**Patient information (Sample)**

**Supported self-management follow-up arrangements**

**Why you have been selected for supported self-management**

Your Consultant has selected you for supported self-management because they believe this is the best way of keeping a close eye on your recovery following your treatment for prostate cancer. Results of your regular PSA tests will be monitored by the hospital and you will be recalled quickly if there are any concerns.

This gives you the freedom to get on with your life, but with the reassurance that there is a clinician monitoring your progress and a fast way back into the hospital should you need it.

At the end of your prostate cancer treatment, you will have an appointment with your Consultant/Clinical Nurse Specialist, who will review your diagnosis, treatment and any possible side-effects.

You will have a discussion about any signs and symptom you need to watch out for and the arrangements for regular PSA tests. Your Consultant will tell you exactly how often you need to have these done, but it will usually be every 6 to 12 months, depending upon the treatment you have had and your progress beyond this point.

**Monitoring your test results**

Your Consultant/CNS will monitor your PSA blood test results and your results will be fed back to you by letter, text or telephone (delete as appropriate) you will only be called back to hospital if it is felt you need further tests or investigations. PSA levels are recorded and monitored and if the PSA level rises above what is normal for you, the Consultant or CNS will contact you to discuss these results and, if necessary, ask you to return to hospital for a clinic appointment.

You will continue to have regular blood tests, but will only be brought back in to hospital for an appointment if your PSA level shows a sustained or worrying rise or you have symptoms which require further investigation. If you have any concerns, please contact the Helpline on XXXXXXXX which is available Monday to Friday 9am-5pm.

When your PSA test is due, you will receive a letter from your Consultant/CNS with a blood form (this will vary from Trust to Trust) asking you to book yourself a blood test with your hospital.

**About PSA (Prostate Specific Antigen) levels**

The best way of identifying that you may need more treatment for your prostate cancer related problems is through a ‘PSA test’. This is a simple blood test which can be taken at your GP surgery or Trust Name. 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 a raised PSA level can be a sign of prostate cancer or its return. However, it can be caused by something less serious like:

* an infection
* exercise
* ejaculation

Following the PSA test, your blood sample is sent to the Trust Name pathology laboratory for checking and the results will be reviewed by the Consultant/CNS.

If the PSA results are within the range that is normal for you, you will receive a letter from the Consultant/CNS confirming this and telling you when your next PSA test will be due. You will not be routinely called for a follow-up appointment at the hospital if your PSA levels are normal and you are symptom-free.

If your Consultant/CNS is concerned about your PSA level, they will telephone you to discuss this with you and will send you a letter offering the first available clinic appointment.

Exercise, such as long-distance running or cycling, or sex may raise PSA levels and patients should not have:-

* prolonged exercise 48 hours before the PSA test or
* sex 48-72 hours before the PSA test

**Signs and Symptoms to report:**

The following is a list of the signs and symptoms which you need to keep in mind following your treatment for prostate cancer. These symptoms could indicate a return or spread of the disease and need further investigation. If you experience any of these or have any concerns, please contact the Helpline on XXXXXXXXX. Your CNS will phone you back within 2 working days of you leaving your message. The Helpline is available Monday to Friday, 0900-1700.

* Stiffness or frequent soreness in areas such as the lower back, hips and thighs
* Swelling in the legs or pain in the pelvic region.
* Bone pain that doesn't stop.
* Unexplained weight loss

Obviously everyone is different and it is you who knows your body best, so we would much rather you telephoned the Helpline with a concern that turned out to be nothing, than have you sitting at home worrying. The sooner you share your symptoms or concerns with us, the quicker we can resolve the problem.

**Helpline: XXXXXXXX**

There is a dedicated Helpline (XXXXXXXXX), which you can telephone and leave a message if you have any concerns about your prostate cancer or are suffering from one or more of the symptoms listed below. Please do not wait until your next PSA test is due before contacting the Helpline. Often patients delay reporting symptoms or problems until their next clinic appointment, particularly if this is not too far away. It is much better to investigate symptoms as soon as they are noticed.

The Helpline is checked for messages between 0900 to 1700 Mondays to Fridays and your CNS will phone you back within 2 working days of you leaving your message. If, as a result of this discussion with you, your CNS thinks that you need to come back into clinic, you will be offered the first appointment available.

**Benefits of supported self-management**

* You will not have to make unnecessary trips to the hospital at times when you are symptom-free and getting on with your life.
* You can phone the Helpline at Trust Name (Monday-Friday 9am-5pm) with any concerns or symptoms relating to your prostate problems in between appointments and receive a call back from your CNS within 2 working days.
* You no longer have to take time off from work or pay travelling or parking charges for out-patient appointments that you don’t need.
* You should receive an improved experience of care, with the advantage of a Helpline you can ring.

**Please remember**

* If you are experiencing any of the symptoms listed above, please phone the Helpline as soon as possible on XXXXXXXX.
* If you are asked to return for a clinic appointment and are unable to make the date and time given, please telephone the Name of Trust outpatient department on xxxxxx to rearrange the appointment.
* Telephone messages to the Helpline will be monitored Monday to Friday 9am to 5pm. They will not be picked up at weekends or on bank holidays. If you have a prostate-related emergency occurring at the weekend or on a bank holiday, you will need to contact your out of hours GP service or your local Accident and Emergency (A&E) Department.