Active Surveillance for men diagnosed with localised (early) prostate cancer (v2 FULL)

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

Prostate Cancer UK are keen to support the NHS to implement best practice active surveillance protocols 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.

We're keen to ensure we receive as full and accurate information as possible. This request should be directed to the hospital Urology department or Urology MDT for completion. It might be helpful to

Ways you can respond:

1. Our preference is for the FoI response to be recorded in this simple online form (You might find it useful to download all the questions before completing the online form - INSERT LINK WHEN AVAILABLE). When complete you can notify us via the *'WhatDoTheyKnow'* platform.

or

2. Email Policy@prostatecanceruk.org If you would like to complete a Word version of form and submit this to us via the *'WhatDoTheyKnow'* platform.

If you have any questions or need support, please 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

1

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

- ◯ England
- ◯ Northern Ireland
- ◯ Scotland
- ◯ Wales

2

Name of Trust/Health Board/Health & Social Care Trust you are replying from *

3

Please tell us your organisation data service (ODS) code if known. Otherwise leave blank or state 'not known'.
(for more informaiton please refer to: https://digital.nhs.uk/services/organisation-data-service/export-data-files/csv-downloads)

Active surveillance inclusion criteria

4

Which patients are recommended active surveillance? (select the 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)

5

If different eligibility criteria are used to those presented above, please provide details: *

6

Please 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

Please 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) *

Diagnosis and treatment decision-making

8

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

- ◯ Yes, Nurse-led service for all men on AS
- ◯ Yes, Nurse-led service for men on AS (CPG1 and CPG2 only)
- ◯ No, Urology consultant led service for all men on AS
- ◯ No, but we're planning on implementing a nurse-led service for men on AS

9

If you plan to implement a nurse-led active surveillance service, please tell us more: *

10

Who counsels patients regarding their diagnosis, prognosis and treatment options? ***(select all 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)

11

Other health care professionals are involved in counselling men eligible for active surveillance? (please specify): *

12

Do clinicians who counsel patients on their diagnosis, prognosis and treatment options (select all 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 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/)?

Follow up pathways and protocols

13

Which protocol do you use to manage patient follow-up whilst on active surveillance? (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 Cance - 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)

14

If a different protocol is used to manage patients on active surveillance follow-up, please tell us more. (otherwise enter n/a). *

15

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)

16

Please describe your AS follow-up model, or enter n/a if not applicable. *

17

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

- ◯ Yes
- ◯ No
- ◯ Don't know

Follow-up testing frequency

18

For men diagnosed with CPG 1 risk prostate cancer, select the relevant follow-up test frequency:

	Once every 3 months	Once every 6 months	Once every 9 months	Once every 12 months
PSA	◯	◯	◯	◯
MRI	◯	◯	◯	◯
Biopsy	◯	◯	◯	◯
Digital Rectal Exam (DRE)	◯	◯	◯	◯

19

For men diagnosed with CPG 2 risk prostate cancer, select the relevant follow-up test frequency:

	Once every 3 months	Once every 6 months	Once every 9 months	Once every 12 months
PSA	◯	◯	◯	◯
MRI	◯	◯	◯	◯
Biopsy	◯	◯	◯	◯
Digital Rectal Exam (DRE)	◯	◯	◯	◯

20

For men diagnosed with CPG 3 risk prostate cancer, select the relevant follow-up test frequency:

	Once every 3 months	Once every 6 months	Once every 9 months	Once every 12 months
PSA	◯	◯	◯	◯
MRI	◯	◯	◯	◯
Biopsy	◯	◯	◯	◯
Digital Rectal Exam (DRE)	◯	◯	◯	◯

21

If you selected 'Other' test frequency for any of the above, please tell us more here. Otherwise enter n/a. *

22

Do you assess the psychological support needs of men on AS? (select all 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 AS? (select all 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. Otherwise state n/a. *

Triggers for stopping active surveillance

25

At what cut-off point do you recommend men start active treatment (surgery / radiotherapy)? *

- [ ] 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, state n/a. *

Technical and data

If the below data is not easily accessible or availble please state - ***'data not available'*** and aim to give some details as to why.
If the collection, analysis and submission of data would take longer than the specified 20 working days response dead-line for an FoI request, please state - ***'not able to collect, analyse and submit data within the given 20 working days'.***

27

Within our Urology unit (please select all statements that are true):

- [ ] We have a formal active surveillance protocol
- [ ] We keep a formal register of active surveillance patients that is regularly updated
- [ ] We audit and report on our compliance and attrition rates of patients on active surveillance
- [ ] None of the above

28

What percentage of men stay on active surveillance up to 2 years? **(if data not collected/available - enter *"do not know or we don't collect this data."*)** *

29

What percentage of men stay on active surveillance more than 2 years? **(if data not collected/available - enter *"do not know or we don't collect this data."*)** *

30

What is the average length of time patients are on active surveillance? **(if data not collected/available - enter *"do not know or we don't collect this data."*)** *

31

Please tell us the percentages of people diagnosed with CPG 1, CPG 2, CPG3 (3+4), and CPG3 (4+3) who are on active surveillance? ***e.g. number of patients on active surveillance classified as CPG 1 (Numerator)*** *divided by* ***all patients classified with CPG 1 (Denominator).***
(if data not collected/available - enter "do not know or we don't collect this data.")
*

32

Of all patients on active surveillance, please tell us the percentage who are CPG 1, CPG 2, CPG 3 (G3+4), and CPG3 (G4+3). ***e.g. number of patients classified as CPG 1 (Numerator)*** *divided by* ***all men enrolled on to active surveillance (Denominator). (if data not collected/available - enter "do not know or we don't collect this data.")*** *

33

What are the main barriers and challenges you have identified in delivering active surveillance for your eligible patients? *

Thank you for taking the time to complete the information requested in this form, we really appreciate your support. Please don't don't forget to click the 'Submit' button to send us your response.