

***Active Surveillance Patients International for Prostate Cancer  
A Town Hall Webinar - Testimonials by International Patients***

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The webinar's objective was to present a number of testimonials by patients on Active Surveillance (AS). The contributors came from the US, Canada, Iceland and Italy. A number of Urologists recently presented webinars on AS, mainly by AnCan and Us TOO International. ASPI saw the need for AS patients to:

- share information and experiences,
- to understand better their PCa treatment path,
- how they could choose AS,
- the difficulties they encountered from their family doctors in their decision-making,
- also the difficulties they had accessing the sources of reliable information needed to take this decision,
- how they faced anxiety during their AS journey,
- support they got during AS and;
- which type of support would best to offer in future to other men facing same experience,
- understanding of both overtreatment and undertreatment risks.

This was seen as a first step in meeting the needs of men with AS. It will need to be followed up with many more structured actions by Active Surveillance Patients International (ASPI). The objective was to verify the different experiences of AS over the years and in different countries in order to plan further actions to support international patients on AS.

ASPI is not "anti-medical" intervention but it is "anti-Unnecessary" intervention risks. While AS treatment is in principle very good to maintain physical Quality of Life, the sense of the meeting was that there should be specific emphasis on the psychological risk of anxiety which result from overtreatment or other side effects.

There will be a series of video recording of these testimonials on ASPI web site.

Quality of Life was a benefit for all these patients, but not to the same level from the psychological standpoint. The patients that had chosen Active Surveillance in the years 2000-07 had to dig for information, discuss with medical specialists who could probably not gave enough credit to AS, due to lack of clinical data and family and friends who did not understand what they saw as "the lack of medical treatment".

In the period till 2018 the situation began to evolve as clinical studies started to demonstrate the equivalent success of patients with low-grade Gleason Score who followed a treatment path with Active Surveillance compared with Radiotherapy and Surgical intervention even though there were very different approaches to AS in the medical world, especially in the sequencing of PSA, MRI and biopsy type. In many cases patients took the step to seek a second opinion on their condition and to make special efforts to inform themselves about the Active Surveillance option. As time moved on the medical environment has a more diffused approach to AS, and starts to apply AS, using more and more specific new approaches including PSA density, MRI , Fusion and transperineal biopsies and even Genomic Testing .

Due to above different situations in the PCa AS journey, the anxiety issue was very different for the patients; from a total difficulty in decisions due to completely opposing choices and also very strong anxiety in the early days of AS. In general the anxiety is now more limited to the yearly pre-checks (PSA, MRI, Biopsies)

In any case a general benefit to most of these patients was taking part and develop Patient Support Groups, both for all PCa patients and in some cases only for AS patients. Even if in many cases a patient with Gleason 3+3 do not move rapidly to a more aggressive grade of cancer. It is also very useful to know more of the other therapies and their development.

Family PCa history is confirmed as very important and AS is also able to change the situation in term of QoL between generations; while many fathers did not have the option to choose AS, their sons are starting to be able to maintain control of their PCa and QoL for longer periods before having to change treatment, mainly to Radiotherapy.

Early detection is in any case a very important asset. PCa education is more important than ever also with early detection as the risk of overtreatment (or even undertreatment) is still high in the journey of those with AS.

Lifestyle is also seen as a major important asset; luckily, there are more and more voices on this aspect for all people, which becomes very significant for PCa patients. This may create a real PCa evolution between generations as we know more about what may create significant issues.

**The Webinar was Introduced and moderated by Mark Lichty, ASPI President.**