

THE DECISIONAL PROCESS FOR THE CHOICE OF ACTIVE SURVEILLANCE IN LOCALIZED PROSTATE CANCER

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Title:	The decisional process for the choice of active surveillance in localized prostate cancer
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Acknowledgements:	Patients who agreed to be interviewed, physicians who have helped in the recruitment of patients or who agreed to be interviewed themselves, the Belgian Foundation against Cancer, the Sickness Funds and the patients' association 'Wij ook' for their support in the recruitment of patients
Other reported interests:	Fees or other compensation for writing a publication or participating in its development: Adams Thomas, Bram Spinnewijn (Domus Medica recommendations) Payments to speak, training remuneration, subsidised travel or payment for participation at a conference: Adams Thomas, Bram Spinnewijn (reading for doctors), Geert Villeirs
Layout:	Ine Verhulst



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Publication date: 07 November 2013
Domain: Good Clinical Practice (GCP)
MeSH: Prostatic Neoplasms; Decision Making; Watchful Waiting
NLM Classification: WJ 762
Language: English
Format: Adobe® PDF™ (A4)
Legal depot: D/2013/10.273/78
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How to refer to this document?

Jonckheer P, Van Landeghem S, Christiaens W, De Winter L, Piérart J, Mertens R. The decisional process for the choice of active surveillance in localized prostate cancer. Good Clinical Practice (GCP) Brussels: Belgian Health Care Knowledge Centre (KCE). 2013. KCE Reports 210. D/2013/10.273/78.

This document is available on the website of the Belgian Health Care Knowledge Centre.



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LIST OF ABBREVIATIONS

ABBREVIATION	DEFINITION
AS	Active Surveillance
AT	Active Treatment
BT	Brachytherapy
CDSR	Cochrane Database of Systematic Review
CPG	Clinical practice guideline
CRT	Conformal radiotherapy
EAU	European Association of Urologists
EBRT	External beam radiation therapy
EM	Expectant management
HIFU	High intensity focused ultrasound
IQ	Intelligence quotient
LE	Life expectancy
MeSH	Medical Subject Headings
MOC-COM	Multidisciplinair Oncologisch Consult – Consultation Multidisciplinaire d'Oncologie
MRI	Magnetic Resonance Imaging
NIHDI-RIZIV-INAMI-	National Institute for Health and Disability Insurance – Rijksinstituut voor ziekte- en invaliditeitsverzekering – Institut national d'assurance maladie-invalidité
PCa	Prostate Cancer
PSA	Prostate specific antigen
QOL	Quality of Life
RCT	Randomised controlled trial
RP	Radical prostatectomy
RT	Radiotherapy
SR	Systematic review
TURP	Transureteral resection of prostate
WW	Watchful waiting



■ SCIENTIFIC REPORT

1 INTRODUCTION

1.1 Background

As elsewhere in Europe, prostate cancer is the most frequently occurring cancer in men in Belgium. Several stages are described according to the volume of the tumour, the invasion of the lymph node and the presence of metastasis. The localised prostate cancer (T1-T3a N0 M0) refers to the clinical condition where a cancer is confined to the prostate gland, in the absence of lymph node invasion or metastasis, corresponding to a stage NOM0.

Since the current measurement of the prostate specific antigen (PSA), more cancers are diagnosed at an early stage, before any clinical symptoms appear. However, the management of these localised prostate cancers is not clear since many men diagnosed with low risk prostate cancer may ultimately die from other causes. Given the adverse effects of therapeutic interventions, physicians and patients are faced with a dilemma: they have to choose between an immediate curative treatment, quite invasive and an observational approach with deferred treatment, also named active surveillance (AS).^a

This study is part of a broader project which aims at developing a clinical practice guideline (CPG) on the management of localised prostate cancer. A first part of this guideline (KCE Report 194C)¹ was published in the beginning of 2013. It concerns more specifically the role of watchful waiting and active surveillance in the treatment of prostate cancer at the localised stage. Another part is in preparation about the role of other treatments such as radical prostatectomy, radiotherapy, high intensity focused ultrasound, etc. in localised prostate cancer.

^a Active surveillance involves close monitoring of biochemical or histological progression with initiation of curative therapy at a given moment. There is currently no clear protocol of active surveillance but periodic exams (as digital rectal exam, PSA measurement and sometimes biopsy) are always foreseen. This approach should be distinguished from watchful waiting (WW) which involves a policy of observation and the provision of (palliative) treatment when symptoms arrive.



