

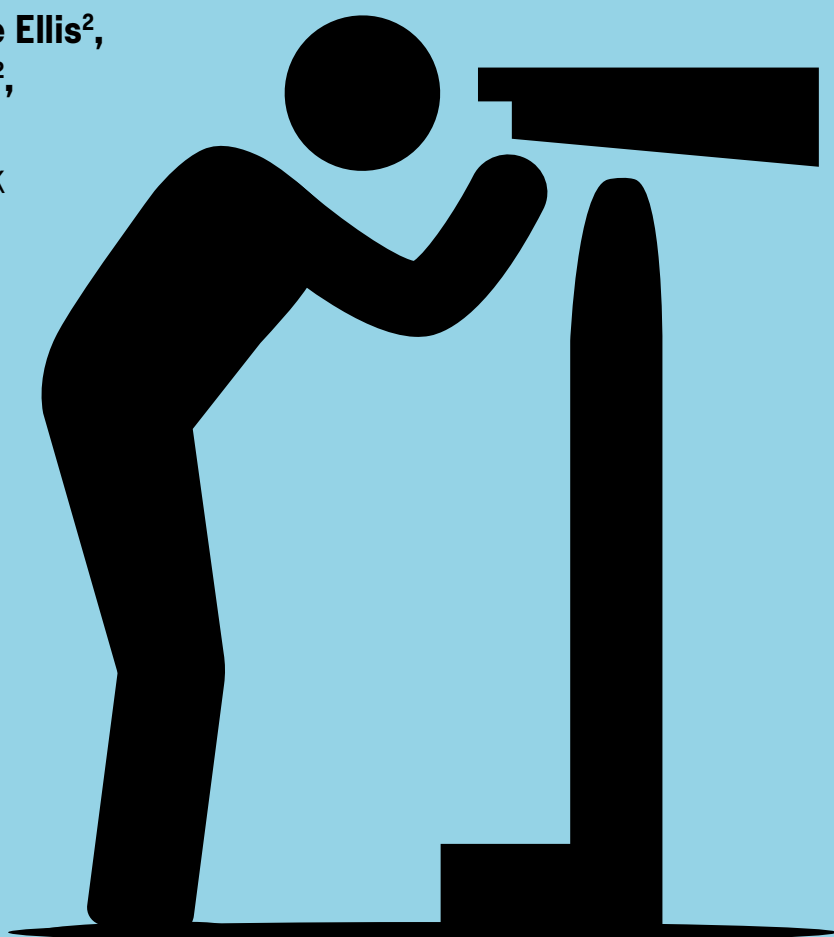
Prostate Cancer Active Surveillance: results and policy recommendations following a UK Freedom of Information (FOI) request.

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**PROSTATE
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Executive Summary

- **More than 56,000 men are diagnosed with prostate cancer in the UK annually.**
- Estimates suggest a third of men diagnosed with localised, non-metastatic prostate cancer, that isn't likely to spread or cause harm during their lifetime, are potential candidates for Active Surveillance (AS).
- Overtreatment of these cancers remains a challenge and is one of the reasons why screening for prostate cancer is not currently recommended in the UK.
- AS is a conservative approach where prostate cancer is monitored using PSA and MRI (and potentially biopsy) over a period of years rather than treating immediately.
- The intention is to avoid the harmful side-effects associated with treatments such as surgery or radiotherapy. However, men on surveillance, and their families, can worry about not treating their cancer immediately.
- To help understand how AS for men with localised prostate cancer is currently being managed in the UK a review of NHS Hospitals' clinical protocols for the management of AS was undertaken during September 2024 to February 2025.
- Our aim was to understand how AS for men with localised prostate cancer is currently being managed in the UK.
- 75/147 (51%) of NHS Hospital Trusts and Health Boards in the UK responded to a Freedom of Information (FOI) request from which we completed our analysis – comparing what NHS Hospitals told us they do in practice, with current published guidelines and recommendations.
- We observed variation in protocols and deviation from guidelines which are detailed in the report.
- Our study concludes that NICE guidelines for AS must be updated to keep pace with the latest evidence-base and advancing clinical practices, so that men get the benefits from AS and avoid the harms of over-treatment and their associated side-effects.
- More men are being diagnosed with prostate cancer and therefore robust and reliable AS programmes are essential, especially if national screening for prostate cancer is to be introduced in the future.
- We hope the findings and recommendations from this study can support policy- and decision-makers to optimise AS approaches that balance the individual needs of men against the optimal use of NHS resources.

Key Findings and Insights

Our research highlights differences between NHS Hospitals active surveillance protocols, and where NHS Hospitals deviate from current NICE NG131 guidelines.

We observed variation in AS protocols including – which men are recommended AS, whether AS follow up is stratified based on CPG or the same follow up for all men irrespective of their prognosis; frequency of testing (PSA, DRE, mpMRI and biopsy), and the clinical end points used to determine when active treatment should be recommended.

NHS Hospitals highlight capacity, funding and resources as some of the challenges and barriers affecting the implementation of AS for their eligible patients. Alongside this, system change, and patient safety-netting are highlighted as areas where NHS Hospitals require support.

AS has a role in reducing overtreatment of prostate cancers that aren't likely to spread outside the prostate (metastasize) or cause death. **Our findings add weight to the argument for guidelines and policy relating to AS to be brought up to date to reflect the latest evidence-base and current clinical practices.**

AS must to be acknowledged as an integral part of the prostate cancer diagnosis and management pathway. It must be given the attention, funding and resources needed to ensure all NHS Hospitals' can provide optimal, safe, and high quality AS services that reduce the psychological burden on patients, and their family members, whilst realising opportunities for the NHS to optimise the use of resources. This will be crucial in reducing the burden of overtreatment and associated harms, if prostate cancer screening programmes are introduced in the future.

