COVID-19 pandemic. A significant impact was observed on bladder cancer treatments in terms of surveillance routine, delays or alteration of treatments. The impact during the March–May period of 2020 has varied across countries. There were some similarities to reported patient impact by patient organisations. Some 78% reported cancellations of routine surveillance of patients, and the same number reported alteration of treatment protocols. Falling levels of participation in clinical trials or changes to clinical trial treatment and testing plans were also reported by 44% of responding organisations. Bladder cancer patients have also experienced mental health and well-being challenges. 89% of organisations reported patients experiencing isolation, 78% facing stress, anxiety or even depression, whilst 78% had decreased access to healthcare teams. These numbers represent the number of patient organisations who have reported having experienced or supported bladder cancer patients in these areas. Patient organisations have been playing an important role in reassuring patients, carers and managing anxiety. Elderly patients were reported to be more significantly impacted, as they were less able to count on the support provided by families and loved ones. Carers themselves were increasingly anxious since they were not able to visit patients or even attend medical appointments due to distancing norms.

Funding challenges

There is no doubt that the financial impact of COVID-19 was felt by all patient organisations, and in the bladder cancer community. It was no different. Fundraising events and community fundraising have been most severely affected by the COVID-19 pandemic.

Over two-thirds of organisations are trying to find new ways to raise money because of the pandemic, transforming personal walks and community events into virtual experiences. Online shops were set up, and many have encouraged fundraisers to think more broadly about what could be done, from setting up, and many have encouraged fundraisers to think more broadly about what could be done, from setting up personal walks and community events into virtual experiences. Online shops were set up, and many have encouraged fundraisers to think more broadly about what could be done, from setting up personal walks and community events into virtual experiences. Online shops were set up, and many have encouraged fundraisers to think more broadly about what could be done, from setting up personal walks and community events into virtual experiences. Online shops were set up, and many have encouraged fundraisers to think more broadly about what could be done, from setting up personal walks and community events into virtual experiences. Online shops were set up, and many have encouraged fundraisers to think more broadly about what could be done, from setting up personal walks and community events into virtual experiences. Online shops were set up, and many have encouraged fundraisers to think more broadly about what could be done, from setting up personal walks and community events into virtual experiences. Online shops were set up, and many have encouraged fundraisers to think more broadly about what could be done, from setting up personal walks and community events into virtual experiences.

Leadership challenges

More than 40% have concerns for fundraising and philanthropy in the post-pandemic world. The most significant impact was on fundraising events (78%) and community fundraising (67%), whilst other fundraising activities have been affected for over a third of members. Almost 70% of bladder cancer patient organisations predict a drop in income in the next 12 months, which could have a potential impact on the ability to continue all organisational activities and support for bladder cancer patients. There is evidence of agility in our member organisations, who are stretchishing themselves to provide the support and information for those who need it most in our community.

Invasive bladder cancer C67

C67 is what is usually referred to as ‘bladder cancer’ in statistical publications. It is defined as bladder cancer which has spread to the connective tissue that separates the lining of the bladder from the muscles beneath, or further into the muscle around the bladder.

Non-invasive bladder cancer D09.0 and D41.4

D09.0 Carcinoma in situ of bladder. Carcinoma in situ is a flat bladder cancer that is confined to the surface layer of the bladder and is more likely to lead to invasive bladder cancer. D41.4 Neoplasm of uncertain behaviour of the bladder. This is how most of the other bladder cancers are classified, including non-invasive papillary carcinoma – a growth which sticks out of the bladder wall.

Unfortunately, Cancer Research UK only counts invasive bladder cancer (C67), which means that if we use their statistics, we are not counting everyone. We contacted the relevant departments in England, Scotland, Wales and Northern Ireland to see if we could get some more accurate statistics.

My diagnosis counts

20,000 a year – the number of incidences of bladder cancer in the UK

Every diagnosis of bladder cancer is personal and no one should feel like just a number. However, it is important to collect statistics on bladder cancer so we can understand it better and provide the best treatment and support for everyone.

A staggering 8 out of 9 organisations noticed a drop in the number of people seeking help about symptoms which could lead to cancer. A significant impact was observed on bladder cancer treatments in terms of surveillance routine, delays or alteration of treatments.

Leadership challenges

More than 40% have concerns for fundraising and philanthropy in the post-pandemic world. The most significant impact was on fundraising events (78%) and community fundraising (67%), whilst other fundraising activities have been affected for over a third of members. Almost 70% of bladder cancer patient organisations predict a drop in income in the next 12 months, which could have a potential impact on the ability to continue all organisational activities and support for bladder cancer patients. There is evidence of agility in our member organisations, who are stretching themselves to provide the support and information for those who need it most in our community.

