

https://actionbladdercanceruk.org/primary-care-education/

ABC UK Symptoms Guide: ABC UK Symptoms Guide.pdf

Poor Outcomes for Patients

About 50% of those diagnosed with bladder cancer will die – this is very high for a UK cancer survival rate.

Survival rates for bladder cancer have also worsened in recent years, in contrast to the general trend across all cancers. This can be clearly demonstrated by looking at survival rates when compared with a cancer such as prostate cancer. Survival rates for prostate cancer show significant improvements, moving from survival rates in the 1970's of 31% (5-year survival) to 84.8% (1996-2000). Whereas, outcomes for bladder cancer patients have only improved by **1%** in a similar timeframe.

Diagnosis Pathway

ABC UK has been working closely with NHSE and the regional Cancer Alliances on improving the pathway to diagnosis for those with bladder cancer.

An interesting area of development is the use of new urinary biomarker testing for bladder cancer. The Galeas test is currently being trialled in practice with several major Trusts across the UK. Data has shown this new genetic test to be accurate when compared with invasive cystoscopy testing. One of the major early stage benefits of such a test could be to remove those patients who do not have bladder cancer from the diagnostic pathway, freeing capacity for those patients who do require further tests and to receive timely appointments, and progress to treatment more quickly. ABC UK were pleased to be able to grant fund early stages of this work to develop a urinary biomarker test for bladder cancer.

Women and Bladder Cancer

The need to improve early diagnosis is an especially urgent issue for women, among whom survival outcomes are significantly worse. Whilst more men than women are diagnosed with bladder cancer, women are more likely to be diagnosed at a later stage – which sadly can lead to poorer outcomes.

Why is this?

This can be for a variety of reasons. Symptoms, such as seeing blood in the urine, can be mistaken for something else in women. It may be assumed to be a UTI (urinary tract infection) and just require antibiotics – many female bladder cancer patients tell us they were given several courses of antibiotics over lengthy time periods, before being sent for further investigation (see ABC UK's Women and

Bladder Cancer leaflet, which includes evidence from female patients about their diagnosis journey).

Symptoms may also be assumed to relate to the menopause, or be masked by menopausal symptoms. If a woman has had previous gynaecological issues or procedures, even several years earlier, bleeding may be assumed to be the consequence of this.

The person themselves might delay going to the GP, thinking that it's their age, or 'just one of those things'.

Resources: ABC UK's Women and Bladder Cancer: ABC UK Bladder Cancer in Women 2025.pdf

Bladder cancer has a high level of recurrence.

Bladder cancer has the highest recurrence rate of any known cancer, ranging from 30% to 70%, with rates of progression as high as 10% to 30% for high-risk tumours.

Even after treatment, it can come back, and also return at a high risk level. Many patients experience more than one recurrence. Patients have to live with the anxiety of surveillance, including tests such as invasive cystoscopies (where the inside of the bladder is viewed with a camera).

There are limited treatment options

A startling fact is the lack of **significant new treatments coming into use for treating bladder cancer in the past 40 years.** For many decades there has been no significant advance in treatment options for all types of bladder cancer, leaving the patient (and the health professionals treating them) with few options or choices.

For example, for those with high risk non muscle invasive bladder cancer (where the cancer is still within the outer wall of the bladder, but has a high risk of progressing) any treatment choice is mostly between lengthy courses of BCG immunotherapy (which can have cumulative effects which can lead to a patient ceasing the therapy) or life-changing surgery to remove the bladder (cystectomy).

Bladder cancer often has a significant and lasting impact on **patient quality of life**.

Any cancer patient will face challenges once diagnosed with the disease – but those with bladder cancer can face particular, and long-lasting, challenges. These

include a complex, prolonged care pathway and life changing surgery (with radical cystectomy to remove the bladder, often the only choice for high risk forms of the disease), and the high recurrence rates will also frequently require intensive surveillance over the lifetime of the patient.