1. Introduction

Context

More than 56,000 men are diagnosed with prostate cancer in the UK annually.¹

Estimates suggest that annually, in England alone, up to 1-in-3 men diagnosed with non-metastatic prostate cancer are CPG1 and CPG2 and are potentially suitable candidates for AS.²

The 15-year *ProtecT* trial has shown equally high survival rates in men with prostate cancer with no significant differences in prostate cancer specific mortality amongst the trial treatment groups – monitoring, surgery and radiotherapy. Although AS practice has evolved since the completion of this study, *ProtecT* highlights that treatment choices involve trade-offs because surgery and radiotherapy can lead to more side-effects and treatment-related complications compared to active surveillance.³

Concerns about overtreatment are listed as one of the reason The UK National Screening Committee (UK NSC) do not recommend routine screening for prostate cancer.⁴

The National Prostate Cancer Audit (NPCA) reports an average 8% potential overtreatment rate of patients diagnosed with CPG1 prostate cancer in England; in Wales it is 11%. In England there is variation in potential overtreatment rates with Specialist MDTs (SMDTs) reporting between 2-24% for patients diagnosed with CPG1 prostate cancer.⁵

Previous studies have identified variation in approaches to AS.⁶ Our study aimed to understand how AS is currently being done in the UK, and the barriers and challenges being faced in implementing it. We hope the results from this study, alongside the latest evidence base, can support policy-and decision-makers to continue to optimise AS approaches that balance the needs of men against the optimal use of NHS resources.

Guidelines

Current NICE guidelines state AS is the recommended management for men with CPG1, and an option alongside radiotherapy and prostatectomy for CPG2.⁷ More recently, NHS Getting It Right First Time (GIRFT) published guidelines in which active surveillance is stated as the recommended management for both CPG1 and CPG2.⁸

In 2019, the National Institute for Health and Care Excellence (NICE) updated the clinical guideline *NG131: Prostate cancer: diagnosis and management* . *NG131* was last updated in December 2021 based on a review of evidence leading to a new recommendation that the five point Cambridge Prognostic Groups (CPG1-5) should be used for people with newly diagnosed, non-metastatic prostate cancer; this update was also reflected in some of the AS recommendations under *Section 1.3 Localised and locally advanced prostate cancer* .⁷

Patient factors

Previously, consensus groups have recommended research into, and implementation of, personalised risk-adapted and dynamic approaches to AS.^{9 10} Since the last update to *NG131*, examples of personalised, risk stratified active surveillance approaches have been developed and show promising signs of being able to meet the needs of patients eligible for surveillance, with high patient compliance rates, whilst freeing up NHS resources (i.e. fewer clinical appointments, no DRE, fewer MRI scans, and fewer biopsies which can be redirected to areas of greater need).^{11 12}

Uptake and adherence to active surveillance continues to be a challenge and many factors influence men's choice and ability to adhere to an AS protocol.¹³ **Being diagnosed and living with untreated prostate cancer can have a negative impact on men's psychological wellbeing, quality of life and adherence to AS.**

The support and informational needs of men suitable for AS have been well documented, in addition to the needs of their partners. Men have mixed experiences on AS – some are content with monitoring, others anxious and uncertain, supporting the need for personalised care for each patient.¹⁴ Family also plays an important, and often unrecognised, role in the decision-making process, and studies show they would benefit from more support.¹⁵



2. Data sources and definitions

2.1 Active surveillance protocols

For this review of guidelines, we asked NHS hospitals to answer specific questions about their active surveillance protocols and practices or to submit a copy of their AS protocols for review. All the FOI request questions can be found in **Appendix A**, but in summary we asked about the following areas of AS practice to facilitate our review and comparison against current NICE guidelines:

- **Inclusion criteria** – following diagnosis, which men according to their Cambridge Prognostic Group (CPG) are recommended active surveillance and what other criteria or tools are being used to determine eligibility, i.e. age, biopsy cores involved, PSA density.
- **Diagnosis and treatment decision support** – covering topics like which healthcare professionals are involved in counselling men on their diagnosis, prognosis and treatment choices and the resources and tools being used to deliver counselling.
- **Follow-up pathways and protocols** – in which we asked about the various national and international AS guidelines being used in protocols, whether men were stratified according to their Cambridge Prognostic Group (CPG), whether the service is Nurse-led, how follow-up MRI results are reported, and arrangements for recording, auditing and reporting on AS cohorts.
- **Follow-up testing frequencies** – in addition to asking which guidelines are used for follow-up, we asked for more specific details on each of the follow-up test frequencies by CPG level. Tests include prostate-specific antigen (PSA), magnetic resonance imaging (MRI), prostate biopsy, and digital rectal exam (DRE). Frequency options included 3, 6, 9, and 12 months, based on other test results, or other. We also asked about assessments for psychological needs and fitness to receive treatment, and whether this was part of annual reviews or on a patient led basis.
- **Triggers for stopping active surveillance** – we explored a range of clinical indicators such as MRI or biopsy changes, reclassification to CPG3, and patient preference to better understand which clinical endpoints are being used to determine a recommendation for the patient to commence active treatment.
- **Challenges and barriers to implementing active surveillance** – to support policy and practice change we wanted to know what challenges and barriers NHS hospitals experience in delivering AS to their eligible patients. We didn't give specific options here; we offered a free text field for responders to tell us in their own words.

3. Methods

The study group used insights and knowledge from current guidelines, published evidence and previous audits on AS protocols to inform this audit. Expert clinical stakeholders were asked to review and feedback on the final audit questions.

The audit questions were uploaded to Microsoft Forms ('MS Form'). Questions covered various aspects of AS including which patients are being recommended surveillance based on their Cambridge Prognostic Group (CPG); follow-up testing frequencies for prostate-specific antigen (PSA), digital rectal exam (DRE), multiparametric magnetic resonance imaging (mpMRI or 'MRI'), prostate biopsy; treatment decision counselling; psychological support; clinical thresholds for recommending treatment; governance and audit of AS cohorts; and challenges and barriers to implementing active surveillance. A full list of questions and response options can be found in **Appendix A**.

The Freedom of Information (FOI) Act 2000 was used to request information from NHS Hospital NHS Hospitals and NHS Health Boards across the UK ('NHS Hospitals')¹⁶. 147 NHS Hospitals were contacted either by direct email, or via the online platform 'What Do They Know', with the request and a link to the MS Form; requests were sent out during September and November 2024. The FOI Act 2000 requires organisations to respond to a request within 20 working days.

Responses were either emailed back or directly entered on to the MS Form by the responding NHS Hospital. For responses that were emailed the information was interpreted and entered on the MS Form by two of the study team from Prostate Cancer UK.

Only the responses received within 20 working days (totalling 75) were included in the official analysis. Beyond that point we received a further 6 responses, which have been included in a sub-analysis (section 3.8), giving a total of 81 responses overall.

