



**Action**  
Bladder Cancer UK

Results from the  
ABC UK Covid-19  
Bladder Cancer  
Patient Survey

June 2020



Action Bladder Cancer UK (ABC UK) conducted this survey to find out how the current Covid-19 pandemic is affecting the treatment, monitoring and well-being of people with bladder cancer. The survey was developed and reviewed by the ABC UK team working with bladder cancer patients and clinicians.

We hope to use the results of the survey to better understand the impact for people with bladder cancer and what the longer-term implications may be. It will also prove valuable in helping ABC UK ensure it provides the right support and information for patients and inform how we can best support the NHS, and other organisations, to provide safe services for people with bladder cancer. We are very grateful to the 142 people who took the time to complete this survey.

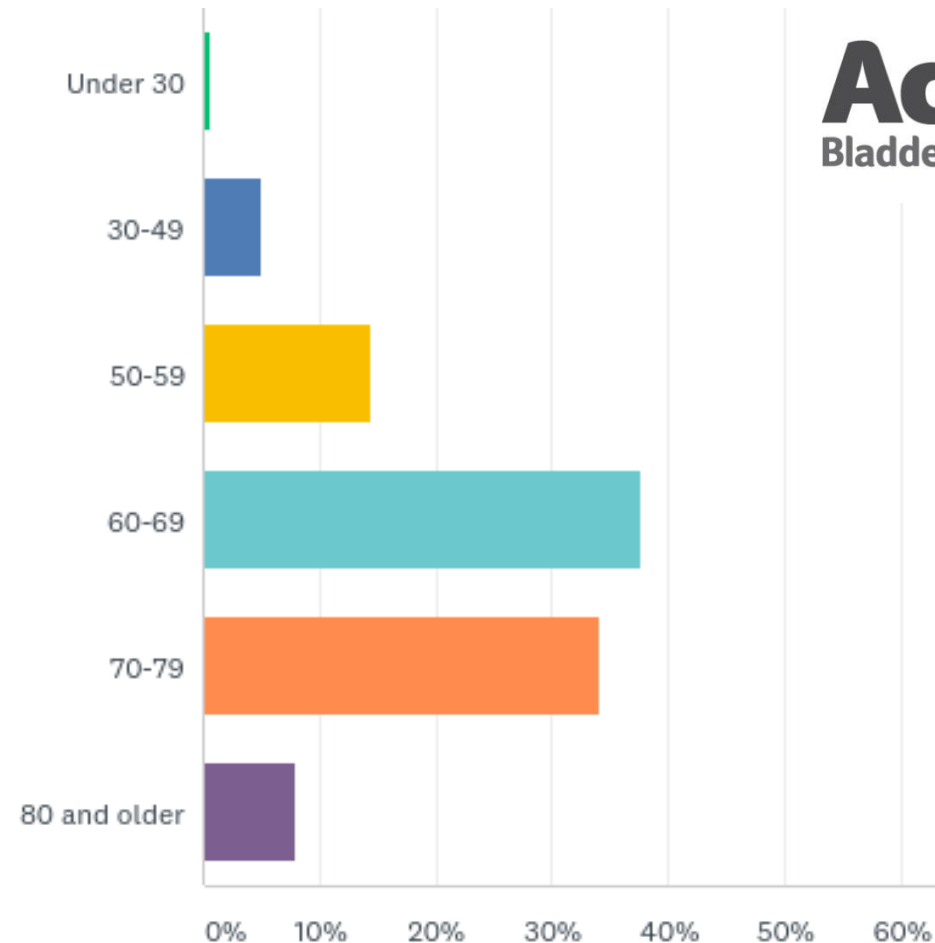
# Headlines



- The survey ran from 27<sup>th</sup> April 2020 Until 8<sup>th</sup> June 2020.
- There were 142 responses
- Just under half the respondents (47%) reported that their treatment or monitoring had been stopped, cut short or delayed.
- 47% of respondents had been advised to shield.
- A further 41% of respondents thought they should have been placed in the shielding group.
- 72% of respondents felt a little anxious or very anxious about Covid-19 affecting their bladder cancer treatment.

# What is your age?

72 % of respondents (99 of 138) were aged between 60 and 79. While 20% of respondents (28 of 138) were under 60 years of age. Almost 6 in 10 (56%) of people who get bladder cancer in the UK are aged 75 years and over\*

