ACTIVE SURVEILLANCE FOR LOW TO INTERMEDIATE GRADE PROSTATE CANCER

Frequently-asked questions from
The British Association of Urological Surgeons (BAUS)

This leaflet contains evidence-based information about active surveillance for prostate cancer. We have consulted specialist surgeons during its preparation, so that it represents best practice in UK urology. You should use it in addition to any advice already given to you.

To view the online version of this leaflet, type the text below into your web browser:

http://www.baus.org.uk/_userfiles/pages/files/Patients/Leaflets/Active surveillance.pdf

Key Points

- Active surveillance is a way of monitoring prostate cancer that is contained within the prostate, to avoid immediate treatment
- Whilst it may seem strange not to have treatment, many types of prostate cancer are slow-growing and may do no harm, so active surveillance can allow a man to avoid the side-effects of treatment
- Active surveillance involves regular appointments & blood tests, and may require further biopsies and/or MRI scans

Who is eligible for active surveillance?

It is used mainly for two groups of men with prostate cancer:

- **low-risk prostate cancer:** a PSA less than or equal to 10mg/ml, a Gleason sum score of 6, clinical stage T1 or T2, and cancer involving less than 50% of the biopsy cores; and
- **low-volume intermediate-risk prostate cancer:** a PSA between 10 & 20 ng/ml, or Gleason sum score of 7 and clinical stage T1 or T2.

There are a few other factors such as age, family history or other illnesses which can also be important when considering active surveillance. Your urologist or specialist nurse will advise you about these.

What does active surveillance involve?

This may differ from patient to patient, depending on specific circumstances. Your urologist or specialist nurse will discuss this with you but, typically, your programme will usually follow the schedule below:

- Regular PSA blood tests (ussually 3-4 monthly) ;
- Annual prostate examniations;
- Repeat MRI scan at 12-18 months from diagnosis, and 3-5 yearly thereafter; and
- Repeat biopsies if there is any concern about progression of your cancer.

If the PSA, MRI and/or repeat biopsies confirm that your disease is stable, we will continue active surveillance using the protocol above.

We will consider re-investigation, or a change to active treatment, if we find any of the following:

- a significant rise in your PSA (typically over a few consecutive values);
- a change in your MRI scan and/or the findings on rectal examination of your prostate;
- your preference for a change to active treatment; or
- an increase in tumour volume or grade on repeat biopsies.

Are there any risks to active surveillance?

There are a number of factors that may influence your decision to continue with active surveillance:

- **Changes in your cancer**
  There is always a chance that your cancer could grow. The tests we use to monitor your cancer are designed to detect changes early enough to start treatment. The monitoring plan is designed to be as rigorous and robust as possible, so that it can detect any change in your cancer at an early stage. There is, of course, a small chance that such changes may be missed. You should talk to your urologist or specialist nurse about your own, individual risk factors
- **Changes in your health**
  There is a chance that your general health could, for some unforeseen reason, deteriorate. This might make some forms of treatment (e.g. surgery) potentially unsuitable for you if the cancer were to grow. There are, however, many effective options available to treat prostate cancer
- **Concerns about the psychological impact on you**
  Active surveillance is not for everyone. Some men find it difficult not to have active treatment for prostate cancer and worry that the tumour will change or spread. You do not have to stay on active

surveillance if you do not want to; your urologist or specialist nurse will be happy to discuss any issues with you

- **Side-effects from repeat biopsies of the prostate**
  You will require repeat prostate biopsies as part of the active surveillance programme. Biopsy of the prostate does carry a small risk of infection and bleeding. The risks apply for each re-biopsy, although we will take every precaution to minimise them

What are the advantages & disadvantages?

Advantages	Disadvantages
Because you are not having any treatment, you will avoid the potential side-effects of the various forms of active treatment	You might need to have more prostate biopsies which can cause side-effects, as well as being uncomfortable or painful
Active surveillance does not interfere with your everyday life as much as treatment might do	Your general health could change and this might make some treatments unsuitable, if you need them
If tests show that your cancer is growing, there are treatments available that can still cure it	Your cancer might grow more quickly than expected, although the chances of this happening are small
	Not having treatment can cause high levels of anxiety in some men about the possibility of their cancer growing

What should I expect after deciding to go ahead?

- You do not need to change your lifestyle or activities;
- Your first outpatient appointment will be 3 to 4 months from the diagnosis;
- You need to have your PSA measured before this appointment, at your GP's surgery;
- You may need an MRI scan before your first appointment (although it is sometimes organised after the appointment);

- At your first appointment, the MRI and PSA results will be discussed, together with the need for repeat biopsy and subsequent follow-up plans;
- You will always be able to contact your prostate cancer nurse specialist if you have any concerns or worries; and
- You can stop active surveillance at any point if you are worried.

What are the alternatives?

Other treatment options may include:

- **Brachytherapy:** a form of "internal" radiotherapy which involves implanting seeds of radioactive material directly into your prostate under a general or spinal anaesthetic
- **External beam radiotherapy:** treatment with externally focussed radiation to destroy the cancer cells
- **Radical prostatectomy:** complete surgical removal of your prostate gland by open or robotic-assisted laparoscopic (keyhole) surgery;
- **High intensity focussed ultrasound (HIFU):** external treatment with a powerful ultrasound beam (under assessment by NICE, restricted to clinical trials only and very limited availability)
- **Cryotherapy:** freezing your prostate using probes inserted through the skin in front of your anus (under assessment by NICE, restricted to clinical trials only and very limited availability).

What should I do with this information?

Thank you for taking the trouble to read this information. Please let your urologist (or specialist nurse) know if you would like to have a copy for your own records. If you wish, the medical or nursing staff can also arrange to file a copy in your hospital notes.

What sources have we used to prepare this leaflet?

This leaflet uses information from consensus panels and other evidence-based sources including:

- the Department of Health (England);
- the Cochrane Collaboration; and
- the National Institute for Health and Care Excellence (NICE).

It also follows style guidelines from:

- the Royal National Institute for Blind People (RNIB);
- the Information Standard;
- the Patient Information Forum; and
- the Plain English Campaign.

Disclaimer

We have made every effort to give accurate information but there may still be errors or omissions in this leaflet. BAUS cannot accept responsibility for any loss from action taken (or not taken) as a result of this information.

PLEASE NOTE

The staff at BAUS are not medically trained, and are unable to answer questions about the information provided in this leaflet. If you do have any questions, you should contact your urologist, specialist nurse or GP.