Each question was analysed individually. The methodology for each type of question is documented below.

- **'Select all options that apply':** responders could select multiple options for one question. As the responders were allowed to select all responses which applied, all NHS Hospital responses were analysed separately. NHS Hospital responses were reported as number and percentage of all NHS Hospitals with a particular response.
- **'Single choice option':** NHS Hospitals could only choose one option per question. For data analysis, each NHS Hospitals' response to the multiple choice was counted and reported. NHS Hospital responses were reported as the number of NHS Hospitals which had a particular response, and what percentage of the total NHS Hospitals agreed on said response.
- **'Free text':** NHS Hospitals were offered a free text response box, enabling them to provide their own free text response with no restrictions of a pre-prepared list of options. In data analysis, the data analyst grouped each NHS Hospitals' response into broad categories that represented a theme in the NHS Hospitals' responses. Once grouped, the number of NHS Hospitals in each group was counted.
- The free text box served many purposes for responders, including to provide more detailed information, to echo responses they had voiced elsewhere in the survey; to provide information that contradicted their response to a previous question; or to provide responses that were not relevant or appropriate for the question, among other uses. Thus, an analysis was conducted specifically for the free text questions to clean the data.
- In cases where an NHS Hospital response contradicted their response in other questions, their response was modified to reflect this. This goes to say, that if a trust's free text response was incongruent with the multiple-choice option that was chosen, the multiple-choice option was modified to reflect this. For example, one NHS Hospital reported that they used PREDICT as a tool to determine AS eligibility within the free text box but failed to select the option 'PREDICT' in the question prior. Therefore, the option 'PREDICT' was retrospectively selected on their behalf within the previous question.
- One thing to note is that the response rate differed for each question, this is made clear for each set of analysis in the next section.

4. FOI data analysis

A summary analysis of this FOI request was previously presented during at the British Association of Urological Surgeons (BAUS) conference 2025.¹⁷

The BAUS conference analysis focused on six key areas – which patients are recommended AS, AS guidelines used, AS follow-up protocols, testing frequencies, clinical end points for recommending active treatment and challenges and barriers to implementing AS.

This report includes the analysis of all questions in the FOI, which are presented below. All percentages are calculated based on the 75 NHS Hospitals that responded, unless otherwise stated. A sub-analysis that includes six additional NHS Hospital responses that were sent in after our main analysis, is presented in section 5.

Audit response rates

Of the 147 eligible NHS Hospitals contacted, 75 (51%) responded by the 20-day deadline (Figure 1). Several NHS Hospitals responded after the deadline and were not included in this analysis; however a sub-analysis of six key topics has been included.

Of the four UK nations, all had at least 50% response rates to our audit questionnaire.

▼ **Figure 1.** Number and percentage of NHS Hospitals' responding to the Freedom of Information (FOI) request, by UK nation.

Devolved nation	Requested	Responded	% of NHS Hospitals responding	% of survey responses
England	120	62	52%	83%
Northern Ireland	5	4	80%	5%
Scotland	14	5	50%	7%
Wales	8	4	50%	5%
Total	147	75	51%	100%

Active surveillance inclusion criteria

Clinical factors

Figure 2 shows the NHS hospitals' response to inclusion criteria. 97.3% and 81.3% of NHS hospitals recommend active surveillance to men with CPG1 and CPG2, respectively. A combined 20% of NHS Hospitals recommended active surveillance to men with CPG3, including Gleason 3+4 or 4+3. A further 10.7% selected 'Other'. NHS hospitals also cited PSA density (PSAd) (54.7%), number of biopsy cores involved (49%) and biomarkers (e.g. Phi, PCA3, 4K) (6.7%) to determine inclusion of patients into active surveillance.

▼ **Figure 2.** NHS Hospitals' response to the question- 'What patients are recommended AS?' This question followed the format of 'select all options that apply'.

Cambridge Prognostic Group (CPG)	Number of NHS Hospitals	Percentage of NHS Hospitals
CPG1	73/75	97.3%
CPG2	61/75	81.3%
CPG3 (3+4)	14/75	18.7%
CPG3 (4+3)	1/75	1.3%
Other	8/75	10.7%

Patient factors

Most NHS Hospitals, 55 (73.3%), stated that patient choice/willingness is a factor. Although this is likely to be higher in practice because patient choice is a legal right with the NHS framework. Patient life expectancy 39 (52%), age cut-off 31 (41.3%), family history of prostate, breast or ovarian cancer 27 (36%), patient ethnicity 20 (27%), where other reported factors.

Prognostic tools

32 (42.7%) NHS Hospitals reported using the Predict Prostate online tool. Predict Prostate is an individualised prognostic model for men newly diagnosed with non-metastatic prostate cancer.

Diagnosis and treatment decision support

Workforce

For patients eligible for AS, those counselling patients on their diagnosis, prognosis and treatment options a multi-disciplinary team (MDT) approach is apparent from our results. Urologists (84%), Urology/Prostate Cancer Clinical Nurse Specialist (CNS) (68%), Oncologist (36%), and other specialist Healthcare Professionals (HCPs) are involved in supporting patients in the early stage of the pathway (Figure 3).

▼ **Figure 3.** For patients eligible for AS, who counsels them regarding their diagnosis, prognosis, and treatment options? This question allowed NHS Hospitals to 'select all options that apply'.

Healthcare Professional	Number of NHS Hospitals	Percentage of NHS Hospitals
Urologist	63/75	84.0%
Urology / Prostate Cancer Clinical Nurse Specialist (CNS)	51/75	68.0%
Oncologist	27/75	36.0%
Uro-Oncology CNS	24/75	32.0%
Urology / Prostate Cancer Advanced Nurse Practitioner (ANP)	16/75	21.3%
Other (e.g. care navigator, cancer support worker, nurse consultants, registrar, physician associate)	11/75	14.7%
Uro-Oncology ANP	6/75	8.0%

