

Freedom of Information Request: Active Surveillance for Prostate Cancer.

Freedom of Information request - Active surveillance for men diagnosed with localised (early) prostate cancer

Prostate Cancer UK is keen to support the NHS to implement best practice active surveillance for eligible men, diagnosed with clinically localised (early) prostate cancer. We'd like to understand the state of the UK nations, and the current barriers and challenges being faced, in implementing active surveillance. Our findings will be used to inform policy and practice recommendations in addition to helping us set priorities for support.

We're keen to ensure we receive as full and accurate information as possible. This request should be directed to either the hospital Urology Clinical Lead, Urology Cancer Nurse Specialist, or Urology MDT for completion.

How to send your response: Our preference is for the FoI response to be recorded in this simple online form (you might find it useful to download all the sections before completing the online form - prostatecanceruk.org/active-surveillance-FOI-pdf). When complete you can notify us via the 'WhatDoTheyKnow' platform. If you have any questions or need support, contact Policy@prostatecanceruk.org.

Please complete all sections as fully and as accurately as possible using the check boxes and free text fields where applicable. We appreciate your support with this request.

* Required

About your NHS Trust/Health Board/Health & Social Care Trust

1. In which country is your NHS Trust/Health Board/Health & Social Care Trust located? *

- England
- Northern Ireland
- Scotland
- Wales

2. What is the name of the NHS Trust/Health Board/Health & Social Care Trust you are replying on behalf of? *

Southern Health and Social Care NHS Trust

3. Please tell us your organisation data service (ODS) code if known. *

You can download our ODS look-up list using this link - <https://prostatecanceruk.org/ods-lookup>. Once downloaded:

1. Use the filters in the column headings to narrow down the list.
2. Or use the 'Search' function in the filter options in the 'Name' column.
3. Use the 'Organisation code' from the blue highlighted column.

If your ODS code is still unknown, state 'unknown' and proceed to the next section.

Active surveillance inclusion criteria

4. Which patients are recommended active surveillance? **(select all options that apply)** *

- CPG1 - Gleason score 6 (grade group 1) and prostate-specific antigen (PSA) less than 10 microgram/litre and Stages T1–T2
- CPG 2 - Gleason score 3 + 4 = 7 (grade group 2) or PSA 10 microgram/litre to 20 microgram/litre and Stages T1–T2
- CPG 3 - Gleason score 3 + 4 = 7 (grade group 2) and PSA 10 microgram/litre to 20 microgram/litre and Stages T1–T2
- CPG 3 - Gleason 4 + 3 = 7 (grade group 3) and Stages T1–T2
- Other (please provide details below)

Recommendations as per NICE guidance - CPG1 = Surveillance recommended, CPG2 = all options offered including active surveillance.

5. If different eligibility criteria are used to those presented above, please provide details: *
answer 'n/a' if nothing to add or not applicable.6. Tell us about any other criteria/tools that are used to determine eligibility for active surveillance. **(select all that apply)** *

- PSA density (PSAd). If yes, indicate value for men eligible for AS in the free text field below.
- Number of biopsy cores involved. If yes, indicate number in the free text field below.
- Biomarkers (e.g. Phi, PCA3, 4K). If yes, tell us the biomarker type(s) used in the free text field below.
- Age cut-off. If yes, indicate age cut-off used where active surveillance is NOT recommended in the free text field below.
- Predict Prostate online tool (<https://prostate.predict.cam>).
- Patient life expectancy / estimated survival. If yes, indicate the method used in the free text field below to assess life expectancy / estimated survival value where active surveillance is NOT recommended
- A positive family history of prostate, breast or ovarian cancer. If yes, please provide details in the free text field below
- Patient ethnicity. If yes, provide details in the free text field below.
- Patient choice/willingness. If yes, provide details in the free text field below.
- No other criteria / tools are used
- Other (please provide details in the free text field below).

7. Provide any additional details about any other criteria/tools that are used to determine eligibility for active surveillance. *

answer 'n/a' if nothing to add or not applicable.

N/A

Diagnosis and treatment decision support

8. For patients eligible for active surveillance, who counsels them regarding their diagnosis, prognosis and treatment options? **(select all options that apply) ***

- Urologist
- Oncologist
- Urology / Prostate Cancer Clinical Nurse Specialist (CNS)
- Urology / Prostate Cancer Advanced Nurse Practitioner (ANP)
- Uro-Oncology CNS
- Uro-Oncology ANP
- Other (please specify below)

CPG2 patients are also seen by oncologists

9. Please tell us about any other health care professionals who are involved in counselling men eligible for active surveillance? *

answer 'n/a' if nothing to add or not applicable.

N/A

10. Which resources and tools are used/made available by HCPs who counsel/support men on active surveillance? **(select all options that apply) ***

- Use the NICE CPG prognostic classification criteria.
- Use the NICE endorsed decision aid online tool – Predict Prostate online tool. (<https://prostate.predict.cam/>)
- Use the East of England Cancer Alliance – ‘Knowing Your Options’ online tool. (<https://www.canceralliance.co.uk/prostate>)
- Signpost patients to Prostate Cancer UK’s published information resources.
- Signpost to Prostate Cancer UK Specialist Nurses?
- Signpost men to Prostate Cancer UK’s 1-2-1 Peer Support.
- Signpost patients to Prostate Cancer UK’s online Active Surveillance Support Group.
- Use a locally developed counselling tool.
- Provide 1-2-1 (clinician – patient) counselling / education sessions before and during active surveillance follow up?
- Provide group (clinician – multiple patients) counselling / education sessions before and during active surveillance follow up?
- Have dedicated active surveillance clinics, which separates this cohort of men from those receiving surgery, radiotherapy, or chemotherapy?
- Offer patients access to tools / digital platforms such as My Medical Record – (<https://mymedicalrecord.uhs.nhs.uk/>)?
- Other, please tell us more below

11. Tell us more about the tools and resources used to counsel/support patients. *
answer 'n/a' if nothing to add or not applicable.

