

Does empowering men on active surveillance for prostate cancer improve patient compliance and reduce conversion to treatment?

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Active surveillance is a major treatment option for patients with favourable prognosis prostate cancer, such as those regarded as Cambridge Prognostic Group (CPG) 1 and 2 [1]. The rationale for this management strategy is the lack of survival benefit from radical curative treatment for patients with CPG 1 and 2 cancers [2]. Active surveillance protocols that are commonly used lack an evidence base for how to risk stratify follow-up. Consequently, the Stratified Cancer Surveillance (STRATCANS) protocol was developed using an evidence-based approach to identify predictors of progression and hence which men were at the lowest risk of progression [3]. STRATCANS tailors the intervals for prostate specific antigen (PSA) testing, repeat MRI scans, and the need for repeat biopsies based on the risks of the cancer progressing to a stage where treatment is usually recommended. The STRATCANS protocol and evidence base can be accessed at www.stratcans.com. We present our experience of implementing the STRATCANS risk stratification system, and how we empowered men on surveillance to be involved in and support their own management.

What did we do?

The East of England's Cancer Alliance Best Practice Guidelines for Prostate Cancer endorsed STRATCANS in 2019. A key part of implementation of the programme in our centre was the recognition that men who had been on the previous programme needed to be transferred smoothly across to the new protocol. All patients were contacted by letter and advised to contact their prostate cancer specialist nurse if they had any questions. Unsurprisingly, this led to an increase in men contacting the specialist nurse telephone line to enquire about the change and so they could fully understand the impact on their care. I collated their queries to develop a 'Frequently Asked Questions' resource which was sent to all patients on active surveillance. The extra communication with patients demonstrated that many men had a fear of missing the opportunity to cure their cancer if their follow-up was extended.

To educate and empower our patients we developed an educational seminar for men who are on active surveillance. The content of the seminar was selected to provide reassurance to patients based on the queries we had already received. The seminar focused on explaining the risk and benefit of active surveillance, the risk of prostate cancer and the overall risk from other causes. We included a supported self-management strategy and informed men about what is expected from them. We covered the importance of PSA monitoring and using an online tracker (e.g., Track My PSA) or the My Chart Patient Portal of the local health record. This helped to provide patients with a sense of ownership and encouraged involvement in their own care. We highlighted the expected natural progression of prostate cancer, as well as the expected slow increase / fluctuation of PSA to help aid patients' understanding of the nature of PSA. Urinary tract symptoms was one of the most common

reasons for patients to contact the telephone help line and we therefore addressed this in the seminar by informing patients about the reasons for urinary symptoms. The seminar included non-clinical support available through a cancer navigator and information on how to contact this service directly.

All men were invited to attend the seminar and verbal feedback was gained. We found that some patients were unable to attend sessions due to work commitments, which led to us recording the session with the help of the Addenbrookes Charitable Trust (ACT). The video link of the recorded session is now sent to all patients at the time of their decision to have active surveillance (for those unable to access the internet we provide a printed version of the presentation).

We published the early outcome of our protocol in 2023 [4]. This has shown the positive outcome of a high level of patient compliance, reducing the number of MRIs, biopsies and clinic visits, as well as an opportunity to develop nurse-led services. The number of men contacting their specialist nurse by telephone has significantly reduced despite an increase in the number of men on active surveillance.

Benchmarking with international sources and STRATCANS has shown better adherence to surveillance. It is hard to prove that it is directly related to the patient education seminar, however, we are convinced that better patient education has reduced patients' anxiety and verbal feedback reports that patients feel empowered and more in control.

Discussion and summary

There are some studies demonstrating the psychological impact of living with non-treated prostate cancer leading to conversion to treatment. This is mainly related to anxiety, fear of progression and losing control, which is a reason for non-acceptance of active surveillance [5]. A mixed method systematic review by Kinsella et al. reported that compliance to active surveillance can be improved by information provision, patient education, standardised protocol and psychosocial support [6]. In another study anxiety due to lack of control was noted to be significant [7].

Although it is debatable that the patient education seminar alone improved patient compliance with surveillance, our experience shows that the session improved patients' understanding of the STRATCANS protocol and reduced their anxiety and need to contact their specialist nurses. Notably in the recent report of our five-year outcomes from STRATCANS implementation, only 3.4% of men left surveillance due to anxiety (compared to 13% from internal consortium data) [8-9]. Currently, other centres are establishing the STRATCANS protocol, and it will be interesting to see a comparison of outcomes with and without a patient education seminar. A formal record of patient feedback and evaluation of the service is planned in the future, which will further inform us about our patients' experience.

References

1. NICE. *NICE guideline [NG131]: Prostate cancer: diagnosis and management*. Published 2019, updated 2021. <https://www.nice.org.uk/guidance/NG131> [Last accessed 25 February 2025].
2. Hamdy F, Donovan J, Lane A, et al. Fifteen-year outcomes after monitoring, surgery or radiotherapy for prostate cancer. *N Engl J Med* 2023;**388**:1547–58.
3. Gnanapragasam VJ, Barrett T, Thankappannair V, et al. Using prognosis to guide inclusion criteria, define standardised endpoints and stratify follow-up in active surveillance for prostate cancer. *BJU Int* 2019;**124**(5):758–67.
4. Thankappannair V, Keates A, Barrett T, Gnanapragasm V. Prospective implementation and early outcomes of a risk-stratified prostate cancer active surveillance follow-up protocol. *Eur Urol Open Sci* 2023;**14**:15–22.
5. Van Dev Bergh RC, Korfagel J, Bagma CH. Psychological aspects of active Surveillance. *Curr Opin Urol* 2012;**22**:237–42.
6. Kinsella N, Stattin P, Cahill D, et al. Factors influencing men's choice of and adherence to active surveillance for low-risk prostate cancer: a mixed-method systematic review. *Eur Urol* 2018;**74**:261–80.
7. Pickles T, Ruether JD, Weir L. Psychological barriers to active surveillance for the management of early prostate cancer and a strategy for increased acceptance. *BJU International* 2007;**100**:544–51.
8. Gnanapragasam VJ, Keates A, Lophatananon A, Thankappannair V. The 5-year results of the Stratified Cancer Active Surveillance programme for men with prostate cancer. *BJU Int* 2025;**135**(5):851-9.
9. Van Hemelrijck M, Ji X, Helleman J, Roobol MJ, et al.; Members of the Movember Foundation's Global Action Plan Prostate Cancer Active Surveillance GAP3 consortium. Reasons for Discontinuing Active Surveillance: Assessment of 21 Centres in 12 Countries in the Movember GAP3 Consortium. *Eur Urol* 2019;**75**(3):523–31.

Useful websites

1. Criteria of the Cambridge Prognostic Groups for non-metastatic prostate cancer CPG 1-3 web tool – <https://cambridgeprognosticgroup.com>
2. STRATCANS Stratified Cancer Surveillance – www.stratcans.com
3. East of England Cancer Alliance- Know Your options website – www.canceralliance.co.uk/prostate

TAKE HOME MESSAGES

- Active surveillance is recommended by national guidelines and avoids over treatment and the impact of side-effects on quality of life.
- Anxiety related to living with untreated prostate cancer and fear of 'missing the boat' for treatment need to be addressed.
- A clear protocol with a surveillance endpoint helps to reduce anxiety-related conversion to treatment.
- Patient education and empowerment improves compliance to active surveillance and reduces the frequency of healthcare contact.

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Declaration of competing interest: None declared.