Decision-making tools and support resources

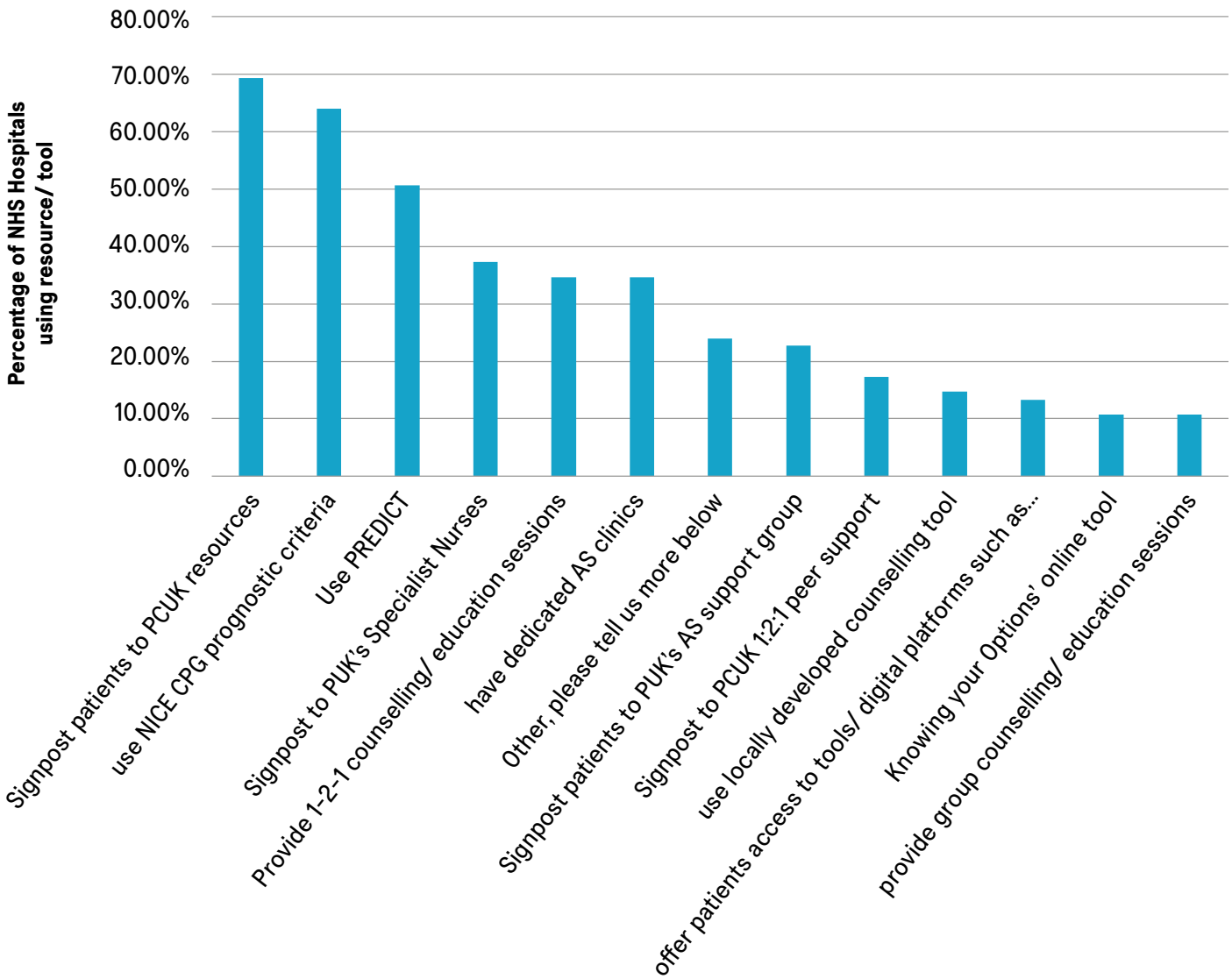
Figure 4 shows that 69.3% of NHS Hospitals say that HCPs, who counsel AS eligible patients, signpost to Prostate Cancer UK (PCUK) resources. Other PCUK services including Specialist Nurses (37.3%), online Active Surveillance Support Group (22.7%), and One-to-One Peer Support (17.3%) are also being utilised.

Evidence-based tools such as the Cambridge Prognostic Group (CPG) criteria in NICE guidelines (64%), *Predict Prostate* (50.7%), and *Knowing Your Options* (10.7%) online decision tools are in use, although with mixed uptake despite NICE guidelines recommending or endorsing these tools.

Some NHS Hospitals provide locally developed services, such as, one-to-one counselling/education (34.7%), locally developed counselling tools (14.7%), online PSA tracking tools (13.3%), and group counselling/education sessions (10.7%).

34.7% said they hold dedicated AS clinics, which separates their AS cohorts from those receiving surgery, radiotherapy, or chemotherapy; the assumption being that men on AS have different needs to men receiving active treatments.

▼ **Figure 4.** NHS Hospitals’ response to the question- ‘Which resources and tools are used/ made available by HCPs who counsel /support men on AS?’ This question followed the format of ‘select all options that apply’.



Follow-up pathways and protocols

Guidelines

Once patients have been enrolled on to AS, NHS Hospitals look to be referencing a range, and combination, of national or locally developed guidelines to determine AS follow-up approaches.

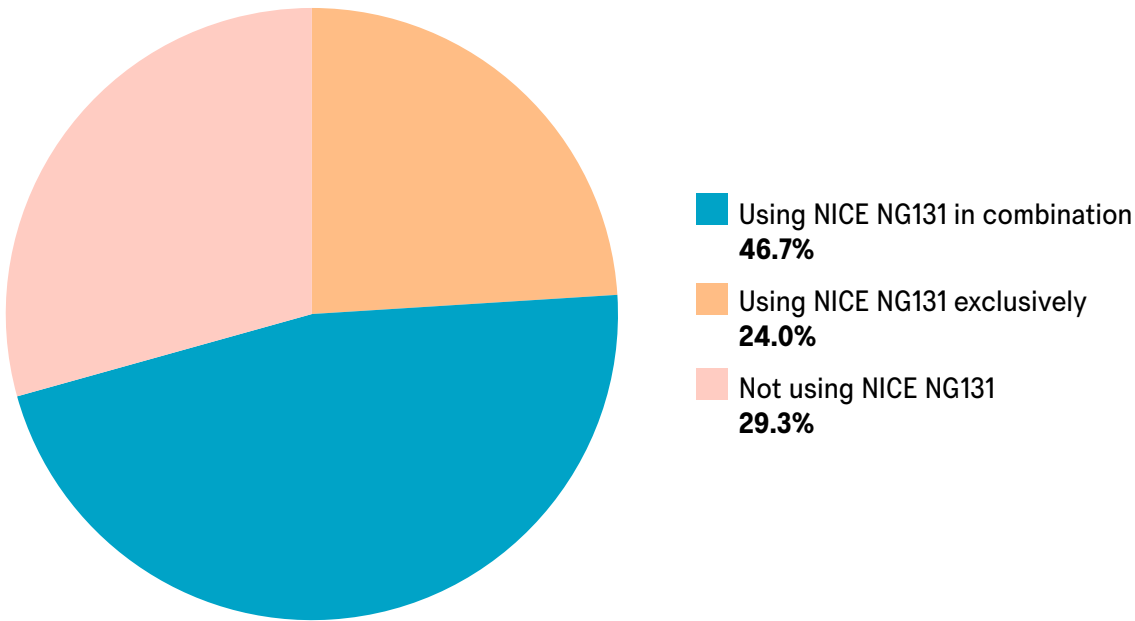
Figure 5 shows the various active surveillance protocols being used by NHS hospitals. 70.7% NHS Hospitals reference using NICE NG131 guidelines in follow up protocols, with 24% following these guidelines exclusively. 76% use NICE NG131 in combination, or not at all, whilst 35 (46.7%) have developed a local protocol. The latter suggests that practice has developed away from current NICE guidelines. Figure 6 shows the breakdown if NHS hospitals which use NICE, don't use NICE, or use NICE in combination with other protocols.