N/A

Follow up pathways and protocols

12. Which protocol do you use to manage your patients on active surveillance follow-up? **(if a combination of guidelines, please select all that apply)**

- National Institute for Health and Clinical Excellence (NICE) NG131 - Prostate cancer: diagnosis and management (2021), <https://www.nice.org.uk/guidance/ng131>
- EAU - ANM - ESTRO ESUR - ISUP - SIOG Guidelines on Prostate Cancer - <https://uroweb.org/guidelines/prostate-cancer>
- STRATified CANcer Surveillance (STRATCANS) - <https://stratcans.com>
- A modified version of STRATified CANcer Surveillance (STRATCANS)
- Prostate cancer Research International: Active Surveillance (PRIAS) protocol – <https://www.prias-project.org/uploads/pdfs/zakkaartv5.pdf>
- A locally developed protocol based on published evidence (please provide details below in section 4.14.).
- A combination of the guidelines selected above (please ensure you also select the guidelines used)
- Other (please provide details below)

13. Do you have a stratified AS programme based on CPG risk, or do all men have the same follow-up regime? Please describe model used below. *

- Yes, men are stratified according to CPG risk
- No, all men have the same follow-up regime
- Don't know
- Other (please provide details below)

14. In relation to fields 12 and 13 above, if a different protocol is used to manage patient follow-up during active surveillance, please describe the protocol here: *
answer 'n/a' if nothing to add or not applicable.

N/A

15. Do you have a nurse-led active surveillance service? *

- Yes, we have a nurse-led service for all men on AS
- Yes, we have a nurse-led service for men on AS (CPG 1 and CPG 2 only)
- No, we have a urology consultant led service for all men on AS
- No, but we're planning on implementing a nurse-led service for men on AS

16. Do you use the MRI PRECISE score in your active surveillance follow-up programme? *

- Yes
- No
- Don't know

17. Within your Urology unit do you have any of the following in place? **(please select all that are in place):**

- A formal active surveillance protocol
- A formal register of active surveillance patients that is regularly updated
- Audit and report on compliance and attrition rates of patients on active surveillance
- None of the above

Follow-up testing frequency

18. For men diagnosed with **CPG 1 risk prostate cancer**, select the relevant follow-up test frequencies for PSA, MRI, Biopsy, and DRE:

	Once every 3 months	Once every 6 months	Once every 9 months	Once every 12 months	Based on PSA and MRI results	Never	Other frequency
PSA	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
MRI	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>
Biopsy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
Digital Rectal Exam (DRE)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

19. For men diagnosed with **CPG 2 risk prostate cancer**, select the relevant follow-up test frequencies for PSA, MRI, Biopsy, and DRE:

	Once every 3 months	Once every 6 months	Once every 9 months	Once every 12 months	Based on PSA/MRI	Never	Other frequency
PSA	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
MRI	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Biopsy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
Digital Rectal Exam (DRE)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

20. For men diagnosed with **CPG 3 risk prostate cancer**, select the relevant follow-up test frequencies for PSA, MRI, Biopsy, and DRE:

	Once every 3 months	Once every 6 months	Once every 9 months	Once every 12 months	Based on PSA/MRI	Never	Other frequency
PSA	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
MRI	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Biopsy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
Digital Rectal Exam (DRE)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Men with CPG 3 prostate cancer are advised as per NICE to pursue active treatment, those who opt to go against this advise and pusue active surveillance are followed up as above

21. If you selected '*Other frequency*' for any of the above tests, please tell us more here. *
answer 'n/a' if nothing to add or not applicable.

Between 12-18 months

22. Do you assess the psychological support needs of men on active surveillance? (***select all options that apply***) *

- Yes, during their annual review
- Yes, when needed (patient led)
- Yes, at first diagnosis
- No, psychological support needs are not assessed
- Don't know
- Other (please provide details below)

23. Do you assess fitness for treatment in men on active surveillance? (***select all options that apply***) *

- Yes, during their annual review
- Yes, when needed (patient led)
- Yes, at first diagnosis
- No, fitness for treatment is not assessed
- Don't know
- Other (please provide details below)

24. On assessment for psychological support needs and fitness for treatment, please tell us more if other selected above. *

answer 'n/a' if nothing to add or not applicable.

N/A

Triggers for stopping active surveillance

25. At what cut-off point do you recommend men start active treatment (surgery / radiotherapy)? **(select all options that apply)** *

MRI changes to T3

Biopsy progression to Grade Group 3

Reclassification to CPG 3: Gleason score 3 + 4 = 7 (grade group 2) and PSA 10 microgram/litre to 20 microgram/litre and Stages T1–T2 or Gleason 4 + 3 = 7 (grade group 3) and Stages T1–T2

Patient preference to stop active surveillance and start radical treatment

Any change in MRI (lesion increase or change)

Any change in biopsy grade

Other (please provide details)

26. Provide details of other cut-off points used to recommend men starting active treatment (surgery / radiotherapy). *

If no other cut-offs used answer 'n/a' for not applicable.

N/A

Challenges and barriers in relation to implementing active surveillance.

Use this section to tell us anything you think would be useful for us to know during our analysis and reporting, not already mentioned previously.

27. What are the main barriers and challenges you have identified in delivering active surveillance for your eligible patients? (this might include things like implementing nurse-led surveillance or risk based stratified follow-up.) *

This is the final form field. When you have provide a response please click the 'Submit' button below to send your response.

Patient numbers increases without corresponding increases in staff and diagnostics capacity

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