During the elaboration of the first part of the guideline, the acceptability for both patients and physicians of certain recommendations was questioned. More exactly, in a context in which several therapeutic options are possible, without clear superiority of one over the other, it appeared crucial to identify the factors intervening in the choice of treatment.

1.2 Objective

The objective of this study is to gather information from patients and physicians about their perception of active surveillance and about the factors that intervene in their treatment choice.

1.3 Research questions

Two research questions were formulated to take the two points of view into account:

- What factors affect the patients' acceptance of active surveillance?
- What factors affect the willingness of the physicians to offer active surveillance?

2 METHODOLOGY

Several steps were followed:

- Firstly, a search of literature was performed to prepare the qualitative research part. The aim of this step was to provide a list of factors previously studied and to identify some items that should be scrutinised more in depth.
- Secondly, patients and physicians were interviewed. We have chosen a qualitative research design because we wanted to identify the particularities of the Belgian situation. Qualitative research is especially suited to explore variation in experiences with, attitudes and opinions about active surveillance. In order to reach saturation, we included 15 individuals in each category defined by the language and the treatment type.
- Thirdly, data analysis was performed by the team.

2.1 Search of literature

2.1.1 Search strategy and selection criteria

Systematic reviews and primary studies were searched in the following databases:

- Ovid MEDLINE and PreMedline
- EMBASE
- Psychinfo
- Sociological Abstract
- CINAHL
- Cochrane Database of Systematic Reviews

The search terms and their combinations can be found in Appendix 1. As the terms “watchful waiting” and “active surveillance” are used inconsistently by different authors (see the national clinical practice guideline on the management of localised prostate cancer - KCE Reports 194C¹), all terms related to these 2 concepts were used.

All searches were run between May 2012 and July 2012. The identified studies were selected based on title and abstract. For all eligible studies, the full-text was retrieved.

2.1.2 Critical appraisal

The quality of the retrieved systematic review was assessed using the AMSTAR checklist (http://amstar.ca/Amstar_Checklist.php)². For the cross-sectional studies, a checklist was created on the basis of several existing tools.^{3, 4} The qualitative studies were assessed using the CAPS 10 questions.⁵ All articles were appraised by one reviewer. In case of doubt, a second reviewer was consulted.

Data extraction was done by 2 reviewers (PJ & JP) using the standard KCE template for evidence tables. As the terms 'active surveillance' (AS), 'expectant management' (EM) or 'watchful waiting' (WW) are rarely defined and confusingly used, we decided to keep studies on these 3 types of management even if watchful waiting is a palliative approach, typically used for older or physically unfit men with limited life expectancy and active surveillance or expectant management are proactive with curative intent.⁶

2.2 Interviews with physicians

Individual semi-structured face-to-face interviews were chosen as these allow going sufficiently in-depth with each respondent and avoid influence from other people's experience.

2.2.1 Physicians' recruitment

At first, urologists and radiotherapists were recruited by means of an invitation letter sent out by the urologists and radiotherapists organisations (Appendix 2). As only one urologist replied to this recruitment tool, the other physicians were recruited by telephone from the Ipsos and the KCE experts' listing. The respondents were included after answering a series of selection questions (Appendix 3).

2.2.2 Conduct of physicians' interview

The interviews were executed in the hospitals or private practices where the physicians work. Moderation was led by an experienced qualitative researcher in the local language (French or Dutch). The interviews were moderated on basis of the semi-structured interview guide including all topics to be discussed (Appendix 4).

Each interview with an urologist or radiotherapist was audio recorded. The recordings were transcribed to facilitate in-depth analysis.

2.3 Interviews with patients

Individual semi-structured face-to-face interviews were chosen for patients as for physicians: because these allow going sufficiently in-depth with each respondent and avoid influence from other people's experience.

2.3.1 Patients' recruitment

A broad arsenal of recruitment techniques was used in two phases.

A first recruitment was performed:

- Through the physicians who participated in the interviews. Each specialist who participated was given 3-4 pre-stamped envelopes to hand out to patients, eligible for the research. These patients had to fill in an informed consent and contact sheet which they had to send back to the KCE offices. The contact sheets were passed through to the Ipsos responsables who sheduled the interviews with the patients.
- Through general practitioners and other urologists who were willing to help to find patients. These physicians were activated through the KCE network. The patients also had to fill in an informed consent and contact sheet which they sent back in pre-stamped enveloppes to the KCE offices.
- By a presentation during the National Congress of the Belgian Association of Urology to find urologists willing to recruit patients.