▼ **Figure 5.** NHS Hospitals' response to the question- 'Which protocol do you use to manage your patients on AS follow-up?' This question followed the format of 'select all options that apply'.

Response	Number of NHS Hospitals	Percentage of NHS Hospitals
NICE NG131, Prostate cancer: diagnosis and management guidelines	53/75	70.7%
Using NICE NG131 guidelines exclusively	18/75	24.0%
Using NICE NG131 in combination	35/75	46.7%
Don't use NICE NG131 at all	22/75	29.3%
A locally developed protocol based on published evidence	35/75	46.7%
EAU - ANM - ESTRO ESUR - ISUP - SIOG Guidelines on Prostate Cancer	23/75	30.7%
A combination of guidelines	22/75	29.3%
STRATified CANcer Surveillance (STRATCANS) or a modified version of STRATCANS	14/75	18.7%
Other (e.g. 'protocol under review' or 'personalised')	10/75	13.3%
Prostate cancer Research International: Active Surveillance (PRIAS) protocol	4/75	5.3%

▼ **Figure 6.** NHS Hospitals’ response to the question - ‘Which protocol do you use to manage your patients on AS follow-up?’ Aggregated by whether the NHS Hospital use NICE NG131, doesn’t use NICE NG131, or uses NICE NG131 in combination with other guidelines.

Percentage of NHS Hospitals using NICE NG131 guidelines in their local protocol (n=75)

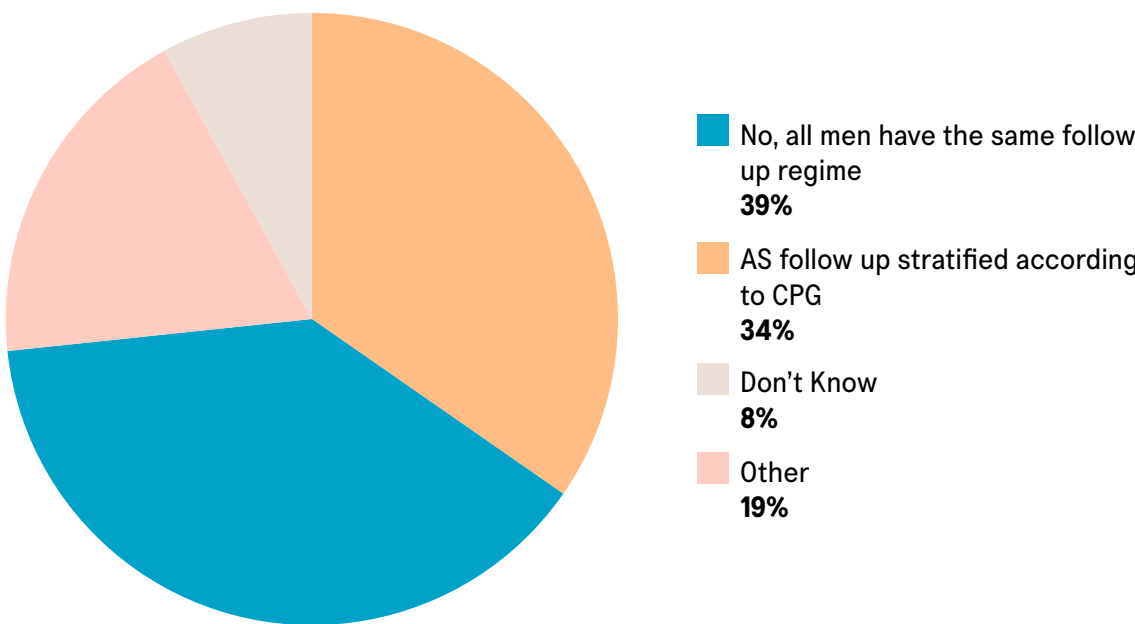


Personalised care

A little over a third of NHS Hospitals reported having a stratified AS programme based on a patient’s CPG classification, which means patients follow up test frequencies change according to their CPG, versus all men having the same follow up irrespective of their CPG as per NICE NG131 guidelines. This is shown in Figure7, where 38.7% of NHS Hospitals said that all men follow the same follow-up regime. The remaining NHS Hospitals reported different protocols in small numbers including personalised follow-up programmes (9.3%), local protocols (8%), and some stratification (4%). Many NHS hospitals that replied with ‘Other’ to either questions regarding the protocol or risk stratification elaborated further in the free text questions later in the survey.

▼ **Figure 7.** NHS Hospitals response to the question, ‘Do you have a stratified AS programme based on CPG?’ This question was single choice only format.

Do you have a stratified as follow up programme based on CGP? (n=75)



Testing frequencies

As seen in Figure 8 and Figure 9, most NHS Hospitals agree that PSA testing is frequent among CPG1 patients, with 43% of NHS Hospitals reporting PSA testing every 3 months and 17% of NHS Hospitals reporting PSA testing every 6 months. This is similar for CPG2 patients at 43% PSA testing every 3 months and 15% every 6 months.