New Treatments

There have been recent, and very welcome, developments in treatments for bladder cancer. These include new immunotherapies, combination therapies and targeted treatments. A small number of these are now in the NICE approval process, with others scheduled for 2026 and 2027. It is vital that these become available for wider clinical use to treat patients who currently have limited treatment options and face potentially poor outcomes.

There are however challenges in bringing these new treatments into wider use.

Access to new treatments

Whilst the development of new treatments for bladder cancer is very welcome, there are significant challenges in bringing these new treatments to wider availability within the UK. As yet, very few of these treatments are available for use within the NHS.

NICE Guideline for Treatment and Management of Bladder Cancer (NG2)

The current NICE Guideline for bladder cancer was published in February 2015 – nearly 11 years ago. It has not been updated since publication. Clinicians have needed to look elsewhere for guidance and evidence of best practice, such as referring to EU guidance. ABC UK has led a group of stakeholders in lobbying for an update since early 2023. In 2025, NICE confirmed that they would be undertaking a partial update of the Guideline. We have, as yet, no definitive timeline for this update, however NICE have recently started recruitment for topic advisors to help map out the process.

This update is of particular importance with the advent of new, very welcome, treatments for bladder cancer.

We feel there should be a review of **NICE appraisal processes and the comparator and cost-effectiveness factors used in assessments** to ensure these are fit for purpose for these newer kind of treatments. A positive and flexible attitude is needed for approval of treatments which will be filling the gap where no comparative treatment is currently available, where treatment choice is extremely limited, and for combination treatments which improve efficacy of a long-term existing treatment.

NICE – cost effectiveness thresholds. Whilst fully supportive of NHS seeking value for money, and companies seeking realistic pricing, the time may have come (with these newer kinds of treatment) to review these thresholds to accommodate new types of treatments.

It is also vital that the **NHS is given the necessary support and funding** to be ready for the rollout of these newer types of treatments - prepared both in terms of pathways and systems, as well as the necessary workforce.

For example, new treatments which combine two therapies will have implications for how the therapy is administered, with perhaps two separate patient appointments necessary, within both urology and oncology, with different health professionals. This will require co-ordination, pathway change, internal cross-department communication, flexible internal funding streams and workforce.

National Bladder Cancer Audit

National cancer audits can have a major impact on clinical practice, diagnosis and treatment pathways, and outcomes for patients. This has been clearly evidenced by the outcomes from audits for other cancers, where systematic, national, data collection and interrogation has led directly to significant improvements in referral pathways, clinical practice and treatment regimes - which is then linked to significantly improved 5-year survival data.

We are calling for a national audit for bladder cancer.

Variances in clinical practice

There are significant variations in treatments and patient pathways across the UK – these variations may occur on a national basis, between regions, and even within a Trust itself.

This is as a direct result of the lack of consistent national data from the point of diagnosis throughout the patient pathway. This pathway can often be long, and complicated by recurrence or treatment side effects. This across the board lack of national evidence of best practice, and an out of date Guideline, has a direct impact on clinical practice and patient outcomes.

ABC UK feels strongly that a full national audit for bladder cancer could be one of the most effective means of providing the evidence for best clinical practice and of improving outcomes for patients.

Research Investment

There is a notable lack of **research investment** - bladder cancer is one of the most expensive malignancies to manage on a per patient basis from diagnosis to death, costing £65million annually, yet it receives less than 1% of UK cancer investment.

This lack of research investment has a direct impact on many aspects of treating bladder cancer – on the development of new treatments and evidence for best practice for existing treatments, developing new, and accurate, testing or improving the patient treatment pathway and experience.

ABC UK: Our Work

ABC UK's driving aim is to make life better for bladder cancer patients.

- Raising Awareness
- Supporting Patients
- Fund and encourage research
- Education health professionals
- Improving outcomes for those with bladder cancer

All of our resources are available on our website or as free print copies.

www.actionbladdercanceruk.org