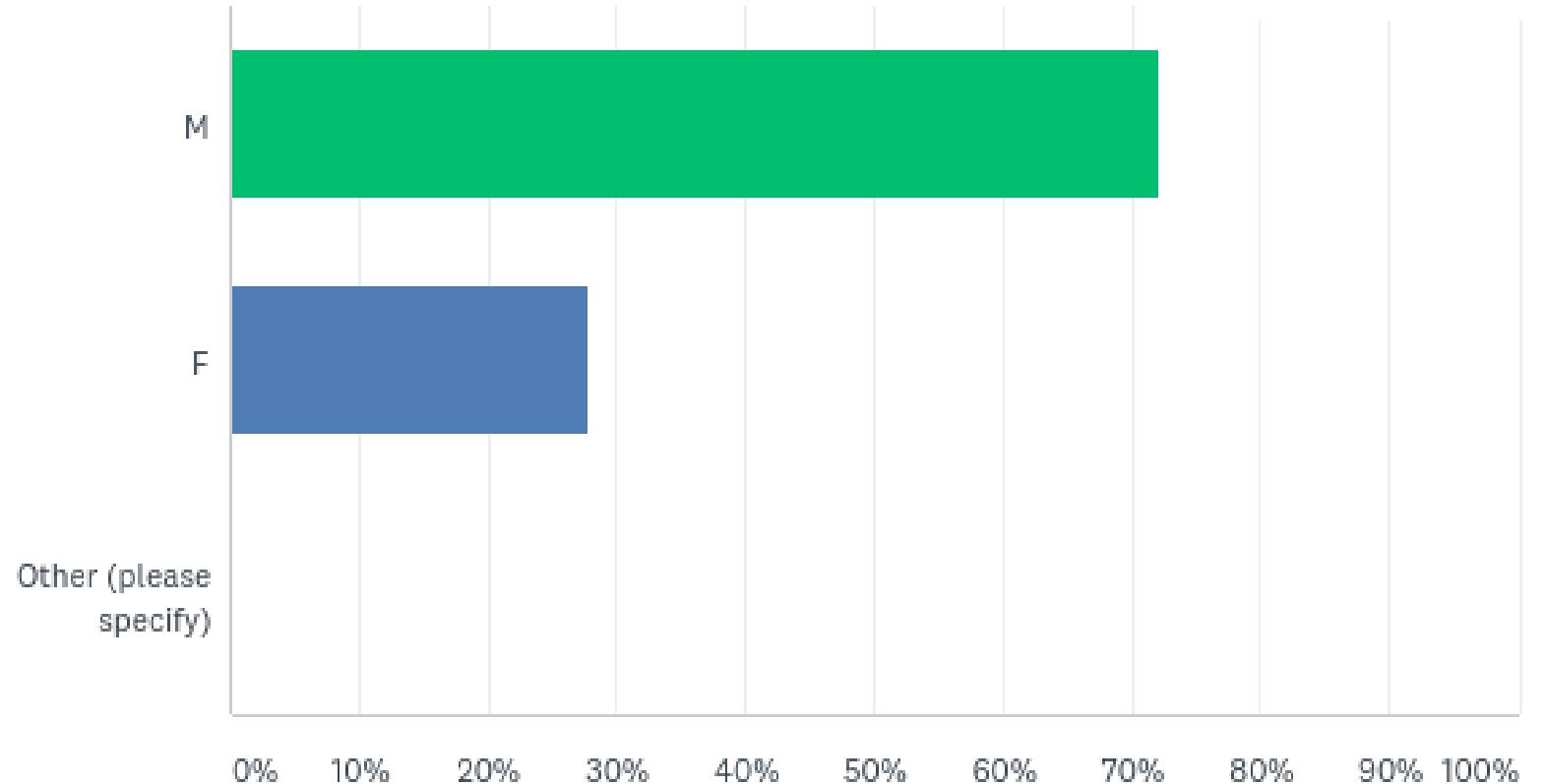


\* Ref: Cancer Research UK

<https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/bladder-cancer#heading-Zero>

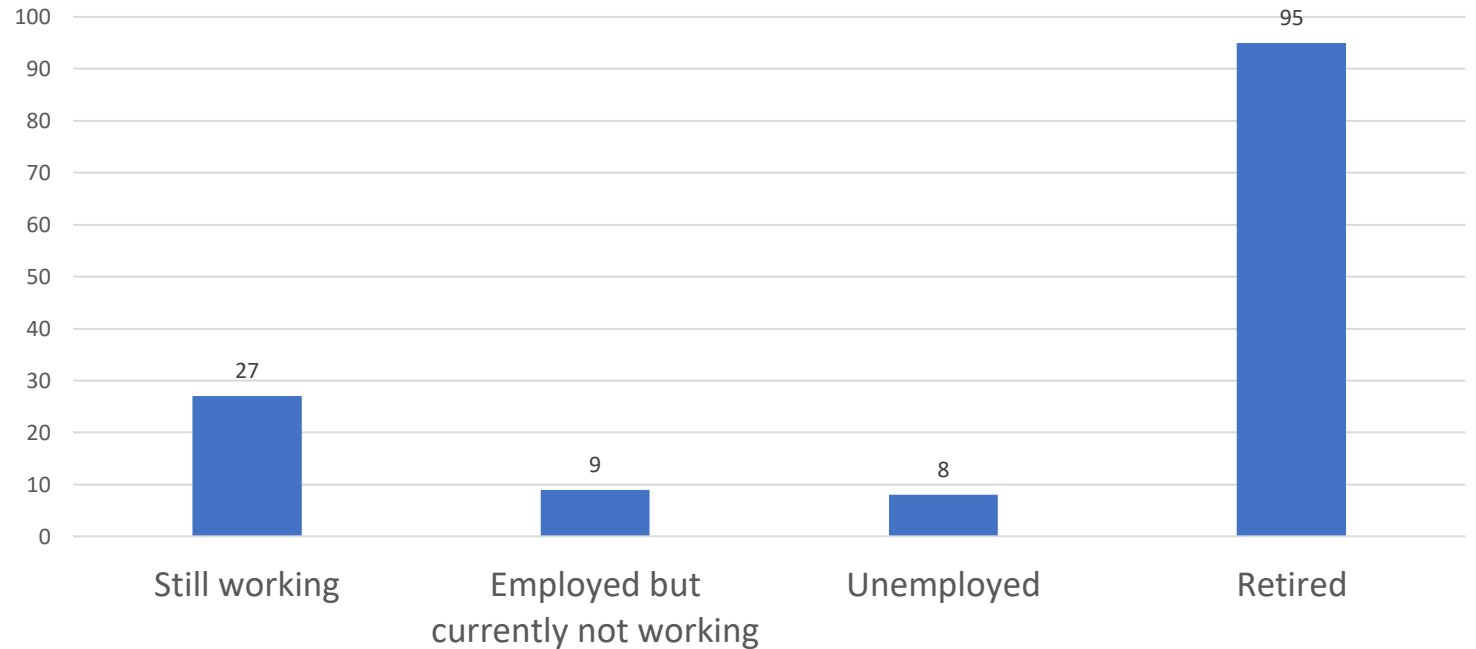
# Gender

72% of respondents were male (101 of 140) and 28% were female (39 of 140). This reflects the gender distribution of bladder cancer nationally.