▼ **Figure 8.** NHS Hospitals response to the question, 'Do you have a stratified AS programme based on CPG?' This question was single choice only format.

CPG1								
Frequency options	PSA		MRI		BIOPSY		DRE	
	#	%	#	%	#	%	#	%
once every 3 months	32/75	42.7%	1/75	1.33%	0/75	0%	0/75	0%
once every 6 months	13/75	17.3%	1/75	1.33%	0/75	0%	3/75	4.0%
once every 9 months	0/75	0%	0/75	0%	0/75	0%	0/75	0%
once every 12 months	0/75	0%	22/75	29.3%	0/75	0%	7/75	9.3%
based on PSA/MRI result	0/75	0%	8/75	10.7%	32/75	42.7%	2/75	2.7%
Other frequency	14/75	18.7%	25/75	33.3%	21/75	28.0%	23/75	30.7%
Never	0/75	0%	0/75		3/75	4.0%	19/75	25.3%
No reply	16/75	21.3%	18/75	24.0%	19/75	25.3%	21/75	28.0%
Sum	75	100%	75	100%	75	100%	75	100%
NHS Hospitals responding	59/75		57/75		56/75		54/75	
Response rate	78.7%		76.0%		74.7%		72.0%	

▼ **Figure 9.** NHS Hospitals' response to the question- 'For men diagnosed with CPG2 risk prostate cancer, select the relevant follow-up test frequencies for PSA, MRI, Biopsy, and DRE.' This question followed the format of 'select one option only'.

CPG2								
Frequency options	PSA		MRI		BIOPSY		DRE	
	#	%	#	%	#	%	#	%
once every 3 months	32/75	42.7%	0/75	0%	0/75	0%	0/75	0%
once every 6 months	11/75	14.7%	1/75	1.3%	0/75	0%	3/75	4.0%
once every 9 months	0/75	0%	0/75	0%	0/75	0%	0/75	0%
once every 12 months	0/75	0%	28/75	37.3%	2/75	2.7%	8/75	10.7%
based on PSA/MRI result	0/75	0%	4/75	5.3%	27/75	36.0%	2/75	2.7%
Other frequency	13/75	17.3%	20/75	26.7%	23/75	30.7%	20/75	26.7%
Never	0/75	0%	0/75	0%	2/75	2.7%	18/75	24.0%
No reply	19/75	25.3%	22/75	29.3%	21/75	28.0%	24/75	32.0%
Sum	75	100.0%	75	100.0%	75	100.0%	75	100.0%
NHS Hospitals responding	56/75		53/75		54/75		51/75	
Response rate	74.7%		70.7%		72.0%		68.0%	

NICE guidelines currently recommend clinicians consider an MRI scan at 12–18 months in the ‘first year’ of surveillance, regardless of the patient’s CPG classification. From year 2 onwards NICE recommend reassessment with MRI (+/- biopsy) based on PSA changes. Our results show that 29% of NHS Hospitals say they conduct an MRI scan annually for CPG1 patients and 37% for CPG2 patients.

Just 9% and 11% of NHS Hospitals conduct an annual DRE exam for men in CPG1 and 2, respectively. This is likely because clinicians’ have access to mpMRI images and can therefore avoid doing a DRE. This also means that patients on AS do not need to attend hospital routinely for an unnecessary physical examination.

NICE recommends repeat biopsies on any change on PSA and MRI results. However, this guidance is vague and does not specify type or amount of change which should trigger a biopsy. For CPG1, 43% of NHS Hospitals conduct a biopsy based on PSA/MRI results and 36% order a biopsy based on PSA/MRI change for CPG2.

For CPG1 prostate cancer, 60% of NHS hospitals or PSA tests every 3 or 6 months, 31.9% of NHS hospitals have a routine MRI (once every 3,6,9, and 12 months and 25.3% of NHS hospitals say they never do DRE. For CPG2, 57.4% of NHS hospitals do a routine PSA every 3 or 6 months, 38.6% do routine MRI (every 3, 6, 9, or 12 months), and 24% never do DRE.

Some follow-up tests drop to as low as 9% adherence with NICE guidelines. This is a concerning difference between self-reported protocols compared to actual conduct and testing.

MRI reporting tools

The Prostate Cancer Radiological Estimation of Change in Sequential Evaluation (PRECISE) score is a standardised system used in prostate cancer active surveillance. It is an assessment of the likelihood of clinically significant radiological changes, based on the review and reporting of serial mpMRI scans. PRECISE is reported on a 7-point scale (Figure 10).¹⁸

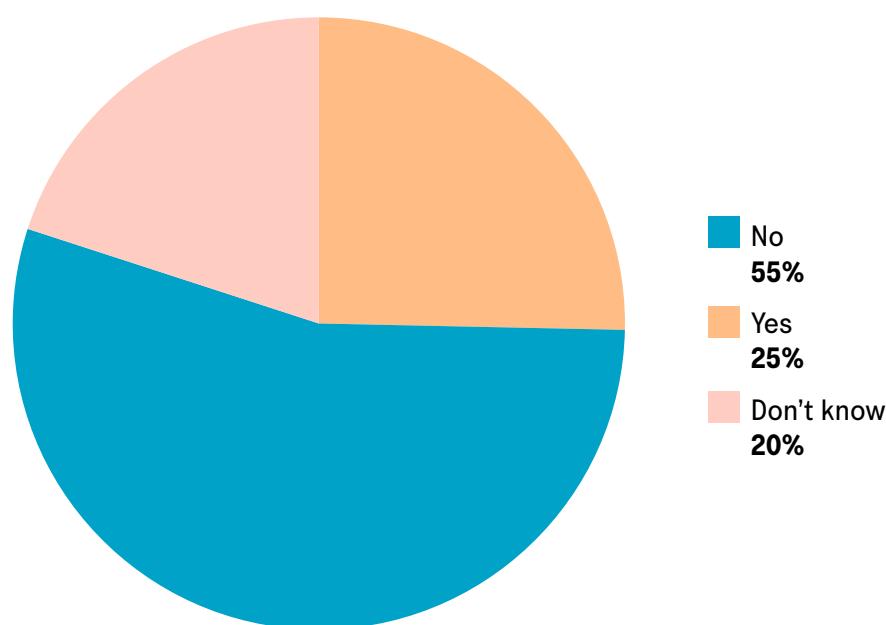
▼ **Figure 10.** The updated PRECISE v2 scoring system (Englman, Cameron et al. 2024).