These findings point to an urgent need to support the very organisations that for so long have played such a critical role in supporting cancer patients, advocating for positive change in cancer policy and practices and raising funds for vital research. The societal and economic value of this contribution should not be under-estimated – its loss would be immeasurable.
England

The National Cancer Registration and Analysis Service is part of Public Health England and records all cancers diagnosed in England. The number of new cases of invasive bladder cancer (C67) has slightly decreased, from 8,900 in 2001 to 8,066 in 2016. Bladder cancer is more common in men than in women. There are many more of these ‘non-invasive’ bladder cancers, and in total, for both invasive and non-invasive cancers, the number of new diagnoses each year is 4,500 for women and 13,500 for men, a total of 18,000 new diagnoses per year in 2016.

For more statistics visit www.cancerdata.nhs.uk/getdataout/bladder.

There is a contrast between the incidence rates of invasive and non-invasive cancers, with the former falling and the latter increasing. This suggests that more cancers are being diagnosed when non-invasive. Once we have a longer set of data on cancer survival by stage, we might be able to see if this is true, which would be welcome news.

Scotland

For Scotland, we filed a Freedom of Information Request with the Scottish Cancer Registry, Public Health Scotland (PHS). In Scotland, in the year 2018 there were 882 diagnosed cases of non-invasive bladder cancer, and 809 diagnosed cases of invasive bladder cancer, for a total of 1,691 cases. There were 1,233 men diagnosed and 458 women diagnosed with bladder cancer.

Wales

We reached out to the NHS Wales Informatics Service Information and Statistics. They informed us that in Wales in the year 2018, there were 170 diagnosed cases of non-invasive bladder cancer, and 499 diagnosed cases of invasive bladder cancer, for a total of 669 cases. The numbers for 2019 were very similar with a total of 672 cases.

Northern Ireland

The Business Services Organisation Information Unit in Northern Ireland provided local data. In Northern Ireland in the year 2018, there were 172 diagnosed cases of non-invasive bladder cancer, and 54 diagnosed cases of invasive bladder cancer, for a total of 226 cases.

**Difference in bladder cancer rates between men and women**

There are differences in rates of bladder cancer between men and women in all four nations, typically in the ratio of about 3:1. This is illustrated in the table below.

<table>
<thead>
<tr>
<th>Nation</th>
<th>Men</th>
<th>Women</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>England</td>
<td>13,500*</td>
<td>4,500*</td>
<td>18,000*</td>
</tr>
<tr>
<td>Scotland</td>
<td>1,233</td>
<td>458</td>
<td>1,691</td>
</tr>
<tr>
<td>Wales</td>
<td>512</td>
<td>157</td>
<td>669</td>
</tr>
<tr>
<td>N Ireland</td>
<td>158</td>
<td>68</td>
<td>226</td>
</tr>
</tbody>
</table>

**Percent of Total**

15,403 (75%) 5,183 (25%) 20,586* (100%)

*approximate numbers; for more precise data see below.

**Incidence rates per million population**

This information compares the rates of bladder cancer per million population within the four nations. It is referred to as ‘crude incidence’ because it is not adjusted for factors that may influence the rates of bladder cancer, such as the age of the population, incidence of smoking or occupational activities. We have included the numbers of all types of bladder cancer, both invasive and non-invasive. Whilst England and Scotland appear to have very similar rates, it is not clear why Wales and Northern Ireland have lower crude rates. It is worth noting that historically when comparing the incidence of bladder cancer between countries, only the numbers of invasive bladder cancers (C67) have been used.

| Bladder cancer type | England | Scotland | Wales | NI | Total |
|---------------------|---------|----------|-------|    |-------|
| C67 Malignant neoplasm of bladder | 8,066   | 809      | 499   | 56 | 9,428 |
| D09.0 Carcinoma in situ of bladder & D41.4 Bladder neoplasm of uncertain or unknown behaviour, and other bladder cancer | 8,955   | 882      | 170   | 5.2 | 11,079 |

Total 17,921 1,691 669 226 20,507

*Due to availability of data the statistics for England are for 2016 and for Wales and NI for 2018.

**How to use the data**

What are we to do with all these data? We think that they are a good prompt to start talking about important questions, such as the static survival rates in bladder cancer, and the disparity between men and women in outcomes. They can inform campaigns such as Be Clear on Cancer, and measure how effective they are. In a wider context, these data inform service planning and commissioning, such as funding for urology specialist nurses. Knowing the number of people affected by bladder cancer puts May’s Bladder Cancer Awareness Month in perspective, and it might be a surprise to many people how common this cancer is, especially in women.

**CONCLUSION**

This is the first publication of bladder cancer statistics from the four nations of the UK indicating that over 20,000 people are diagnosed with bladder cancer in the UK each year. We hope that this statistic is used by everyone passionate about bladder cancer to demonstrate that urgent action is required to address unmet needs for this group.