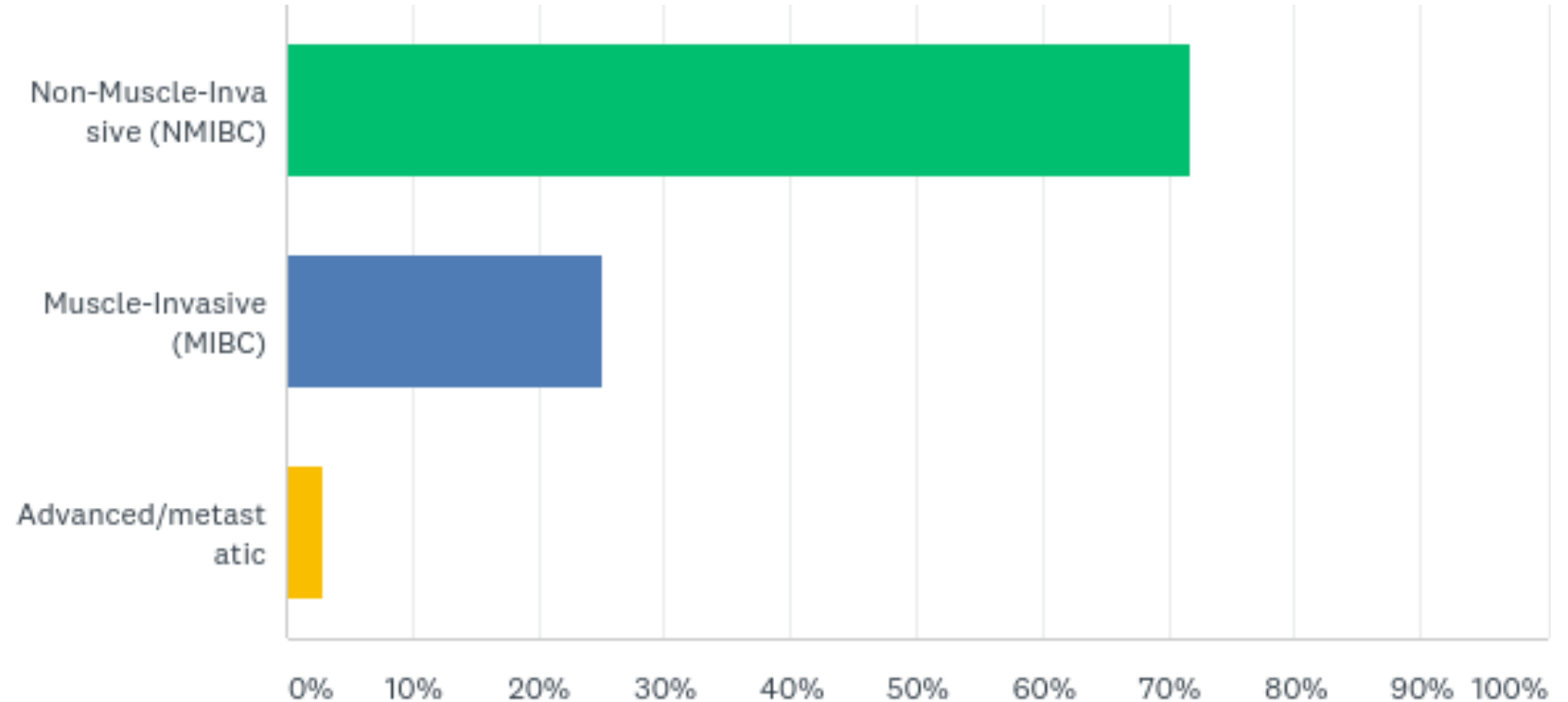
# Are you in work or retired?

The majority of respondents were retired (95 of 139).



# What type of bladder cancer do you have?

The majority of respondents had non muscle invasive bladder cancer (97 of 135). This is reflective of the distribution of types of bladder cancer nationally.



# Have your planned treatment and monitoring arrangements been altered due to Covid-19?



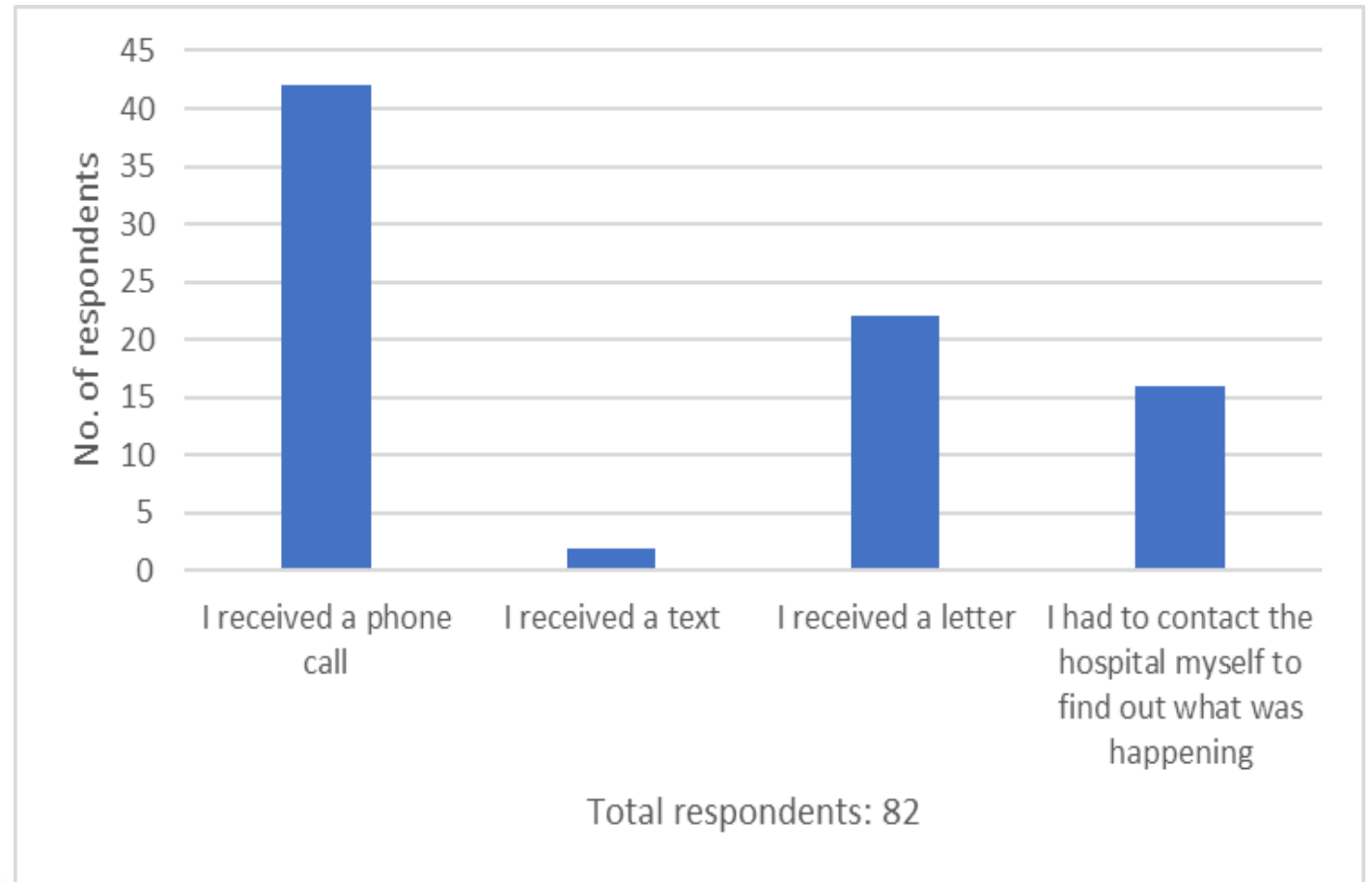
47% of respondents (65 out of 139) reported that their treatment or monitoring had been postponed, delayed or cut short, while 48 people (35%) reported that their treatment or appointments were continuing as normal.