PRECISE score	Likelihood of radiological change
1	Complete resolution of previous suspicious features on MRI
2	Reduction in size and/or conspicuity of previous suspicious area
3 visible	Stable MRI appearance with a visible focal lesion
3 non-visible	Stable MRI appearance with no focal lesion
4	Significant increase in size and/or conspicuity of suspicious features; appearance of a new focal lesion
5	Definitive radiological stage progression
X	Not possible to provide a PRECISE score

NHS hospitals were asked whether they used PRECISE for mpMRI reporting. As shown in Figure 11 below, 41/75 NHS hospitals (55%) said ‘No’, 19/75 (25%) said ‘Yes’, and 15/75 (20%) said ‘Don’t know’.

▼ **Figure 11.** NHS Hospitals' responses to the question 'Do you use MRI PRECISE scoring?' This question was 'select one option' only.

Percentage of NHS Hospitals using precise MRI scoring in their as follow up programme



As covered earlier in the report, meeting the psychological needs of men and their families is an important factor in helping them choose and stick with AS, as long as their cancer remains stable. Figure 12 shows that 49.3% of NHS Hospitals assess psychological support needs at diagnosis, 34.7% during annual review. 56% said this would be done when needed. i.e. they'd be led by the patient.

A patient's fitness to receive active treatment, should it be necessary, is also an important part of the AS follow up pathway. 60% said this assessment would be done at first diagnosis, 53.3% during annual review, and 41.3% when needed (patient led). Figure 13 give us an overview of NHS hospitals offering psychological support and assessment of fitness for treatment.

▼ **Figure 12.** NHS hospitals response to the question, 'Do you assess the psychological support needs or fitness for treatment in men on active surveillance?' This question was 'select all options that apply'.

Response	Psychological support	Fitness to receive active treatment
Yes, during their annual review	(26/75) 34.7%	(40/75) 53.3%
Yes, when needed (patient led)	(42/75) 56%	(31/75) 41.3%
Yes, at first diagnosis	(37/75) 49.3%	(45/75) 60.0%
No, not assessed	(5/75) 6.7%	(3/75) 4.0%
Don't know	(7/75) 9.3%	(6/75) 8.0%

▼ **Figure 13.** Overview of NHS Hospitals which offer psychological support and/or assess fitness for treatment in men on active surveillance.

Combined 'Yes' responses	Number of NHS Hospitals	Percentage of NHS Hospitals
Yes, during their annual review	(26/75) 34.7%	(40/75) 53.3%
Psychological support needs	60/75	80.0%

A third (34.5%) of NHS Hospitals that told us more about their psychological support and fitness for treatment assessments, themes such as Health Needs Assessment (HNA), cancer support workers / care navigators, referral to other organisations, and holistic care were mentioned.

Nurse-led AS services

Nurse-led AS has been shown to be safe, effective and linked to high levels of patient satisfaction, where patients value continuity of care amongst other things. 66.7% of NHS Hospitals say they have a Nurse-led service for patients on AS, 21.3% have a Urology Consultant-led service, and 12% reported they were planning to implement a Nurse-led service in future.

Triggers for switching to active treatment

Patient preference

Most NHS Hospitals (86.7%) said that patient preference to stop active surveillance and start radical treatment was part of their protocol, this means that men could switch from monitoring active treatment if they wanted. As mentioned previously, the percentage is likely to be higher in practice because patient choice is a legal right with the NHS framework. Managing the psychological needs of patients in the absence of disease progression remains important in this respect. Men can worry about disease progression and metastasis, and family members can perceive monitoring as 'doing nothing' or the 'easy option'.

Disease progression

NICE guidelines currently recommend that radical treatment should be offered to patients on AS, when they have 'evidence of disease progression'. Our study suggests that NHS Hospitals are using more clearly defined cut-offs, including - MRI changes to T3 (78.9%), biopsy progression to GG3 (74.7%), and reclassification to CPG3 (68%) shown in Figure 14. Any change in biopsy grade and MRI were cited by 31 NHS Hospitals (41.3%). This suggests that NICE guidelines could move towards a more clearly defined cut-off based on MRI, biopsy and CPG criteria.

▼ **Figure 14.** NHS Hospitals' response to the question- 'At what cut-off point do you recommend men start active treatment?' This question followed the format of 'select all options that apply'.

Types of AS cut-off criteria	Number of NHS Hospitals	Percentage of NHS Hospitals
Patient preference	65/75	86.7%
MRI changes to T3	59/75	78.7%
Biopsy progression to GG3	56/75	74.7%
Reclassification to CPG3	51/75	68.0%
Any change in MRI	31/75	41.3%
any change in biopsy grade	31/75	41.3%
Other	13/75	17.3%

Arrangements for recording, auditing and reporting on AS cohorts

(68%) of NHS Hospitals reported having a formalised AS protocol in place. 25.3% said they had a formal register of AS patients that is regularly updated, and only 9.3% are auditing and reporting on patient compliance and attrition rates. 25.3% said they had none of these in place.

Challenges and barriers to implementing active surveillance

The survey provided an open text field for NHS Hospitals to respond with barriers and challenges to delivering AS to eligible patients. Some NHS Hospitals mentioned more than one barrier or challenge. Figure 15 shows that just over half of the NHS Hospitals responded 43/75 (59%) with the most common answer by far being related to capacity, resources and funding (67.4%). Implementing change and failsafe systems such IT and PSA tracking were also mentioned 27.9% and 25.6% respectively.

▼ **Figure 15.** NHS Hospitals' response to the question- 'What are the main barriers and challenges you have identified in delivering AS for your eligible patients?' This question followed the format of 'free text questions'.

Responses	Number of times barrier/challenge reported	Percentage of Total responding NHS Hospitals
Capacity, funding, resources	29/43	67.4%
Implementing Change	12/43	27.9%
Failsafe systems (IT systems / PSA tracking)	11/43	25.6%
Patient Compliance	5/43	11.6%



5. Sub-analysis of FOI responses

After the deadline for NHS hospitals responses, we received 6 more responses from NHS hospitals across the UK. Due to time constraints, we could not re-do the full analysis with these 6 NHS Hospitals but instead chose to do a sub-analysis which analysed these NHS Hospitals results to the most important questions- inclusion, protocol, urology unit criteria, risk stratification, PRECISE scoring, cut-off, and barriers.

