COVID-19 and Bladder Cancer

ABC UK second COVID-19 patient survey 2021
Key results
ABC UK COVID-19 Patient Survey 2

The COVID-19 pandemic had a serious impact on the NHS - and on the diagnosis, treatment and well-being of those with cancer.

ABC UK wanted to gauge this impact on those who had been diagnosed with bladder cancer or were undergoing treatment during the pandemic.

• The first survey ran towards the start of the pandemic - 27th April to June 8th 2020.
• This second survey was conducted by ABC UK to look at the continuing impact the COVID-19 pandemic was having on bladder cancer patients.
• The 2nd Survey ran from 26th January until 30th May 2021.
ABC UK COVID-19 Patient Survey 2

• Survey 2 ran from 26\textsuperscript{th} January until 30\textsuperscript{th} May 2021.
• 134 people consented to take part in the survey, 96 of which completed the questions.
• For this report we have only counted those people who answered the questions.
• 23\% of respondents said they had also completed our first survey in 2020.
The COVID-19 situation during Survey 1 and Survey 2

This diagram shows the number of confirmed COVID-19 cases recorded in the UK while the two ABC UK surveys were open. Testing became more widely available throughout this period.

Source: coronavirus.data.gov.uk/details/cases
What UK Country do you live in?

- The majority of the respondents lived in England (90%)
The age of the respondents

- Almost 70% of respondents were over the age of 60.
- Almost 10% were aged 30-49.
- 37% respondents were aged 60-69.
The gender of respondents

While the majority of respondents were male (57%) a larger percentage of female respondents answered the survey this time (43%) than the previous year in survey 1 (28%).

In the UK population approximately 75% of bladder cancer patients are male.
A comparison between survey 1 and survey 2 employment status.

The majority of respondents in the second survey were retired (65%) which is to be expected given the age profile of respondents.

The employment status of the two surveys is very similar, with slightly more people currently working in the second survey.
In which year were you diagnosed?
What type of bladder cancer do you have?

- The most common type of bladder cancer was High Risk NMIBC.
- All types of NMIBC accounted for 75% of respondents bladder cancer diagnosis.
Currently undergoing treatment?

- The majority (61 of 95) of respondents were no longer having active treatment but were continuing to be monitored.
- 28 people were currently undergoing active treatment.
What treatment are you having?

I have recently been diagnosed and I am waiting to start treatment

First TURBT

A course or courses of mitomycin into the bladder

A course or courses of BCG into the bladder

Chemotherapy before bladder removal

Bladder removal planned

Bladder removal completed

Chemotherapy before or at the same time as radiotherapy

Radiotherapy
If you had treatment scheduled for 2020 did it happen when expected?

The majority of patients reported their treatment was delivered when expected (39/58)
Did your monitoring happen as planned?

The majority of those respondents currently being monitored reported that their appointment was when expected (57/83).

In comparison to the first COVID-19 and bladder cancer survey, patients were reporting much less disruption to their treatment and monitoring than they had almost a year earlier.
How concerned do you feel about COVID-19?

The vast majority of respondents felt at least some concern about COVID-19, with just over 3% not at all concerned.
How concerned do you feel about COVID-19 affecting your bladder cancer treatment and monitoring?

Overall, people were less anxious about COVID-19 affecting their bladder cancer treatment and monitoring than they were about COVID-19 more generally.
How hospitals have adapted?

- I had to wear a mask
- The staff are using PPE (masks, gloves, visors etc.)
- There is hand sanitation available on arrival
- I am not allowed to bring anyone with me to the appointment
- I had a COVID-19 test prior to being admitted to hospital
- I had my temperature checked on arrival
- I (and my household) had to self isolate before treatment
- They have introduced telephone consultations
- I was asked to wait outside until I was called to enter the...
- I haven't had any contact with my hospital recently
- Other
- They have introduced video consultations
- I'm not sure
Thinking about the changes your hospital has made as a result of COVID-19...

• What changes have been the most positive?
  • Three people mentioned telephone calls as being an efficient way of communicating.
  • Seven people said all of the changes were positive.
  • Six people mentioned efficient appointments and less waiting time.
  • 4 people mentioned the use of different hospitals/buildings.

• What changes have been the most negative?
  • 14 people made comments about not being able to have people with them.
  • Two people mentioned having appointments changed or cancelled.
Quotes: The impact of attending hospital alone

“Admission for radical life saving surgery with no provision for visiting felt inhumane. I had a private single room and my partner had isolated for 14 days with me presurgery. There was a couch bed in my room - provision could have been made for my partner to stay with me.”

“Receiving the news that I have cancer on my own and trying to concentrate on what was being said. Also being admitted for TURBT and chemo on my own.”

“Attending appointments alone. Attending chemotherapy alone. Going for major surgery alone. 10 days in hospital alone with no visitors.”

“Not being able to bring anybody with you to consultations as I suffer from MCI (mild cognitive impairment)”

“Not being able to take support to hospital if you need it. The masks made it hard for me to understand what was being said.”
How supported have people felt during the pandemic?

The majority of respondents felt as supported as before the pandemic, however 22 people felt less supported. Respondents could tick more than one answer. Some people commented that, as they were diagnosed during the pandemic, they had never known what it was like before.
What does this survey tell us?

• By the time of the second survey the majority of people were reporting that their treatment was being delivered on time, when compared with data from the first survey. This suggested that the situation regarding treatment and monitoring had improved from 2020.

• The percentage of people who did not feel anxious about COVID-19 affecting their bladder cancer treatment and monitoring hadn’t changed from survey 1 to survey 2.

• When looking at the changes made by hospitals, not being able to have someone with you for hospital appointments and procedures was clearly something that a lot of people found extremely difficult. Some of the changes made in response to COVID-19 were seen as positive.

• When looking at how supported people were, there is clearly a need to better understand the long-term impact of the pandemic on bladder cancer patients and how charities can help those who have felt less supported during this time.
Any Questions?

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