As these techniques were unable to reach the foreseen number of patients, two methods were added in a second phase:

- By a message on the website of the Belgian Foundation Against Cancer.
- By a message in 3 magazines : one from a patients' organisation 'Wij ook' and two from the magazines of the Christian Sickness Fund ('Visie' and 'En marche').

For these two additional methods (website and magazines), the patients were invited to contact a medical physician at KCE by e-mail or by phone. The mission of this physician was to explain the study, gather the administrative data of concerned patients and send them to Ipsos for the selection.

The respondents were included after completing a selection questionnaire (Appendix 5).



The recruitment process and the patients' interview guide were approved by the Université catholique de Louvain (UCL)' ethical committee (on 5 November 2012 for the first phase and on 18 March 2013 for the additional phase).

2.3.2 Conduct of patients' interview

The patients' interviews were moderated by an experienced qualitative researcher in French or Dutch. A semi-structured interview guide (Appendix 6) was used as a guideline, ensuring all research objectives were covered but leaving sufficient flexibility for the respondent to tell his/her story. Priority was given to the natural conversation over the structure of the interview guide.

Ipsos conducted a pilot interview with a patient in central location with observation facilities (Ipsos Antwerp) to enable KCE to observe the first interview and to fine-tune the methodology, terminology and interview guide. To guarantee the highest sample quality, the other interviews were conducted at the respondent's best convenience – in home or on location.

Each interview with a patient was audio recorded. The recordings were transcribed to facilitate in-depth analysis.

2.4 Data analysis of the interviews

The data analysis was an interactive process within the Ipsos team and between KCE and Ipsos. After all interviews were conducted, an internal debriefing was organized by Ipsos with all moderators involved and the account directors. In this debriefing, initial ideas were shared from the Dutch and French speaking interviews by the moderators and challenged by the account directors. Each moderator also challenged the other moderators to discover similarities or differences based on language. After this debriefing meeting, the project leader read the transcripts from all interviews and made general comments and comments per specific target group. The analysis is based on the information from the transcripts. After the key findings had been elaborated, the project leader focused on detecting specific differences between target groups and highlighting this in the report. A second meeting was organized between moderators and account directors of Ipsos to go through the report and challenge the findings. Ipsos and KCE then further developed the report.

3 RESULTS

3.1 Search of literature

3.1.1 Amount of articles

After exclusion of duplicates, 378 potentially relevant citations were identified. Hand searching provided 4 additional articles. Based on title and abstract evaluation, 268 citations were excluded. The reasons for exclusion can be found in a flow chart in Appendix 7. One hundred fourteen articles were assessed on the full text and 37 were elected. The reasons for exclusion of 77 articles can be found in the same flow chart (Appendix 7).

3.1.2 Type of studies and critical appraisal

Many of the retained studies are cross-sectional. There are 4 systematic reviews and 10 qualitative studies.

The critical appraisal of the **systematic reviews** was relatively low as shown in Appendix 8.1. Moreover, the part focusing on AS or WW in the text was very small. Consequently, we decided to base the analysis on the primary studies only and we checked the references used in the systematic reviews.

The critical appraisal of the **quantitative primary studies** showed a high risk of bias. We found many selection bias, problems of small sample size (particularly for the groups of patients in AS or WW), use of not validated questionnaires, etc. (Appendix 8.2). A great heterogeneity of statistical tests and measures was also observed among the different studies (Chi square, analysis of variance and rarely odds ratio). Due to this heterogeneity, direct comparison between the studies was not possible. Therefore we present only the direction of association (in favour or not) between variables included in the different studies and active surveillance or watchful waiting. Overall, we have to keep in mind the level of evidence is 'low' or 'very low'.

Four **qualitative studies** were eliminated from the analysis because of their very low quality in terms of methods, ethical issues or rigour of the analysis (Appendix 8.3).