With the addition of these 6 NHS hospital the total NHS hospital number responses we received went from 75 to 81. Of the 6 new NHS Hospitals, 3 were from the South West, 1 was from the North East & Yorkshire, 1 was from the East of England, and 1 was from Scotland. Therefore, the UK breakdown of respondents shifted, as shown in Figure 16 below.

▼ **Figure 16.** The national breakdown of respondents for the sub-analysis national breakdown of respondents for the sub-analysis.

	Requested	Responded	% of survey responses
England	120	67	83%
Northern Ireland	5	4	5%
Scotland	14	6	7%
Wales	8	4	5%
Total	147	81	100%

To evaluate whether the sub-analysis notably changed the proportion of responses received, the percentage difference of responses from the NHS hospitals from the original study to the sub-analysis was evaluated. If there was a >5% percentage difference between the original and new study results was achieved, this was considered a meaningful difference.

However, when including the original responses in the sub analysis, the data did not change by more than 5%. Therefore, we can conclude that the 6 new NHS hospitals' response did not considerably change the data. The data above is representative of NHS Hospitals' performance of active surveillance across the UK, from the best of our understanding.

6. Limitations

Our study reports on active surveillance for early prostate cancer based on protocols and practices either self-reported by NHS hospitals, or information gathered by Prostate Cancer UK staff from written protocols received by email. It is possible that some of the reported practices based on written protocols could differ from actual practice.

Some NHS hospitals told us they referred patients to other hospitals for prostate cancer, others told us they would not be able to complete the FOI request within the given timeframes (20 working days), others did not respond. We therefore received responses from approximately 51% of NHS hospitals in the UK which we believe to be a useful representation for analysis.

Some of the questions, and possible response options, didn't align fully with terminology used within NICE guidelines, for example the testing frequencies did not include options to detail year 1 and year 2 onwards testing frequencies. We expect there to be some degree of interpretation in that case, but we don't think this will impact overall on the results which demonstrate variation and deviation from NICE guidelines.

7. Policy implications and recommendations

Addressing variation

The work presented here highlights substantial variation and concerning inconsistencies in how active surveillance is applied in practice across the UK. The results presented cannot in isolation characterise whether this variation is due to inadequate guidelines or poor adherence. It is possible that multiple factors influence the observed variation and this needs to be further investigated. However, accounts from clinicians, the current evidence base and what is currently considered best practice makes it apparent that practice has moved beyond the current version of the NICE guidelines. This means that local protocols have been put into place to fill the gap and determine eligibility for and management of AS, resulting in variation in the care a man receives depending on where he lives or which guidance his clinician follows.

Guideline updates

The NICE guidelines on active surveillance must be updated to ensure that patients receive consistent care that is informed by the latest evidence. Prostate cancer is now the most diagnosed cancer in England and the most common cancer in men in the UK, and the number of men diagnosed with low-risk cancer will continue to rise. Due to this, AS will be a critical management option to avoid overtreatment of cancers, that we know have a low likelihood of metastasising or causing death, and its associated burden on the NHS, so an update is urgently needed to avoid exacerbating inconsistencies in care. This will become even more critical if any type of prostate cancer screening is recommended and rolled-out in the future.

Key publications from urology experts over the last few years^{7 10 12} have highlighted that AS is the now the recommended approach for those in both CPG1 and CPG2, that use of MRI as a component of routine AS monitoring is now standard, that use of DRE is not needed if patients are suitable for MRI-led monitoring, and that follow up intensity should be determined by a patient's cancer risk rather than how long they've been on AS. These represent key aspects of best practice in AS that the current guidelines do not reflect.

Patient and clinician education

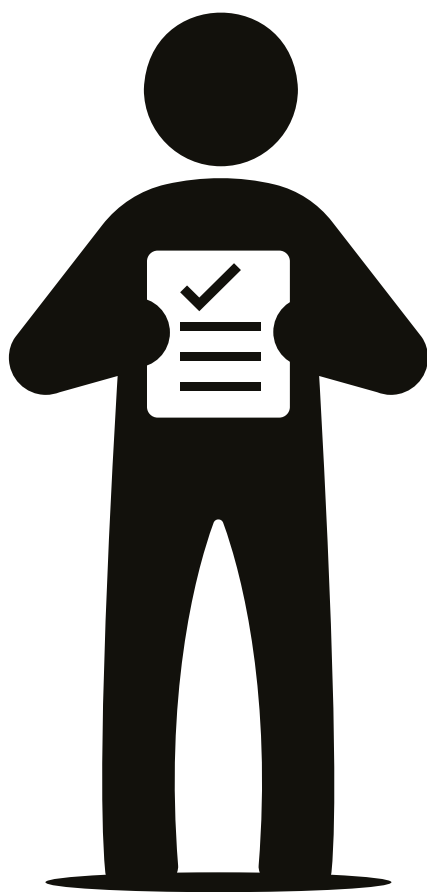
Ensuring effective and consistent implementation of AS also goes beyond the guidelines. It is critical that both clinicians and patients are aware that active surveillance is safe for patients with CPG1 and CPG2 cancer and can enable men in these groups to delay or avoid radical treatment. As well as benefiting patients, increased awareness of active surveillance as a first-choice option will ensure more optimal use of NHS resources for those who most need radical treatment. Additionally, increased awareness of best practice¹⁹ for implementing active surveillance is key, including assessing patients' psychological support needs, ensuring that there are processes in place for auditing and monitoring active surveillance programmes, and critically, ensuring that there are ways of tracking patients on AS, which concerningly a quarter of NHS Hospitals who responded to the FOI request said they do not have.

Funding and resources

Underinvestment in AS has been previously described.²⁰ In this study 70% of NHS Hospitals who responded to our freedom of information request cited capacity, resources and funding as a barrier to implementing AS. As the number of prostate cancer diagnoses increases, AS will become increasingly critical as an option for early prostate cancers that have a low likelihood of causing harm during a man's lifetime, especially in the context of mass screening, so ensuring that NHS Hospitals are properly resourced and able to offer this as a first-choice option is key.

Appendix A – Freedom of Information request

<https://prostatecanceruk.org/active-surveillance-FOI-pdf>



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