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.

Poor awareness about bladder cancer is a major barrier to early diagnosis, especially for those whose initial symptoms do not fit the typical profile. This affects long-term outcomes for patients and their families. However, if we understand more about the different symptoms that can present and the categories of diagnosis, we should improve treatment for ourselves and people we care about.

People affected by bladder cancer in our network have shared their own experience of diagnosis and why they think raising awareness is so important.

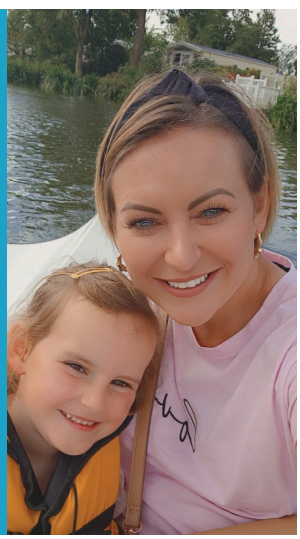
How many people are diagnosed with bladder cancer each year?

When a diagnosis of bladder cancer is recorded in a hospital, different codes are used in the computer system, depending on the type of bladder cancer. These codes are based on the Statistical Classification of Diseases and Related Health Problems, 10th revision (ICD-10).

There are three relevant codes: C67, D09.0 and D41.4.

'At the age of 25, I became pregnant with my first child. Everything went smoothly up until I started having symptoms of urinary tract infections. I visited my GP, but even after several courses of antibiotics my symptoms still persisted. I discussed my growing concerns with her, who told me "Don't worry, some pregnant woman are just unlucky; you're too young for bladder cancer".'

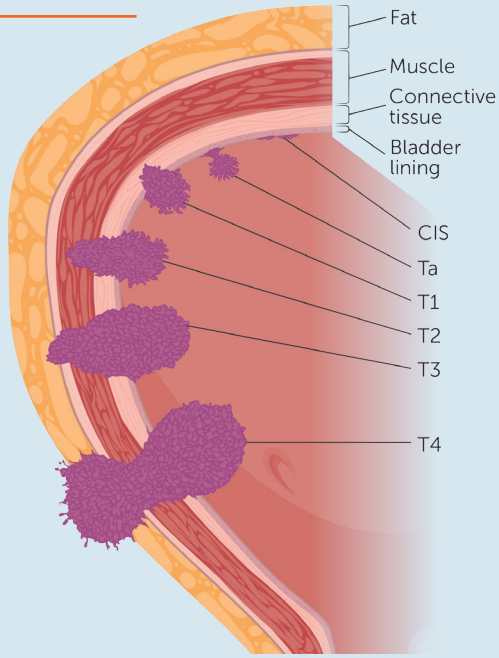
Danielle



INTERVIEW
DR LYDIA MAKAROFF
FBC CEO

AMY RANDALL
FBC Research Lead

DR ROBERT PHILLIPS
FBC Medical Advisor



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 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.

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.

Nation	Men	Women	Total
England	13,500*	4,500*	18,000*
Scotland	1,233	458	1,691
Wales	512	157	669
N Ireland	158	68	226
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.

	Total number of bladder cancer cases	Population (millions)	Crude incidence per million population
England	17,921	56	320
Scotland	1,691	5.2	310
Wales	669	3.2	209
Northern Ireland	669	1.8	125

'I'd never heard of bladder cancer before I was diagnosed. It wasn't until I was having the flexi cystoscopy done and the doc said: "You've got bladder cancer." '

Clive

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

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	9,855	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 statistics for the rest of the UK are 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 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.

'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 and 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/10.1177/2051415816674103

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/s41416-018-0029-6

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