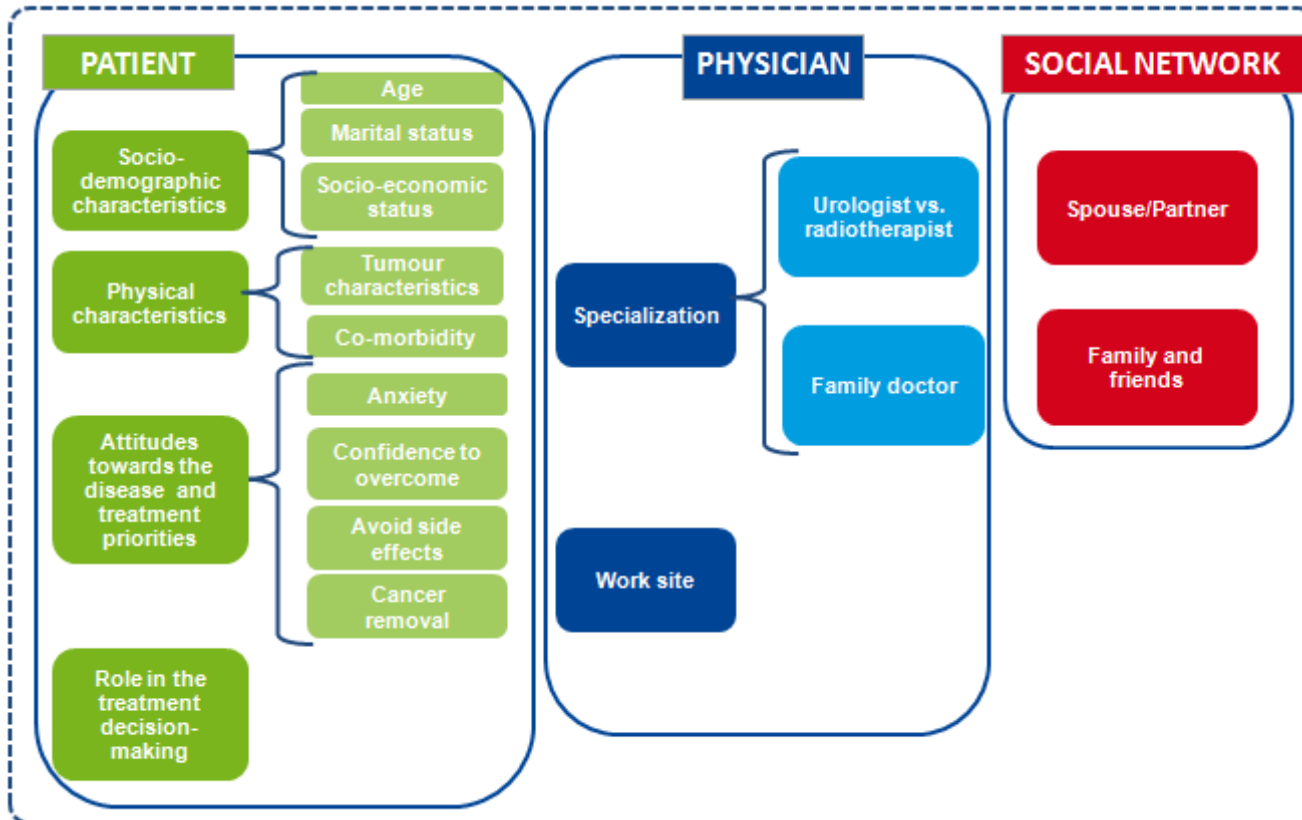
The data extraction table of the 29 selected articles is available in Appendix 9.



3.1.3 Factors influencing the treatment decision-making process in prostate cancer according to the patients

A majority of the retained studies concern the patients' point of view in the treatment decision-making. We describe the results in 3 parts: the patient's characteristics, the physician's influence and the social network. Each of these parts encompasses several factors (Figure 1). A summary of the literature results is available in Tables 1, 2, 3 and 4.

Figure 1 – Factors influencing treatment choice of patients regarding localised prostate cancer according to the patients: literature review





I. THE PATIENT

A. SOCIO-DEMOGRAPHIC CHARACTERISTICS

Age at time of diagnosis

Age at time of diagnosis is important for the decision to go on active surveillance for prostate cancer (PCa). Several studies show that older patients at time of diagnosis are significantly more likely to be treated by active surveillance⁷⁻⁹ or watchful waiting¹⁰⁻¹³ or expectant management¹⁴. Even physicians who support the concept of AS are more apt to suggest invasive treatment to younger men.⁸

Marital status

In only one study, being married is linked negatively to active surveillance. In this survey of 488 patients <50 years old, more married men opted for surgery or radiation than active surveillance ($p < 0.002$).¹⁵ Non-married men in this study found treatment-related decision more difficult to make and were worried about their decision.