ANSWER CHOICES	RESPONSES	
YES, the start has been postponed	7.91%	11
YES, the treatment schedule has been stopped or cut short	6.47%	9
YES, my (next) treatment has been delayed	9.35%	13
YES, my next cystoscopy has been postponed	15.83%	22
YES, my (next) scan has been postponed	2.16%	3
YES, my next consultant appointment has been postponed	2.16%	3
YES, my treatment has been changed	2.88%	4
NO, my treatment is continuing as normal	14.39%	20
NO, my outpatient appointment(s) haven't been changed	20.14%	28
Other (please specify)	18.71%	26
<b>TOTAL</b>		<b>139</b>



# If there have been changes – how did the hospital notify you?

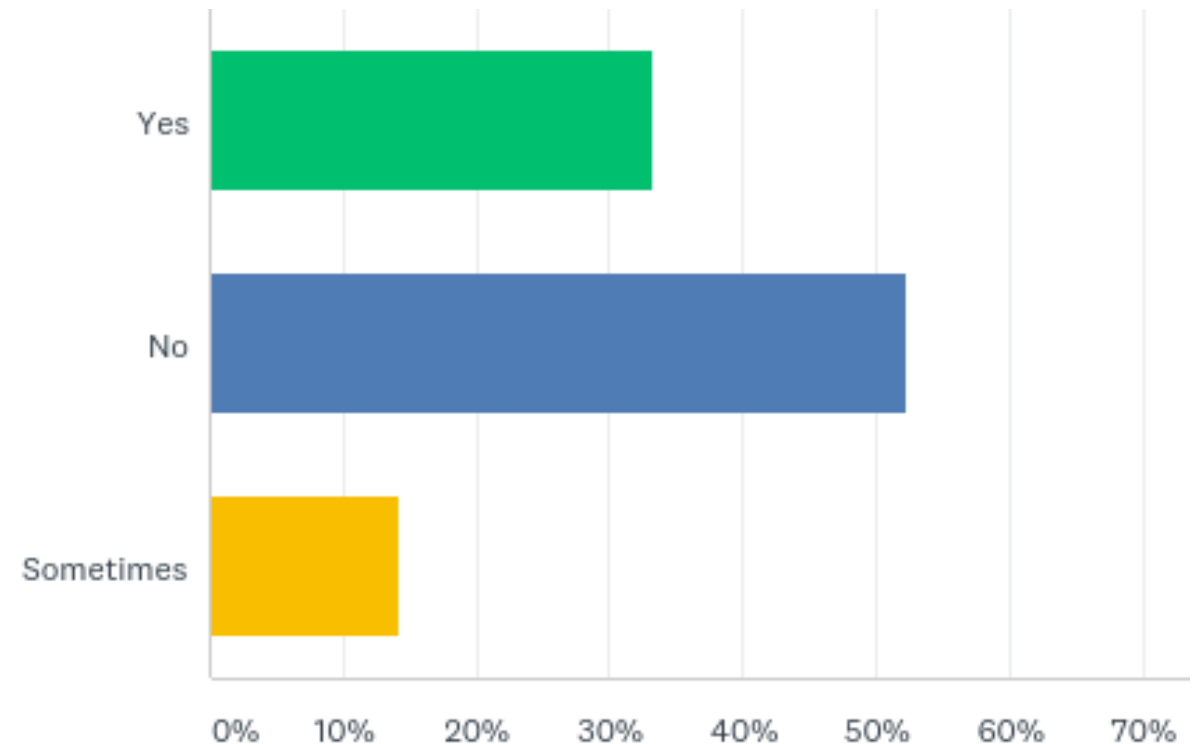
Most people were notified of changes to their appointments by phone call. 16 out of 82 (20%) had to contact the hospital themselves to find out what was happening.



