

Background - About Bladder Cancer

Bladder Cancer is not a rare cancer.

It is one of the top ten most common cancers in the UK - with one of the highest mortality rates. Over 10,500 people in the UK are diagnosed each year – half of these will die. 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. There are few available treatments and limited, low awareness amongst the public and a need for better understanding by health professionals and little support available for patients.

The key issues

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

There is an urgent need for **earlier diagnosis** – bladder cancer diagnosis is often late, particularly in women. This can be due to a combination of reasons - a lack of symptoms awareness, a hesitancy in seeking medical advice, low GP awareness of when to refer for further examination and a lack of accurate and widely available testing for use at an early stage. A significantly high proportion of bladder cancer patients are diagnosed upon an emergency admission when compared to other cancers (24% of women, 16% of men). Late diagnosis of bladder cancer impacts significantly on survival - early detection saves lives.

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 only got 0.6% research investment (in 2013-2014).

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. Treatment pathways can be long and often complex, and the high recurrence rate means a patient may often have repeat treatments and surgical procedures. A startling fact is that there have been **no significant new treatments come into use for treating bladder cancer in the past 30 years** - leaving the patient (and the health professionals treating them) with few options or choices. There has been some recent movement in the development of new immunotherapy treatments but these treatments are in the early clinical trial stage and none as yet are widely available.

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 no reliable test which could be used on a wide scale or within primary care. The need to improve early diagnosis is an especially urgent issue for women, among whom survival outcomes are significantly worse. This is partly due to women being more likely to be treated for persistent urinary tract infections rather than being referred for investigations to whether bladder cancer is the cause of the symptoms.

There is also a necessity to improve understanding amongst health professionals – there is the need to offer urology cancer nursing specialists further training and learning opportunities about bladder cancer, and there is an argument that a bladder cancer specialism should be embedded within all urological services (bladder cancer specialist knowledge can vary considerably across the UK).

Bladder cancer also 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. There is little understanding of the key issues amongst decision makers – whether within health service provision and commissioning or within government.

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.

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 that 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.

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. These facts are what drive our work at Action Bladder Cancer UK.

We want to change this. ABC UK is working to turn the spotlight on bladder cancer – for it to receive the urgent attention it requires - for bladder cancer to be recognised as a common cancer and to receive the acknowledgement, level of public awareness, improvements in treatments and medical research investment which it merits - and which those with bladder cancer deserve. Recent developments in treatments are welcome, but so much more needs to be done. We want bladder cancer patients to have a voice and the support that they, and their families, need.

January 2019

Action Bladder Cancer UK - Organisation Overview

ABC UK was established in 2009 (as Action on Bladder Cancer) by a group of urologists and patients who were deeply concerned about the low profile of bladder cancer as a serious disease and the lack of support and information for patients.

In April 2016, we relaunched with our new name - Action Bladder Cancer UK, which better reflects our role as a UK-wide, pro-active, charity - and our new website www.actionbladdercanceruk.org. Reinforced by significant strategic planning, we have launched new projects and programmes - with exciting plans for the future.

Our Trustee board and executive is a unique mix of bladder cancer patients and leading medical and research specialists. Our medical trustees represent specialists within urology, research, cancer nursing and general practice. Our patient trustees provide the insight of direct personal experience, and are also leading members of advisory panels, patient support groups and regional cancer networks. Much of our project work is carried out by volunteers, also patients, or project staff. Our administration and finance support is based in Gloucestershire. We employ a full-time Director.

Our Work

ABC UK's driving aim is to make life better for bladder cancer patients. Our work has three strands:

- Raising Awareness
- Supporting Patients
- Improving outcomes

Informed by the wealth of expertise and experience provided by our trustees, volunteers and advisors, the charity has created exciting new programmes of patient support, directly improving outcomes and research, as well as educating the medical profession and the public about bladder cancer and the symptoms and the importance of early diagnosis.

There is a great need for our work, and a strong desire amongst patients for a charity which can not only provide information and support but can drive improvements and new programmes of work. Our programmes are already demonstrating strong beneficial impacts for bladder cancer patients, and our plans for 2019 and onwards are exciting and ambitious.

ABC UK Trustees

Allen Knight – Chair: bladder cancer patient;

Professor Roger Kockelbergh – Treasurer: Honorary Professor of Urology (Cancer Studies) University of Leicester, Consultant Urologist & lead clinician in Uro-oncology, Leicester General Hospital;

Jeremy Crew - Vice Chair: Consultant urologist & honorary senior lecturer, Oxford University Foundation Hospital Trusts;

Paula Allchorne: Senior Cancer Nursing Specialist;

Richard T Bryan: Senior Research Fellow, The Institute of Cancer & Genomic Sciences, University of Birmingham;

Peter Harper: Oncologist, founder London Oncology Centre;

Phil Kelly: Bladder cancer patient;

Mark Page: Bladder cancer patient;

Caroline Raw; Bladder cancer patient;

Dr Jon Rees: GP, Backwell & Nailsea Medical Group, specialist interest in Men's Health & Urology.