Other socio-demographic characteristics

In a United States context, three characteristics are quoted as factors in favour of WW or AS: being non-African-American¹³, having a Medicare insurance¹² and a higher socio-economic status.^{11, 13}

Key Points

- Older men are more likely to be treated by AS or WW than younger men.
- To be married appears to be linked negatively to AS in one study among men <50 years old.
- Higher socio-economic status could be a factor favourable to AS or WW.

B. PHYSICAL CHARACTERISTICS

Tumour characteristics

Localised prostate cancers are defined as those not extending beyond the prostatic capsule (cT1a-T2c N0M0). Localised prostate cancers are classified into three categories according to their risk of progression, as initially proposed by d'Amico. This classification was established on the basis of three criteria: the TNM stage; the Gleason score, which measures the aggressiveness (degree of differentiation) of the cancerous cells and the PSA value. The physicians' recommendations for AS depend clearly on these criteria^b.

Health status

The co-morbid conditions of the patients are other criteria for active surveillance. Some studies put this item in patients' questionnaire and outline a positive relation between pre-existing co-morbidity and AS¹⁶ or WW¹² but it plays particularly a role in older men.¹³

Key Points

- Tumour characteristics (including the risk category) influence clearly the physicians' recommendations.
- Pre-existing co-morbidity is positively linked to active surveillance or watchful waiting, particularly in older patients.

^b The risk category taken into account for active surveillance is defined in part 1 of the KCE guideline on localised prostate.¹ The classification used in the guideline is proposed by the European Association of Urologists (EAU). The 3 risk categories are:

- low risk (T1-2a and Gleason<7 and PSA<10 ng/ml)
- intermediary risk (T2b-c or Gleason=7 or PSA between 10 and 20 ng/ml)
- high risk (T3a or Gleason>7 or PSA>20 ng/ml)



Table 1 – Patients’ personal characteristics and the treatment decision-making process for PCa according to the patients: literature review

Factors	Relation	Context	Level of evidence
Demographic characteristics			
Older age at time of diagnosis	+ ⁹	180 patients on AS <10 years	Moderate
	+ ⁷	61 patients choosing AS	Low
	+ ¹⁰	110 patients choosing WW or AT	Low
	+ ¹⁷	654 patients of which 37 on WW	Low
	+ ¹⁴	140 patients choosing EM or surgery	Low
	+ ¹¹	810 patients on WW or AS/11892	Moderate
	+ ¹²	402 patients on WW/5365	Moderate
	+ ¹³	152 patients on WW/1809	Moderate
Marital status	- ¹⁵	488 patients < 50 years old of which 26 on AS	Low
	0 ¹⁰	110 patients choosing WW or AT	Low
Education	0 ¹⁵	488 patients < 50 years old of which 26 on AS	Low
	0 ¹⁴	140 patients choosing EM or surgery	Low
Employment	0 ¹⁵	488 patients < 50 years old of which 26 on AS	Low
	0 ¹⁰	110 patients choosing WW or AT	Low
Income	0 ¹⁵	488 patients < 50 years old of which 26 on AS	Low
Race/Ethnicity	0 ¹⁵	488 patients < 50 years old of which 26 on AS	Low
	+ ¹³	152 patients on WW/1809	Moderate
Insurance	+ ¹²	402 patients on WW/5365	Moderate
Socio-economic status	+ ¹¹	810 patients on WW or AS/11892	Moderate
Co-morbidities	+ ¹²	402 patients on WW/5365	Moderate
	+ ¹¹	810 patients on WW or AS/11892	Moderate
	0 ¹⁰	110 patients choosing WW or AT	Low
Current health status	0 ¹⁴	140 patients choosing EM or surgery	Low

AS = active surveillance; AT = active treatment; WW = watchful waiting; EM = expectant management.

The signs +, 0 and – are used to present the results from the analysis. They are not related to the value of coefficient or tests (given the heterogeneity of the measures used).