# Do you feel Covid-19 has made it more difficult to communicate with your hospital team?

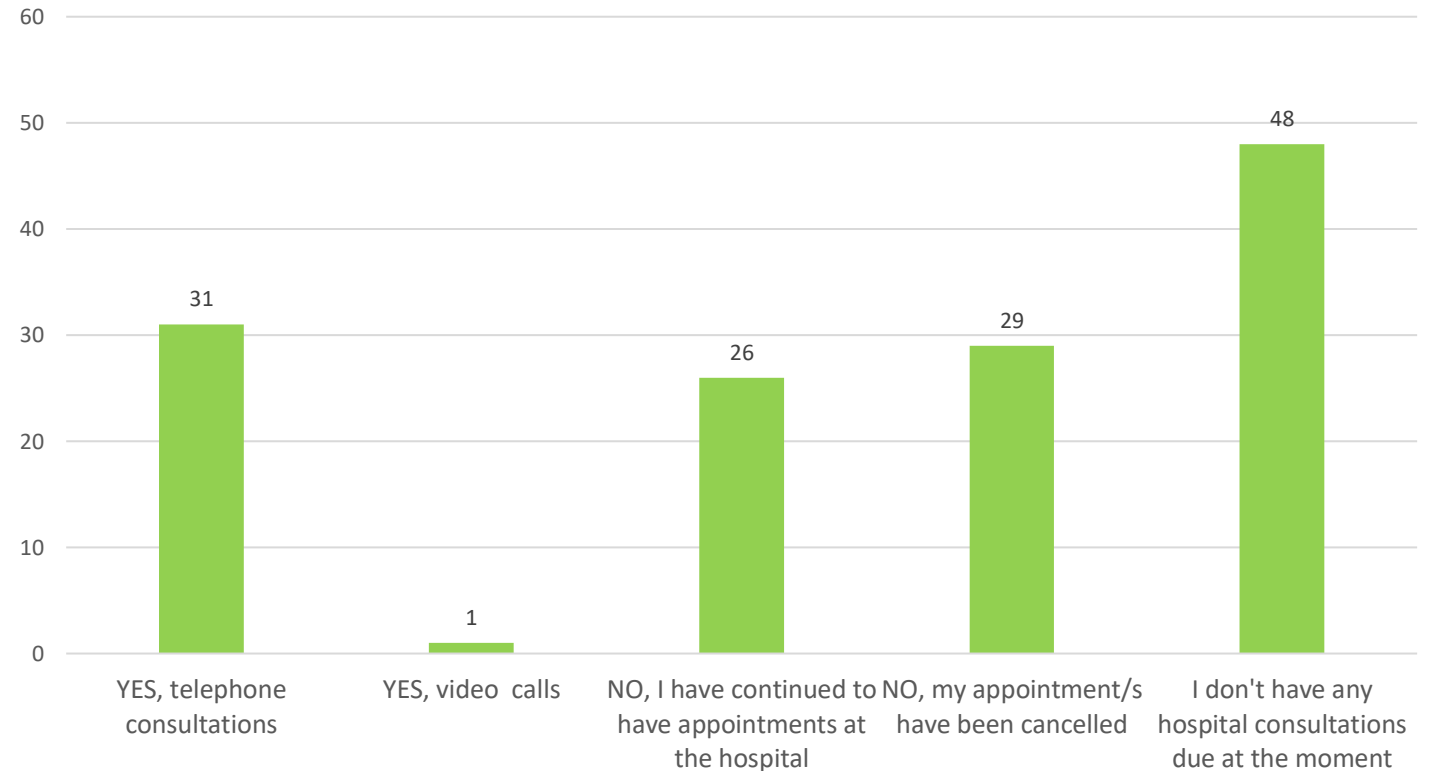


60 out of 126 answered yes or sometimes, while a similar number answered no (66 of 126).



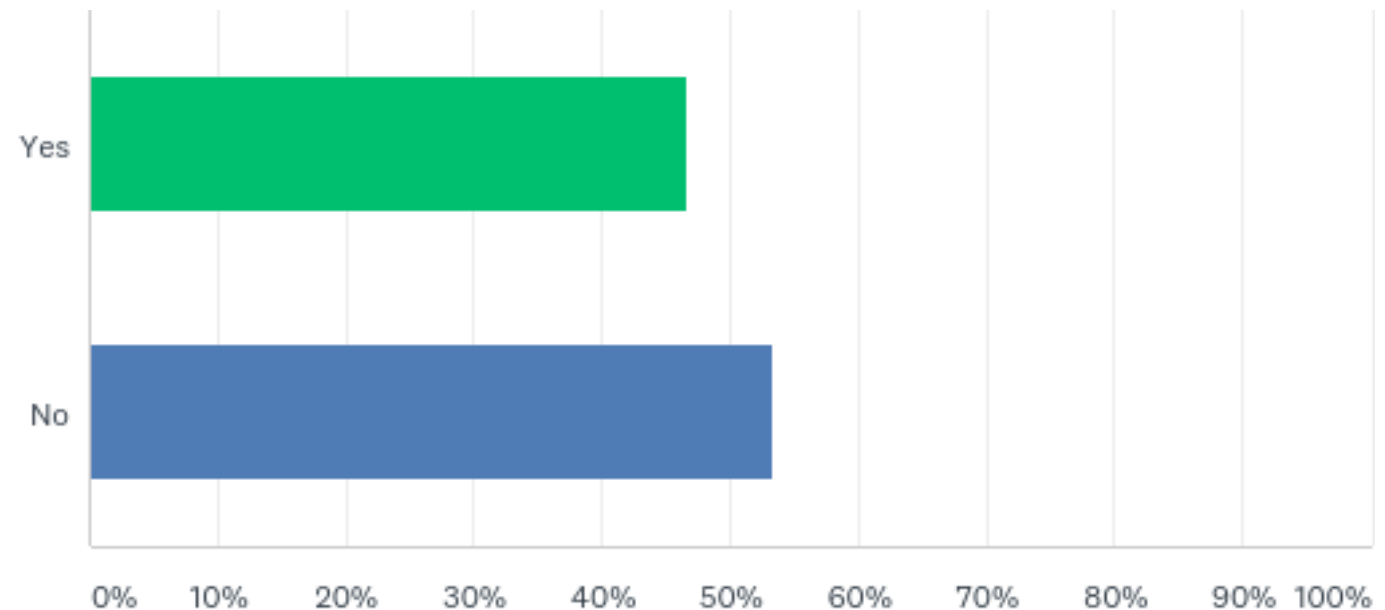
# Have you been offered alternative methods to attending hospital appointments?

31 out of 135 respondents (23%) had been offered a telephone consultation instead of attending hospital.



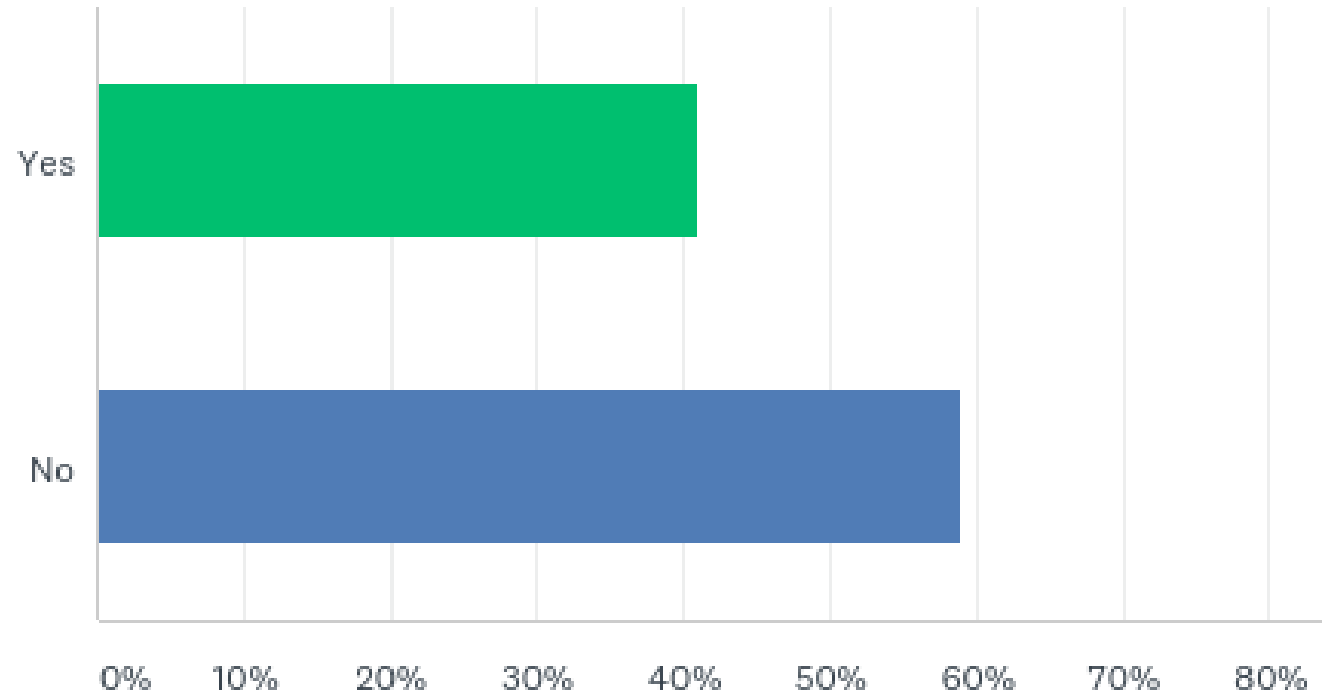
# Have you been advised to shield?

