

Dear Friend

Many thanks for participating in our short survey to find out about the effect COVID-19 has had and is still having on men with prostate cancer. We very much appreciate your help and support.

### Question 1 Appointments at your GP Practice

Did your appointment(s) at your GP practice e.g. for PSA tests, hormone injections go ahead as planned? Please let us know of good experiences or indeed any challenges that you had?

If your appointment(s) were not face to face how successful/helpful do you think the telephone or video consultation was?

- Extremely helpful   
Very helpful   
Somewhat helpful   
Not so helpful   
Not at all helpful

Is there anything else that you would like to share about your experience at the GP practice?

### Question 2 Getting prescriptions

Did you have any concerns or problems when ordering or getting your prescriptions?

Yes  No  Not applicable

If yes, would you like to say what those problems/concerns were?

### Question 3 Newly diagnosed with prostate cancer

If you perhaps received a diagnosis of prostate cancer just before or during lockdown, can you say **if** or **how** you think the COVID-19 pandemic has potentially impacted on you and how you feel going forward?

Did the Covid -19 situation affect the appointments you had? Yes  No  Not applicable

Appointments were: Face to Face  By telephone  By video

Do you think that because of the impact of the COVID-19 pandemic, this could have influenced the number and type of tests/investigations that you had? Yes  No  Not applicable

Do you think that because of the impact of the COVID pandemic, this could have any influence on the number and type of future tests/investigations? Yes  No  Not applicable

Were you concerned about the length of time to get test results back? Yes  No  N/A

Did you have the support you felt you needed when making decisions about treatment? Yes  No   
Not applicable

Is there anything you would like to add?

#### Question 4 My treatment

If you perhaps have had treatment with curative intent, that is with the aim of curing the cancer, (eg surgery, radiotherapy or brachytherapy) previously, just before or during lockdown, can you say **if** or **how** you feel the COVID-19 pandemic has potentially impacted on you and your treatment now/ in the future and how you feel going forward.

My treatment:

- Has continued as expected
- Has continued as expected, but in a different venue
- Has been delayed, postponed or rescheduled
- Has been altered
- I have received a 'holding' treatment

Is there anything you would like to add?

If it was necessary due to the COVID 19 pandemic to delay, cancel, postpone or re-schedule or alter your treatment or planned treatment e.g. surgery, radiotherapy or brachytherapy - do you have any perspectives/comments about this that you would like to share?

What sort of impact, if any, has it had on you?

(e.g. did the pandemic make you feel more anxious or needing more information/ support)

#### Question 5 Chemotherapy

If you were already having chemotherapy or due to start chemotherapy for your prostate cancer, did this change?

Yes  No

If yes, would you mind sharing what changes took place, were you offered an alternative treatment, or perhaps your oncologist discussed a different treatment pathway with you?

## Question 6 Shielding

If you are currently 'shielding', have the following measures that have been put in place been helpful?

- Information on shielding Yes  No  SMS text shielding service Yes  No
- Letters about shielding Yes  No  Haven't seen/received these
- Guidance about shielding Yes  No  Haven't seen/received this
- Weekly grocery boxes Yes  No  Haven't used this service
- Priority supermarket delivery slots Yes  No  Haven't used this service
- Ordering and having medicines delivered to your door Yes  No  Haven't used this service
- For personal reasons, I decided not to shield

Please share your thoughts on shielding and how this possibly had an impact on your life using the following scale

- No impact at all
- A little impact
- A moderate impact
- A lot of impact
- A great deal of impact

If you found shielding hard going, what additional type of help do you think might have eased any worries or anxieties?

It is likely that the next set of shielding guidance for Scotland may include further information giving people updated clinical evidence about their particular condition(s) and what that means for their risk from COVID-19.

Would such additional information and advice would be helpful/useful for you? Yes  No

Can you say a few words to let us know why or why not?

It is likely that the next set of shielding guidance for Scotland may include information about the infection rate in your local area and how to reduce the chance of catching the virus.

### Do you think?

- This is likely to reassure me and give me more confidence to venture out
- This is likely to make me more nervous/apprehensive about venturing out
- I'm not sure yet how this would be helpful or useful or affect me until I see the guidance

As shielding is now gradually being relaxed or when shielding potentially comes to an end, what other information or support do you think you might need around this time and where would you go for this information or support?

### Question 7 Living with prostate cancer in the time of COVID-19

With COVID-19, there is a good deal of uncertainty around for everyone at the moment. As a man living prostate cancer, would you please share with us if COVID-19 has perhaps made you more anxious or worried by using the following scale

- I am not more anxious at all
- I am a little more anxious
- I am a moderate amount more anxious
- I am a lot more anxious
- I am a great deal more anxious

Would you mind sharing why you have chosen this answer?

Would you please share any thoughts you have on practical support or help that could be offered to men who are perhaps feeling more anxious at this time?

### Question 8 Prostate Scotland

As Prostate Scotland is keen to be as helpful and supportive as possible, what thoughts do you have on how we could potentially build on the information, support and help that we currently offer?

If you read the 'Info Guidance pages' on our website how helpful did you find these?

- Extremely helpful
- Very helpful
- Somewhat helpful
- Not so helpful
- Not at all helpful

Using the following scale, how likely would you be to read these again as they are updated?

- Definitely would
- Probably would
- Probably would not
- Definitely would not

Using the following scale, how likely would you be to recommend these pages to someone?

- Definitely would
- Probably would
- Probably would not
- Definitely would not

In your opinion, was there anything missing that we didn't cover, and you would have liked information on?



**Is there anything else you would like to share with us about your experience of COVID-19 while living with prostate cancer:**

This information will be treated with the utmost confidentiality and utilised for survey and analysis purposes and information given will be anonymised. Any quotations used, if you have given us permission to potentially use quotes, will be anonymised. Your personal details will not be passed to any third party. You do not have to give the details below, but if you do, they will help our analysis. These will be kept confidential.

**We should be grateful if you could let us know the following (which are all optional):**

- Name:** ..... optional
- Email:**..... optional
- Age** ..... optional
- City or Area that you stay in** ..... optional
- I have early prostate cancer**  **I have advanced prostate cancer**  optional
- Treatment type** ..... optional
- I am a family member of a person with prostate cancer**  optional
- I would like to receive further information from Prostate Scotland**  optional

I consent to quotes being used from my response to the survey and understand they will be anonymised

Yes  No

I consent to Prostate Scotland processing this information and understand that it will be used for statistical and analytical purposes Yes

Signature ..... Date.....

Many thanks for your time, trouble and patience in participating in this short survey. The information you have so kindly provided will be invaluable to Prostate Scotland in helping us to understand the needs of and build on the support for men with prostate cancer, especially at this difficult time, but also in the future.

**Please reply by Sunday 26<sup>th</sup> July 2020**

You can email this to me at [mae.bell@prostatescotland.org.uk](mailto:mae.bell@prostatescotland.org.uk), call me on 0131 603 8663 or send to the office at 14 Torphichen Place, Edinburgh, EH3 8DU.

Take care and stay safe.  
With kindest regards

Mae Bell  
Information and Advice Manager