



Oxford University Hospitals
NHS Foundation Trust

Prostate Cancer Follow-up Care

Information for patients



This leaflet is to provide you with information about the care you will receive after your treatment or clinical reviews for prostate cancer (follow-up care).

How the service can support you

Two options are available:

1. Clinical appointments at regular intervals (traditional option).
These may be face to face or over the telephone.
2. Remote monitoring with appointments only if needed (patient led follow-up - PLFU).

Some patients find pre-arranged appointments useful and reassuring, but others do not find them particularly helpful, unless they have something specific to discuss. Symptoms and concerns can be addressed more quickly if patients report them as and when they occur, rather than waiting for a routine appointment. This is the model of patient led follow-up (PLFU) instead of pre-arranged appointments.

In both options we keep a close eye on you:

- You will need to visit your GP practice to have bloods taken regularly.
- We will ask you to fill in some short questionnaires regularly so that we can check if everything is ok.
- All results will be reviewed by our hospital team.

For option 1 (traditional option):

Results review will coincide with your appointment.

For option 2 (PLFU):

Results will be checked remotely by the hospital team without any need to schedule time for an appointment. You will be contacted within 2 weeks of your results being due to let you know that everything has been checked. If these results suggest clinical input could be useful we will contact you. If at anytime whilst you are on follow-up you have concerns or think you would benefit from an appointment, contact our team. We can book an appointment for you within 2 weeks.

Whichever pathway you choose, we encourage you to check your results (these can be found on patient portal, within your letter or by contacting the specialist nursing team), and if you have any concerns, please contact the nurse specialist team.

Benefits and risks

Our aim is to improve patient experience, promote well-being, maintain quality of life, and to empower individuals to take an active role in their cancer care to improve outcomes.

PLFU gives you the option to avoid unnecessary journeys, annual leave, time and associated costs with visiting the hospital for appointments. It also benefits the clinical team by freeing up clinics for patients that need face to face care.

The follow-up pathway chosen is a joint decision between you and your consultant, taking into consideration your suitability and preference. Support that might be useful to you will be explored during a **holistic needs assessment** with the nursing team. The follow-up decision will be made at the appointment with your consultant, around 6 to 8 weeks after your treatment.

To be able to choose Option 2 (PLFU)

- Your prostate cancer must be stable (without the need for treatment at present) following treatment or with ongoing treatment.
- If you have had treatment, you are recovering from the expected side effects.
- If you are on medication, your condition is stable with acceptable side effects.

You will participate in a workshop to:

- provide you with the skills and confidence to understand how and when to complete symptom assessments (questionnaires) and blood tests,
- explain how to address any ongoing symptoms you may be experiencing,
- optimise your health and wellbeing,
- highlight examples of symptoms of concern,
- explain how to contact the team if these occur (see below for details).

You will have watched a video outlining the service.

We will provide you and your GP with a treatment summary which will summarise your care and detail your schedule for follow up. This includes frequency of follow up tests, symptom assessments and how to contact the department.

If you would like more information before you decide, please ask us. Remember you can always contact the clinical team for advice no matter what follow-up plan you are on.

Table 1. Comparison between follow-up options

	Patient Led Follow-Up	Routine Hospital Follow-Up
Blood tests at local GP	Yes	Yes
Questionnaire to check if ok	Yes	Yes
Hospital team review results	Yes	Yes
Hospital appointment every few months	No	Yes
Patient can call for advice	Yes	Yes
Holistic Needs Assessment	Yes	Yes
Receive information on supported self-care	Yes	Yes
Invited to health and wellbeing events	Yes	Yes
Access available to Patient Portal	Yes	Yes

What you are responsible for:

- Arranging regular appointments to have blood taken at your GP surgery.
- Completing and returning questionnaires we send you.
- Letting us know if you have any problems or concerns.
- Being aware of your own results and discuss any concerns you have with us (these will also be reviewed by our hospital team).

What we are responsible for:

- Providing you with information to help you support yourself (supported self-care).
- Sending blood forms/stickers to allow you to have tests at your GP (Oxfordshire results will come straight to us).
- Checking your test and questionnaire results and acting on this as appropriate.
- Enabling you access to our clinical teams when you need us (by telephone or clinical appointments).

You can change your mind on the option you have chosen. Please discuss this with your clinical team.

When your follow-up period ends (as detailed in your treatment summary), we will contact you to let you know. Your GP will then take over from us for prostate and any other health needs.

Patient portal

Oxford University Hospitals have a patient portal called Health for Me. This enables you to access to your own digital health record from a smart device such as a phone, tablet, or computer.

Here you can have access to your blood results as soon as they are available rather than waiting for your letter. Completing health questionnaires through this platform will enable the clinical team to review them in the shortest time.

The departmental administrative team can give you access to the Patient Portal. You will then receive an access invitation to Health for Me for you to sign yourself up.

Access to the Patient Portal is optional. We can alternatively send you paper forms in the post to complete questionnaires. Results will always in addition be communicated by letter.

Supported self-management

We will support you to manage your condition yourself. This puts you in control of your care and allows you to take an active role in your healthcare. This is called supported self-management.

There are lots of things you can do to look after your own health during and after cancer treatment. Many of these can be done without the involvement of your clinical team, such as physical activity and healthy eating.

Health and Wellbeing Workshops

All patients will be invited to workshops to inform them more about their condition, explore areas of support and have opportunities to discuss any of this with their care team and other individuals with the same diagnosis.

Workshops provide information on:

- Introduction to the service.
- What is PSA tracking and surveillance?
- Long term complications arising from a prostate cancer diagnosis and treatment.
- Thrivorship issues.
- Feeling well after your treatment.
- Signposting to other areas of support.
- How to arrange a review.
- Your responsibility in managing your well-being and blood tests etc.

What symptoms do I need to look out for?

Symptoms to look out for are detailed in your treatment summary and will be monitored by our hospital team via questionnaire.

If you do get an associated symptom that lasts 3 weeks or more or you are concerned, please talk to your specialist nurse team.

We want to know about PSA rises above a certain level. This will be monitored by our hospital teams and will trigger an automatic review if you are on PLFU.

What support will I have?

You can contact your specialist nurse team by phone if you have any concerns. We can offer:

- Advice and support for you, your relatives, and friends.
- Advice on management of symptoms.
- Someone to talk to about worries or problems.
- Advice on sexual problems.
- Signposting for Advice and help on how to manage financial problems.
- Arranging visits to clinic or remote consultations as needed.

The specialist nursing team are available to offer help, support and advice. Our working days are Monday to Friday, 8am to 4pm and we are happy to talk over the phone or meet in person.

If you have not had your blood tests or completed the health questionnaires our administration team will be in contact with you.

Contact details

Uro-oncology Clinical Specialist Nursing Team

Stratified Admin - Personalised Care Co-ordinator

Telephone: 01865 222 583

Email: ProstateCancer.Stratified@ouh.nhs.uk

Further information on personalised stratified follow-up pathways can be found at:

www.england.nhs.uk/wp-content/uploads/2020/04/cancer-stratified-follow-up-handbook-v1-march-2020.pdf

Your opinions and views are important to us.

Please ask us about the NHS Friends and Family Test which gives you the opportunity to tell us what we did well and what we can do to improve. You can also have an informal conversation at any point if there is something you would like to ask or tell us about.

We have tried to make this information meet your needs. If it does not meet your individual needs or situation, please ask your healthcare team for more details or information. They will be happy to help.

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

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Author: Jacqueline Redgewell
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Oxford University Hospitals NHS Foundation Trust
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charity@ouh.nhs.uk | 01865 743 444 | hospitalcharity.co.uk

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