64 out of 137 respondents (47%) had been advised to shield



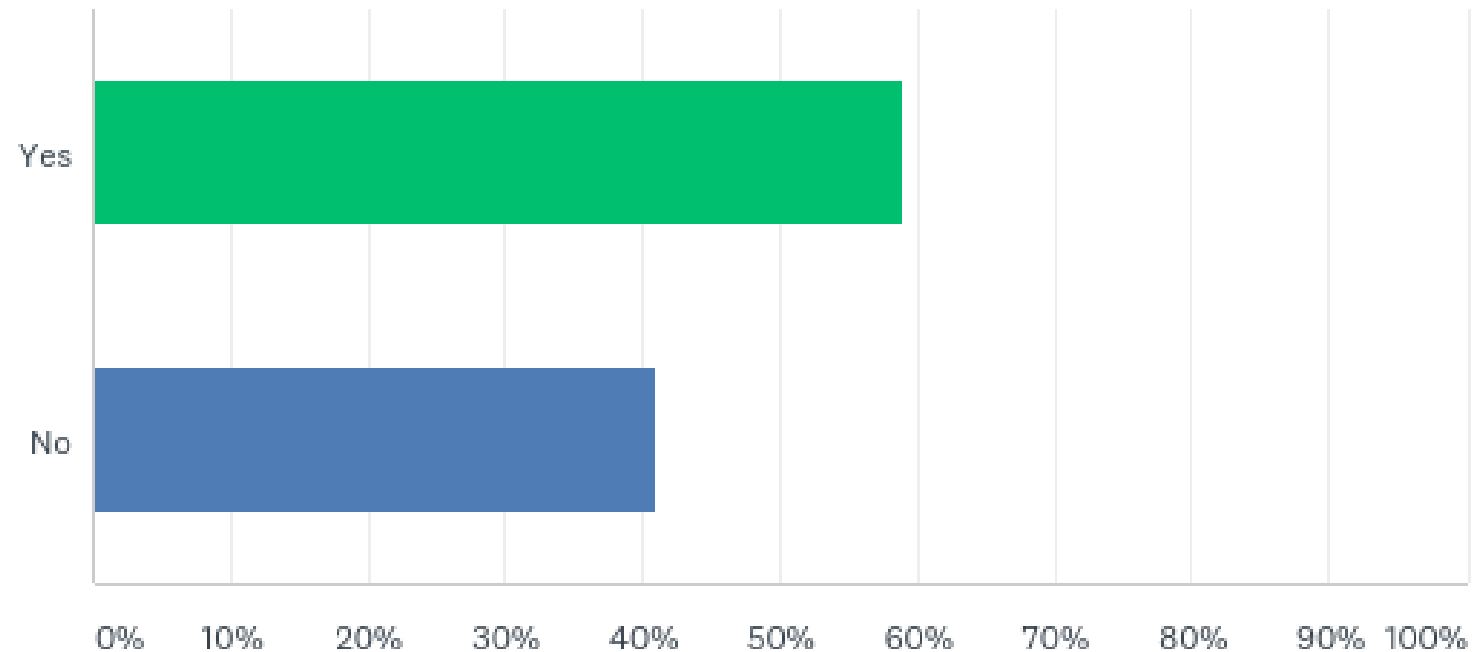
# If you weren't placed in the shielding group do you feel that you should have been?

Of those people who weren't placed in the shielding group 39 (41%) out of 95 respondents felt they should have been placed in the shielding group.



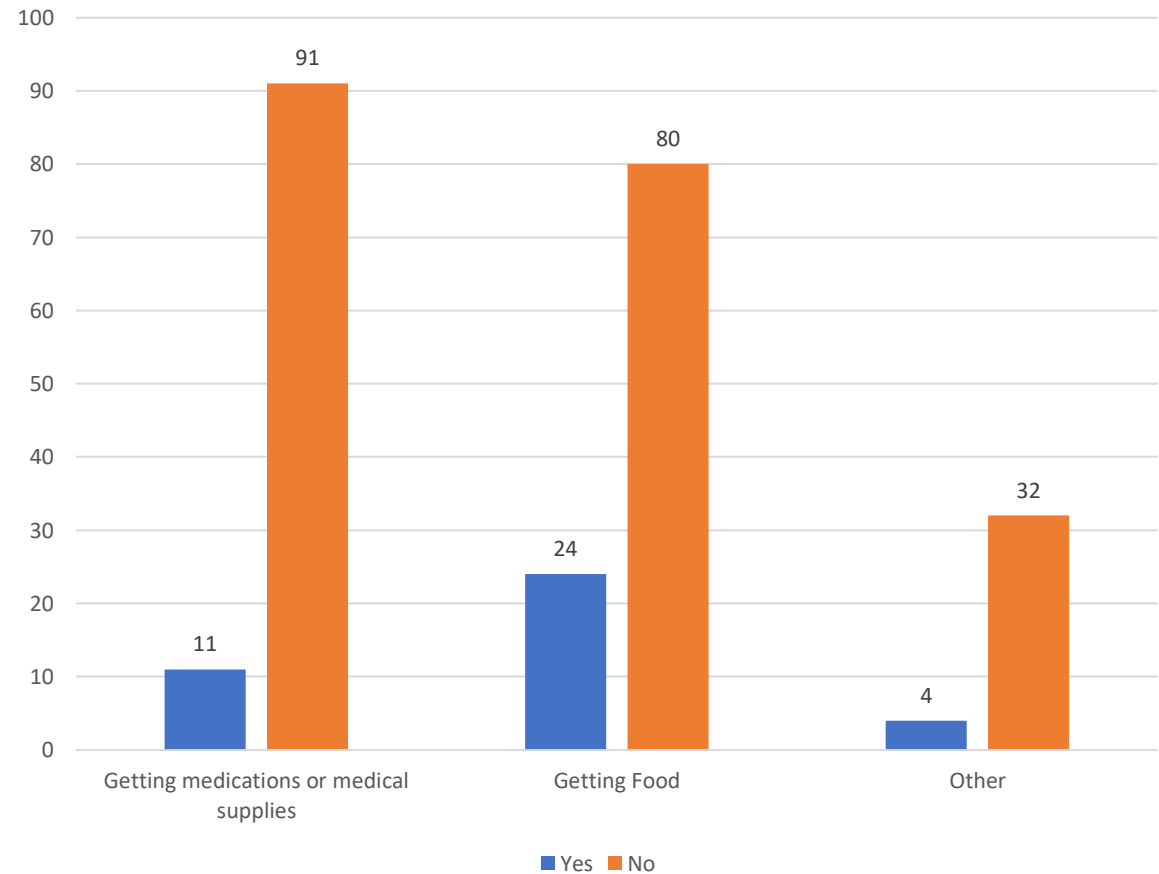
# Have you decided to self isolate yourself without being directly advised to?

