

ProtecT Study

(Prostate testing for cancer and Treatment)

Newsletter 15: Summer 2018

The ProtecT study 2018 to 2021

Thank you for participating in the ProtecT study of treatments for localised prostate cancer. This newsletter provides information about the next phase of the ProtecT study up to 2021

ProtecT study: influence on UK policy and healthcare

The ProtecT study, funded by the National Institute for Health Research (NIHR), is the largest study of its kind in the world. The information you have provided means that active monitoring, radiotherapy and surgery have now been directly compared for men with PSA-detected localised prostate cancer. These results are being used to improve treatments for men with prostate cancer. We are pleased to let you know that we have been awarded some funding to continue the study until July 2021 when participants will have been in the study between 12 and 20 years.

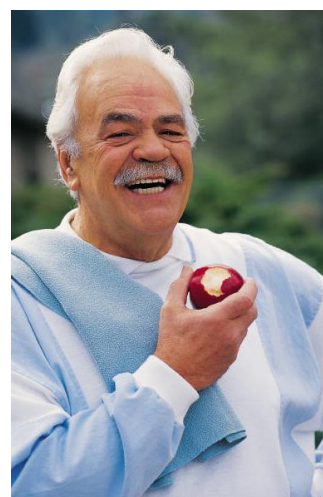
ProtecT study questionnaires

It is very important that we continue to find out how you are. We have shortened the study questionnaire to focus on key symptoms and quality of life issues over the longer term. It is much shorter than before and should take about 10-15 minutes to complete. We will send you a questionnaire each year by post (unless you asked to opt out). The information you provide in the questionnaire is really important for our understanding of the effects of treatments you have had over the longer term.

There is also now an option to complete the short questionnaire on a secure website if you would like to do so (email info-protect@bris.ac.uk giving us your name and email and postal address).



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Your clinical care

The ProtecT study continues and is now in the longer-term follow-up period, and so some things have changed. During 2017, in most centres, your clinical care has been integrated with local NHS services. The ProtecT study research nurses who you used to meet each year have mostly moved into other roles or have retired. During 2017, your care needs were reviewed carefully by your Consultant Urologist and they decided whether you should continue to be seen regularly by the hospital urology or oncology team, or by your GP.

- If you are under the care of the hospital urology or oncology team, you will receive appointments to see specialist staff there at regular intervals and they will advise you about the care you need.
- If you are still following active monitoring, you will usually continue to be under the care of the study consultant urologist at the hospital.
- If you are under the care of your GP, this means that the hospital team believe that your prostate cancer is stable and you do not need specialist care unless things change.

It is very important that you have a PSA test done every year. This is needed whichever treatment you have had to check that things continue to be stable.

Your GP or practice nurse might arrange the PSA test, but it is helpful if you check each year that it has been done. We suggest that on your birthday each year, you check whether you had a PSA test in the previous 12 months - since your last birthday. If so, that is fine. If not, you should ask your GP or practice nurse to arrange for you to have a PSA test.

After you have had the PSA test, the hospital consultant or GP should let you know if you need to discuss the result. You can also ask to know the result and discuss with your doctor any concerns you have. The PSA levels that you need to look out for depend on what treatment you have had. The PSA levels that could require referral to a hospital doctor are:

- 0.2 ng/ml or higher if you had surgery to remove the prostate
- 2.0 ng/ml or higher above the lowest level reached after radiotherapy treatment
- 20.0 ng/ml or higher if you have stayed on active monitoring

If you have any questions or concerns about your prostate cancer care, please contact the consultant urologist at your centre, listed overleaf, who will be happy to help.

Other follow-up information

We will be able to find out some of the things that have happened to you by gaining access to routinely-collected NHS data and your medical records (unless you opted out). If you have been interviewed previously as part of the study you will continue to be contacted by the researcher every few years. Please continue to fill-in the short study questionnaire each year.

Study results and publications

Over 200 scientific papers have been published based on results from ProtecT study or blood samples that you have donated. These papers are helping clinical staff and policy decision makers to make evidence-based decisions about prostate cancer treatments and care.

We have also carried out a consultation with some ProtecT study participants to advise us about how best to present the study results to men who need to make decisions about treatment for localised prostate cancer.

Patient involvement: consulting men on information provision

A meeting was held with nine ProtecT participants and three of their partners, with another two men involved in another NIHR study. The purpose of the meeting was to discuss the information that should be provided to men newly diagnosed with localised prostate cancer to support them in making treatment decisions. All involved in the consultation found the ProtecT study results so far to be reassuring, particularly the large number of participants alive 10 years after their prostate cancer diagnosis.

Most thought that the terms 'cancer growth' and 'cancer spread' to refer to cancer progression and cancer metastases were understood and acceptable. Some men thought that a diagram would be helpful. Some participants found that use of the word 'bothersome' in relation to the impact of treatment side effects diminished their experiences: "I think the problems you have after surgery are slightly more than bothersome".

In terms of the delivery of information, some felt that written profiles were helpful, but it was important that information was presented by a qualified health professional, such as a clinical nurse or consultant, who could talk through the findings and answer questions. Men could then make a more informed choice. They considered that the timing of information giving was important, with men likely to be anxious following diagnosis to avoid "at the beginning, too much – information overload".

There was also recognition by the group that people have "different ways of absorbing data" so that "a graph might be good for some people, pictures better for others, and some others might like a good description." We now know that any presentation of information should cover all these options.

We are going to take on board all these points in preparing information to be included in the NHS Prostate Cancer Risk Management Programme for men and GPs.

Further details, study contacts

If you want to receive more information or have any questions about the ProtecT study please contact us on: Freephone 0800 7833167 or email: info-protect@bristol.ac.uk or ProtecT Study, University of Bristol, Canynge Hall, 39 Whatley Road, Bristol, BS8 2PS. We are committed to handling the data used in the ProtecT study securely and confidentially. For more information about how we process your data, please go to our website <http://www.bristol.ac.uk/population-health-sciences/projects/protect> in the Taking Part section.

ProtecT study Consultant Urologists

Birmingham	Mr Alan Doherty: 0121 6978273
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Edinburgh	Mr Prasad Bollina: 0131 5371581
Leeds	Mr Alan Paul: 0113 2064949
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