‘My Medical Record’ Prostate Specific Antigen (PSA) tracker

Introduction
This leaflet contains information for you about My Medical Record, the PSA Tracker and how it will be used to provide remote monitoring of prostate cancer after treatment.

About PSA (Prostate Specific Antigen)
PSA is a protein made by the prostate gland, which naturally leaks out into the blood. The PSA test measures the level of PSA in your blood. Sometimes an increase in the PSA level can be a sign of prostate cancer or its return.

During and following the treatment for prostate cancer, there is a need to have regular PSA tests. A PSA test is useful for identifying if there is some activity relating to the prostate that may require further investigation or treatment.

About My Medical Record
My Medical Record is a computer database system which allows us to monitor PSA blood test results from the laboratory. We can see if a blood test has been completed at the correct time. We can send a reminder if the blood test has not be taken and we can check the result level.

The PSA Tracker records and monitors the PSA levels and alerts us of your PSA results. We will notify you of this by letter and if there is a rise in your PSA levels, above what is normal for you, we will contact you to see if you have any symptom changes.

We will then either ask for a repeat blood test or arrange for you to be seen again at the hospital by a member of the urology team. The system is checked weekly by the Uro-Oncology PSA Tracker Specialist Team based at Cheltenham General Hospital. The PSA tracker team are the uro-oncology nurse specialists and Macmillan support workers based in the Urology Department at Cheltenham General Hospital.
When you are registered on the tracker a unique password will be created and given to you. This will allow you to log on via the internet to view your own PSA results using the patient portal ‘My Medical Record’. It will also give you access to information relating to treatment side-effects, non-clinical issues that may have arisen as a result of a cancer diagnosis and both local and national support links. There is also an email link to the uro-oncology specialist team. This can be used to ask questions.

**Your data**

- You can choose whether you want your information to be placed on the PSA Tracker. Face-to-face appointments can continue to be arranged if you would prefer
- You can request that your information is removed from the PSA Tracker at any time
- The PSA Tracker stores and displays the same personal and medical information that is held in your Gloucestershire Hospitals NHS Foundation Trust electronic record
- The PSA Tracker/My Medical Record online system is owned and operated by the University Hospital, Southampton NHS Foundation Trust (UHSFT). The data controller for personal information stored is University Hospital Southampton NHS Foundation Trust, data protection registration number Z4989884. This means your data is stored outside of Gloucestershire Hospital NHS Foundation Trust
- Any personal information you add to the PSA Tracker may be used by us in a number of ways, for example:
  - to update your main hospital record
  - to give you the best healthcare and treatment, both now and in the future
  - to give you the chance to take part in research and development projects run at Gloucestershire Hospitals Foundation Trust
  - to make sure you get the best advice and information about your treatment and care
  - to give you the opportunity to take part in surveys and audits to find out how we can improve our services
• We make every effort to make sure that the data we hold about you is accurate and up to date. The Trust will not be held liable for any loss, damage, distress or inconvenience caused as a result of any error or inaccuracy in the personal data provided in personal health records by account holders.

• If you move home, please contact the PSA Tracker team with your new address details. They will make sure that the system is updated. The team can be contacted by email ghn-tr.psatracker@nhs.net or by telephone, on 07741 331 309.

• Please do not change your address or any other details on the PSA Tracker. Doing so will mean that your results will not be able to link to the system.

Benefits of the PSA Tracker

• The system will prompt us when your PSA test is due. This is in line with a follow up plan, designed around your diagnosis and treatment.

• Test dates and results are monitored so you no longer need to attend so many outpatient appointments. Fewer face-to-face appointments can mean less travel and parking costs and less time off work.

• The PSA Tracker will allow you, when your results are stable, earlier discharge from hospital clinic follow ups. Allowing you freedom not to have to come in for regular outpatient appointments at all.

• You will have the peace of mind that test results are being monitored and action will be taken by the hospital team.

Why have you been selected for the PSA Tracker?

Your urologist, oncologist or specialist nurse will suggest your inclusion on the PSA Tracker as part of the follow-up to treatment when your results and cancer management is stable.

Remote monitoring is believed to be the best way of keeping an eye on recovery following treatment for prostate cancer. It is part of the national cancer recovery programme. In Gloucestershire we are including men who still need treatment and hospital follow-up in preparation for future discharge.
How the PSA tracker works

After you have been treated for your prostate cancer your specialist hospital team will introduce you to the idea of self-management and remote monitoring. This will be as part of your management and follow-up plan. The team will explain what the PSA tracker is and how it can be used. Both you and your GP will receive a letter with the results of the PSA test. It will also confirm whether there is a need for additional treatment and when your next test will be due. The frequency of the PSA blood test will be set specifically for you by the hospital uro-oncology specialist team. The tests may be repeated every 3, 6 or 12 months.

Included with your PSA test results letter will be the date and blood form for your next test. You will need to book the blood test with your GP or local hospital. Please take the form with you so that the person taking the bloods knows which tests are needed.

After the PSA blood test, the blood is sent to the Pathology Laboratory at Gloucestershire Hospitals NHS Foundation Trust. The results are automatically put into the PSA tracker system. This will be is checked weekly by the PSA tracker specialist team.

If the nurses or consultant notice a change in your PSA level, they will contact you to discuss any new symptoms that may have developed.

The specialist may ask for a repeat blood test or they arrange for a hospital appointment.

Changes in your symptoms

If any of the following symptoms develop please contact the Uro-Oncology PSA Tracker Specialist Team. Further tests may be needed.

- Stiffness or soreness in areas such as your lower back, hips and thighs
- Swelling in your legs or pain in the pelvic region
- Bone pain that does not ease, bone fractures or numbness of your lower limbs
- Not completely emptying your bladder (urinary retention)
- Change in urinary habits or unusual symptoms
- Unexplained weight loss
- Blood in your urine

**Contact information**

If you have any concerns about your prostate cancer please contact:

**Uro-Oncology PSA Tracker Specialist Team**

Urology Department  
Cheltenham General Hospital  
Tel: 0774 1331 309  
Monday to Thursday, 9:00am to 4:00 pm  
Friday, 9:00am to 1:30pm

Email: ghn-tr.psatracker@nhs.net

We aim to respond to messages or emails within 48 working hours.

**PSA Tracker patient portal**

Website: [http://psatrackerglos.uhs.nhs.uk](http://psatrackerglos.uhs.nhs.uk)

Your unique passcode is: ___________________