69 out of 117  
respondents (59%)  
had chosen to self  
isolate without  
being advised to by  
the NHS.



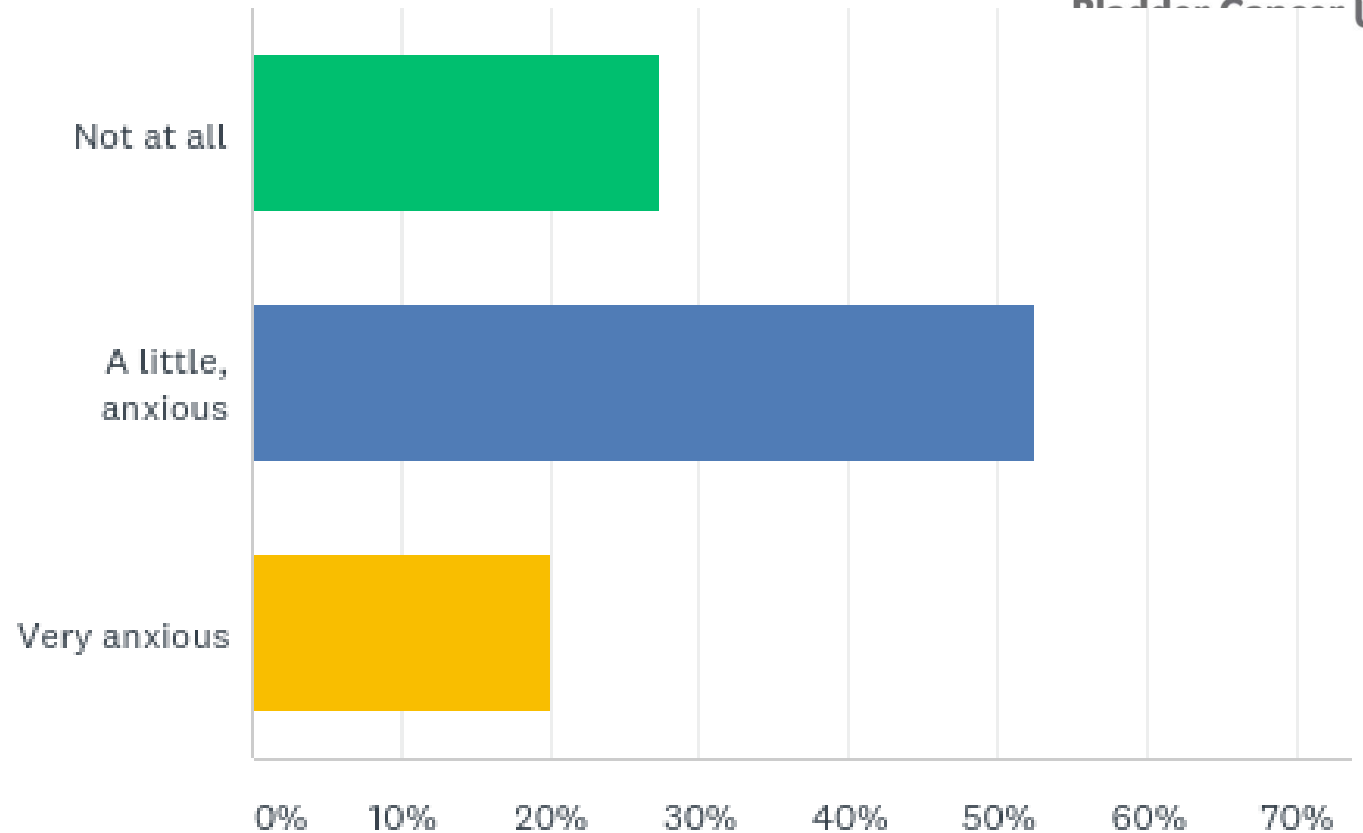
# Have you experienced any difficulty in accessing essential support whilst shielding or self isolating?

Of the 118 people who answered this question, 24 had had difficulty getting food and 11 had had difficulty getting medication or medical supplies.



