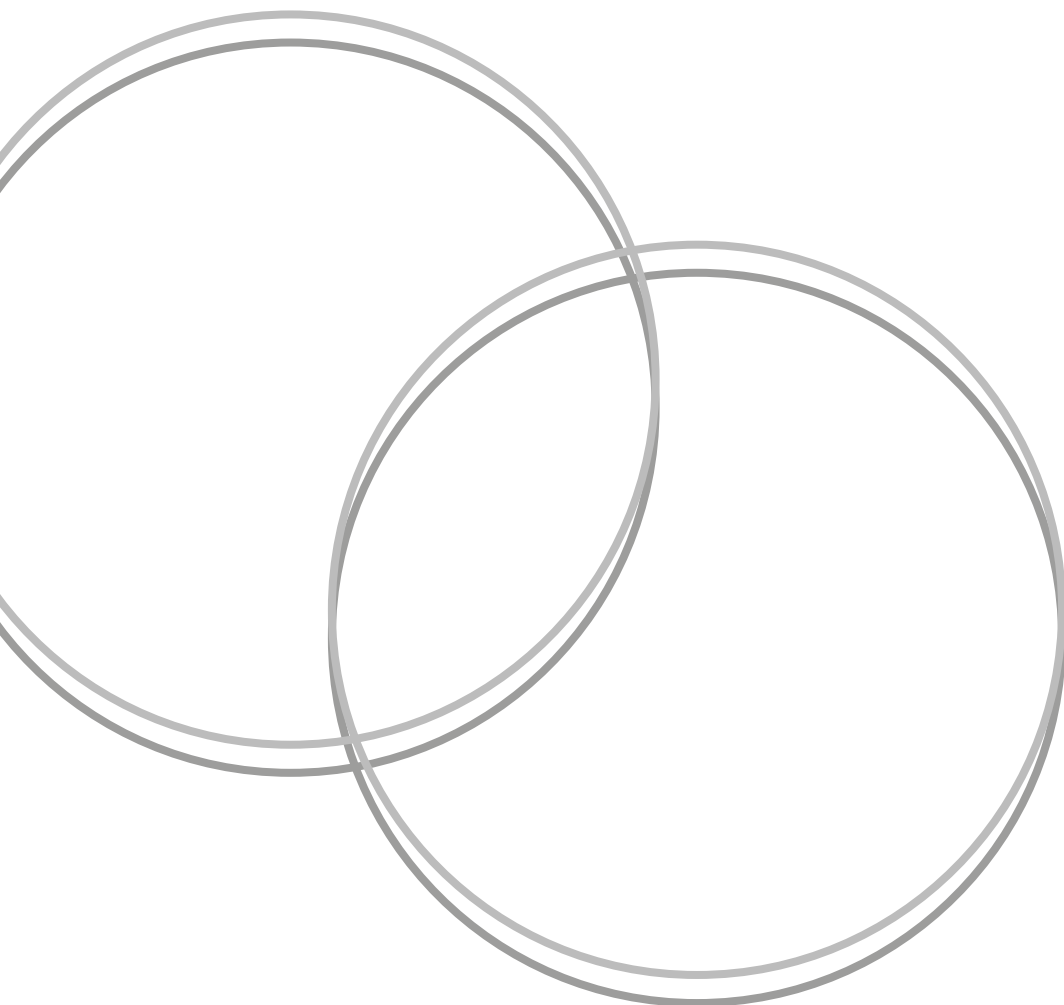


Prostate cancer follow-up care

Patient Led Follow-Up (PLFU)

Information for patients



This leaflet provides you with information about your prostate cancer surveillance (follow-up care).

How the service can support you

In order to respond quickly to any possible changes in your health we will review the following:

- 1) a tumour marker in your blood called Prostate Specific Antigen (PSA)
- 2) your general health, specifically asking you questions about your bladder, bowel and sexual function

You **do not** need regular hospital appointments.

You **do** need to visit your GP practice to have blood tests.

You **do** need to fill in some short questionnaires regularly.

All results will be reviewed by your hospital team.

You can call your clinical team if you have any concerns. If at any point you need an appointment we will aim to see you within 2 weeks.

This type of follow up is called **Patient Led Follow-up (PLFU)**. The purpose of PLFU is to ensure your symptoms and concerns can be addressed more quickly, as you can report them as and when they occur, rather than waiting for a routine appointment.

For any patients that PLFU is not suitable for we will instead offer regular appointments over the telephone or face to face.

How will I know when to have a blood test?

You will be given a personalised schedule of follow-up in your **treatment summary**. This will tell you how often **you will need to book blood tests at your GP**. This coincides with the time to log into the patient portal and **respond to your questionnaires**.

We will contact you by text or phone a few weeks before your test is due to remind you.

When will I know my results?

The hospital team will review your results and will send a letter within 2 weeks of your scheduled test date. This will explain your results and any further actions needed. You may also choose to have your results sent by email.

If you have any concerns or think you may benefit from an appointment, please contact our team.

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.

Patient Portal

Oxford University Hospitals have a patient portal called Health for Me. This enables you to access 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. Alternative ways to complete or receive information can be provided if necessary.

Follow-Up Programme

Patient Led Follow-Up (PLFU) has been shown to improve patient experience, promote well-being, maintain quality of life, and empowers individuals to take an active role in their cancer care to improve outcomes.

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

Your follow-up plan will be created at the appointment with your consultant, around 6-8 weeks after your treatment.

Further support that might be useful to you will be explored during a **holistic needs assessment**. This will be completed with the nursing team.

For Patient Led Follow-Up:

- Your condition 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 Health and Wellbeing workshop

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 about follow-up, please ask us.

Components of Patient Led Follow-up:

- Blood tests at local GP
- Questionnaire to assess symptoms
- Hospital team review results
- NO regular hospital appointments, instead contact us if you need advice or have concerns
- Holistic Needs Assessment
- Receive information on supported self-care
- Invited to health and wellbeing events
- Access available to Patient Portal

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 clinic appointments)

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.

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
- The importance of PSA tracking
- Potential long term side effects arising from a prostate cancer diagnosis and treatment and how to manage these
- How to ask for advice or raise concerns with the clinical team
- Thrivorship (wellness and empowering you beyond cancer)
- Feeling well after your treatment
- Signposting to local/national areas of support
- 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 discussed at the Health and Wellbeing event with you.

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–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 specialist Nursing team

Telephone: **01865 572374**

Email: **uro.nursespecialist@ouh.nus.uk**

Further information on personalised stratified follow-up pathways can be found at **<https://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.

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.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

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