



17 January 2025

Our Ref: FOI 431

Dear

**Freedom of Information Act 2000
Information in relation to Active Surveillance for Men with Prostate Cancer**

I am writing to confirm that the South Eastern Health & Social Care Trust (the Trust) has now completed its search for information relating to above which you requested on 17 December 2024.

A response to each of the questions raised has been provided by the Medicine, Unscheduled Care & Cancer Services Directorate and is attached in Appendix A.

If you are unhappy as to how this request has been handled, you have the right to seek a review within the Trust in the first instance. You should write to the Information Governance Department, Lough House, Ards Community Hospital (informationgovernance@setrust.hscni.net) within two months of the date of this response and your complaint will be considered and a response provided, within 20 working days of receipt.

If, after receiving a response, you remain unhappy, you can refer your complaint to the Information Commissioner at The Information Commissioner's Office –Northern Ireland, 3rd Floor, 14 Cromac Place, Belfast, BT7 2JB. It is important to note that if you refer any matter to the Information Commissioner, you will need to show evidence of having gone through the Trust's internal review procedure to try to resolve the matter with the Trust in the first instance.

If you have any queries about this letter, please do not hesitate to contact me. Please remember to quote the reference number above in any future communications.

Yours sincerely

Rebecca Manning
Information Governance Officer

Q1. In which country is your NHS Trust/Health Board/Health & Social Care Trust located?

- **England**
- **Northern Ireland**
- **Scotland**
- **Wales**

A1. Northern Ireland.

Q2. What is the name of the NHS Trust/Health Board/Health & Social Care Trust you are replying on behalf of?

A2. The South Eastern Health & Social Care Trust.

Q3. Please tell us your organisation data service (ODS) code if known. *

A3. ZT004.

Q4. 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)

A4. Please see below listed:

- 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

Q5. If different eligibility criteria are used to those presented above, please provide details: *
answer 'n/a' if nothing to add or not applicable.

A5. N/A.

Q6. 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).**

A6. Please see below listed:

- 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.
- Patient choice/willingness. If yes, provide details in the free text field below.
 - Under age 80yrs for AS.
 - Patient counselled and only entered into AS programme if patient willing.

**Q7. 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.**

A7. N/A.

Q8. 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)**

A8. Please see below listed:

- **Urologist**
- **Oncologist**

Q9. 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.

A9. N/A.

Q10. 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**

A10. Please see below listed:

- Signpost patients to Prostate Cancer UK's published information resources.
- Have dedicated active surveillance clinics, which separates this cohort of men from those receiving surgery, radiotherapy, or chemotherapy?

Q11. Tell us more about the tools and resources used to counsel/support patients. *
answer 'n/a' if nothing to add or not applicable.

A11. N/A.

Q12. 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)**

A12. Please see below listed:

- National Institute for Health and Clinical Excellence (NICE) NG131 - Prostate cancer: diagnosis and management (2021), <https://www.nice.org.uk/guidance/ng131>
- A locally developed protocol based on published evidence (please provide details below in section 4.14.).

Q13. 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)**

A13. No, all men have the same follow-up regime.

Q14. 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.

A14. N/A.

Q15. 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**

A15. Yes, we have a nurse-led service for all men on AS.

Q16. Do you use the MRI PRECISE score in your active surveillance follow-up programme? *

- **Yes**
- **No**
- **Don't know**

A16. No.

Q17. 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**

A17. A formal active surveillance protocol.

Q18. 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**

A18. Once every 6 months.

Q19. 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**

A19. Once every 6 months.

Q20. 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**

A20. Never.

Q21. 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.

A21. N/A.

Q22. 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)**

A22. Yes, during their annual review.

Q23. 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)**

A23. Please see below listed:

- Yes, during their annual review
- Yes, when needed (patient led)
- Yes, at first diagnosis

Q24. 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.

A24. N/A.

Q25. 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)**

A25. Please see below listed:

- 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

Q26. 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.

A26. N/A.

Q27. 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.) *

A27. N/A.