# How worried do you feel about Covid-19 affecting your bladder cancer treatment or monitoring?

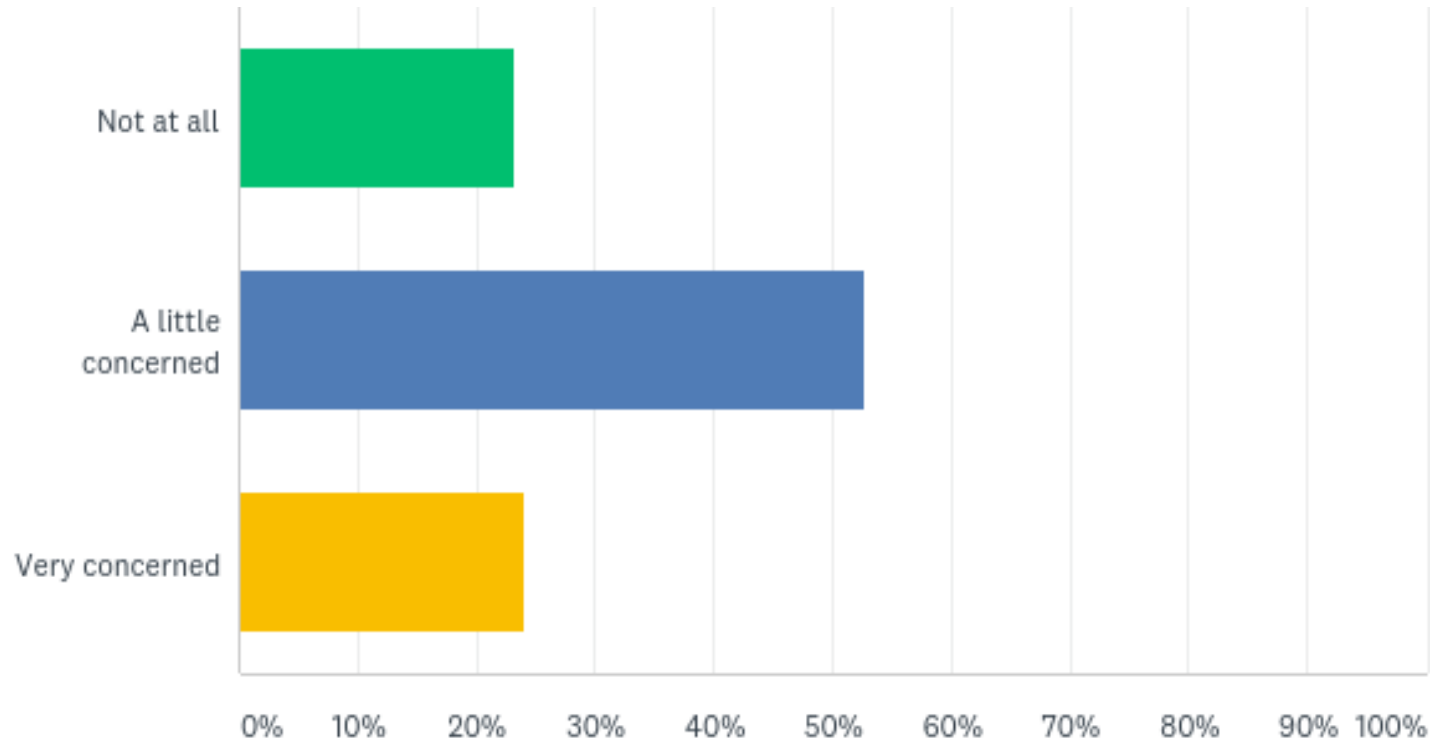
101 out of 139 respondents (73%) felt either a little anxious or very anxious about the current pandemic affecting their treatment for bladder cancer. While 38 respondents (27%) didn't feel at all anxious.



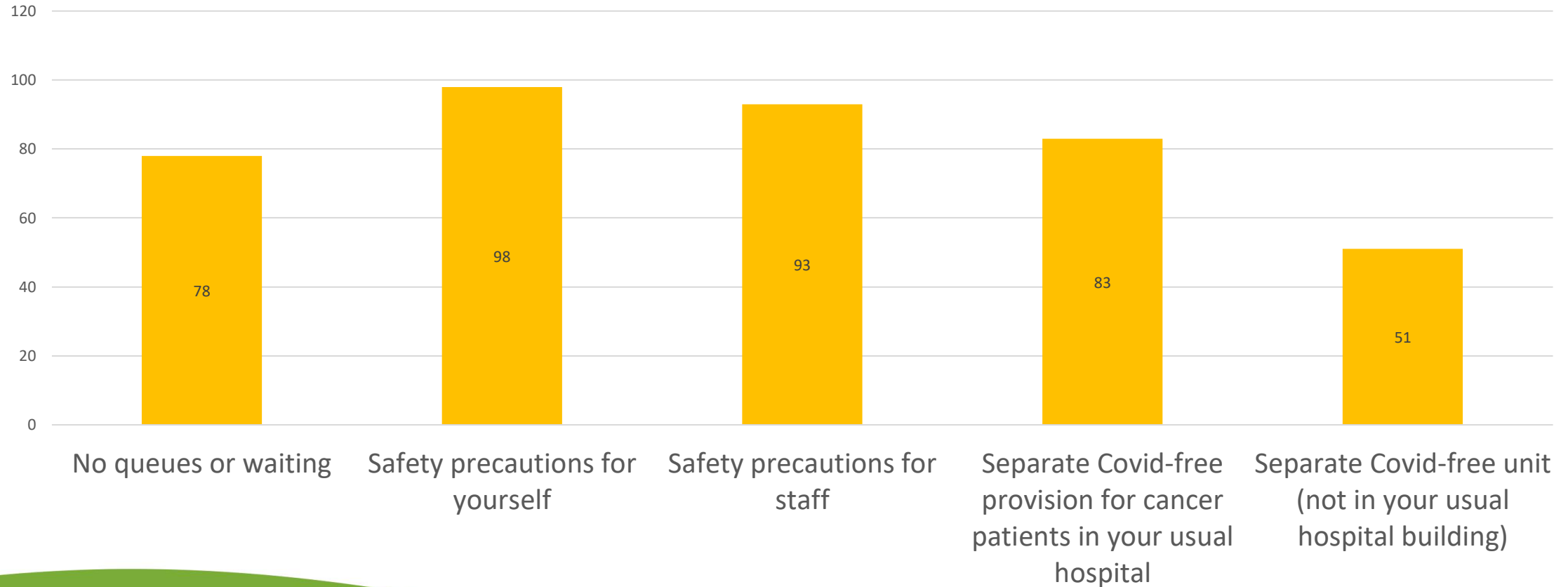


# How concerned are you about attending hospital currently for treatment and follow up appointments?

The majority of people (106 of 138) (77%) feel a little concerned or very concerned about attending hospital for appointments at the moment.



# What might help you feel safe when you do return to hospital for treatment?



Total Respondents: 133

# Next Steps



- ABC UK will share the results publicly.
- ABC UK will seek to influence and support NHS decision and policy makers and other key partners who can use the results to inform services for bladder cancer patients.
- ABC UK will look at the results in more detail for other factors – eg geographical variation.
- ABC UK will use the results to help us in our short and long term planning of support services for people with bladder cancer and their family and friends.
- ABC UK will look for suitable opportunities to share the results of the survey, where it can make the most impact.
- We shall be undertaking other surveys in the future.

Thank you for taking the time to look through our survey results. If you have any questions or comments we'd love to hear from you. Contact us to sign up for our newsletters, further information about the survey or any of our other work.

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