**I went to the doctor and said ‘I’ve got problems with wanting to go to the toilet all the time’ and they said ‘Well, you’ve probably got a bladder infection. We’ll give you antibiotics.’ Two weeks later I go back and get different antibiotics and this went on five or six times and I knew then there was something wrong but I didn’t know what it was, but I knew it wasn’t right. I left it for two months because I thought I was being a nuisance at the doctor’s. GP surgeries need to be made more aware of what to look for, even if it’s somebody older.’

Barbara

**Data sources**

You can access the NHS England paper at https://journals.sagepub.com/doi/full/10.1177/2053445816674103

The data on cancer incidence and mortality are available at the NCRAS CancerData website: https://www.cancerdata.nhs.uk/incidence and https://www.cancerdata.nhs.uk/mortality

A paper on the number of cancers caused by external risk factors can be accessed here: https://www.nature.com/articles/s41416-018-00029-6

Cancer survival data are published by the Office for National Statistics: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/cancersurvivalinengland/nationalestimatesforpatientfollowedupto2017
**Difference in bladder cancer rates between men and women**

There are differences in rates of bladder cancer between men and women in all four nations, typically in the ratio of about 3:1. This is illustrated in the table below.

<table>
<thead>
<tr>
<th>Nation</th>
<th>Men</th>
<th>Women</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>England</td>
<td>13,500*</td>
<td>4,500*</td>
<td>18,000*</td>
</tr>
<tr>
<td>Scotland</td>
<td>1,233</td>
<td>458</td>
<td>1,691</td>
</tr>
<tr>
<td>Wales</td>
<td>512</td>
<td>157</td>
<td>669</td>
</tr>
<tr>
<td>N Ireland</td>
<td>158</td>
<td>68</td>
<td>226</td>
</tr>
</tbody>
</table>

*Percent of Total: 15,403 (75%) 5,183 (25%) 20,586 (100%)

*Due to availability of data the statistics for England are for 2016 and for the rest of the UK are for 2018.*

**Bladder cancer incidents in the UK by type 2016–2018**

<table>
<thead>
<tr>
<th>Bladder cancer type</th>
<th>England</th>
<th>Scotland</th>
<th>Wales</th>
<th>NI</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>C67 Malignant neoplasm of bladder</td>
<td>8,066</td>
<td>809</td>
<td>499</td>
<td>56</td>
<td>9,428</td>
</tr>
<tr>
<td>D09.0 Carcinoma in situ of bladder &amp; D41.4 Bladder neoplasm of uncertain or unknown behaviour, and other bladder cancer</td>
<td>9,855</td>
<td>882</td>
<td>170</td>
<td>5.2</td>
<td>11,079</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>17,921</td>
<td>1,691</td>
<td>669</td>
<td>226</td>
<td>20,507</td>
</tr>
</tbody>
</table>

How to use the data

What are we to do with all these data? We think that they are a good prompt to start talking about important questions, such as the static survival rates in bladder cancer, and the disparity between men and women in outcomes. They can inform campaigns such as Be Clear on Cancer, and measure how effective they are. In a wider context, these data inform service planning and commissioning, such as funding for urology specialist nurses. Knowing the number of people affected by bladder cancer puts May’s Bladder Cancer Awareness Month into perspective, and it might be a surprise to many people how common this cancer is, especially in women.

**CONCLUSION**

This is the first publication of bladder cancer statistics from the four nations of the UK indicating that over 20,000 people are diagnosed with bladder cancer in the UK each year. We hope that this statistic is used by everyone passionate about bladder cancer to demonstrate that urgent action is required to address unmet needs for this group.

---

**Data sources**

You can access the NHS England paper at https://journals.sagepub.com/doi/full/10.1177/2051458616674103

The data on cancer incidence and mortality are available at the NCRAS CancerData website: https://www.cancernedata.nhs.uk/incidence and https://www.cancernedata.nhs.uk/mortality

A paper on the number of cancers caused by external risk factors can be accessed here: https://www.nature.com/articles/s41416-018-0029-6

Cancer survival data are published by the Office for National Statistics: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/cancersurvivalengland/nationalestimatesforpatientsfollowedupto2017

---

**I went to the doctor and said “I’ve got problems with wanting to go to the toilet all the time” and they said “Well, you’ve probably got a bladder infection. We’ll give you antibiotics.” Two weeks later I go back and get different antibiotics and this went on five or six times and I knew there was something wrong.**

Barbara

---

**I’d never heard of bladder cancer before I was diagnosed. It wasn’t until I was having the flexi-scope done and the doc said: “You’ve got bladder cancer.”**

Clive