‘++’ = factor mostly cited in favour of AS or WW; ‘+’ = factor cited in favour of AS or WW; ‘0’ = factor for which no association is found; ‘-’ = factor cited not in favour of the use of AS or WW; ‘+/-’ = factor which can be in favour and not in favour of AS or WW.



C. PATIENTS' ATTITUDES TOWARDS THE DISEASE AND TREATMENT PRIORITIES

Many studies attempt to better understand the patients' perspectives on prostate cancer treatment and their influence on the treatment choice. The results focusing specifically on active surveillance or watchful waiting concern mainly two interrelated attitudes towards the disease (fear of cancer progression, confidence to overcome the disease) and two patients' priorities (need of cancer removed, concern for side effects).

Patients' attitude towards the disease: anxiety versus confidence

Fear about cancer progression and uncertainty about the management of the PCA are sources of anxiety and recurrent reasons to avoid or to stop AS.¹⁸⁻²¹ One study examined the role of anxiety in the decision process and shows that fear of future consequences is the most common reason to reject watchful waiting.²⁰

Anxiety might also play an important role in the amount of information that patients wish to access while on AS according to a survey of 180 patients on AS.⁹

On the other hand, patients can be confident to overcome the disease. However, this confidence can influence the patient's choice in 2 ways:

- The perception of a having the best chance of cure with active treatment and the treatment success rate may have a negative impact on active surveillance as described in a survey of 488 young patients.¹⁵
- The belief that current cancer not required most aggressive treatment or that it could be cured if the cancer progressed²² is positive for AS as described in a survey of 105 patients.¹⁵

Patients' treatment priorities

One main factor dictating treatment decision-making in favour of WW or AS is the desire to avoid active treatment side effects.^{9, 14, 15, 23} More precisely, the potential side effects of incontinence and erectile dysfunction associated with active treatment are recurrent reasons for choosing AS.^{8,9,15,22} Some authors quote also the time needed to recover from treatment⁹ and the will to avoid surgery itself.^{14,22}

Some men only feel satisfied if their prostate is removed; they cannot accept to keep a cancer inside their body. This is not in favour of active surveillance^{15,18} or expectant management¹⁴.

Key Points

- **Several factors disadvantage AS or WW:**
 - **Anxiety linked to cancer progression**
 - **Perception of better chance of cure with active treatment**
 - **Need of tumour removal**
- **Two factors are more favourable to AS or WW:**
 - **Belief that current cancer does not require aggressive treatment**
 - **Desire to avoid side effects of active treatment**

D. PATIENTS' ROLE IN THE TREATMENT DECISION-MAKING

The patient's involvement in the treatment decision-making can be more or less important depending on the patient and notably on his confidence in his own ability for decision making.²⁴ Three categories of roles are described.⁹

- **Passive role** where the physician makes the final treatment decision after considering the patient's opinion;
- **Shared or collaborative role** where the patient makes the treatment decision with the physician;
- **Active role** where the patient makes the final treatment decision after considering the physician's opinion.

In a dynamic process, we can imagine that these roles can be played by the same patient at different times and at different steps of his trajectory.

Concerning the patient's role, the information support can be provided by the health care professionals alone or also searched by the patient himself. This personal search could be useful for patients, particularly in a context of uncertainties. However, few publications give data on the relation between AS and personal search of information:



- The influence of the physician's recommendation is particularly determinant for the patients assuming a passive role in the treatment decision-making as shown in a survey on 180 patients on AS (passive role vs. active role: $F=7.24$, $p=0.001$).⁹
- For 55% of 105 patients enrolled in AS, the research of alternative treatment is the factor contributing most to their decision to enroll in AS.²²
- Written information and the Internet are the most commonly used sources of information for 25 men on AS, even if the vast majority of men do not actively seek information.¹⁶
- In 488 younger men (<50 years), physician's recommendation is less cited by patients on AS than by surgery or radiation patients. Other sources including media, articles in medical journals, books and discussion with someone they knew who had the same treatment are relatively more influential for men selecting AS.¹⁵
- The usefulness of standardised informational materials to decrease inconsistency and reduce decisional conflict is emphasized by a survey with 34 patients on AS²⁵ while another study promotes a flexible process of informing patients with early-stage prostate cancer in order to accommodate a wide range of patients' information needs.²⁶

The patient's age appears to be linked to the level of involvement: younger men on AS seem to be more involved in the treatment decision-making than older men:

- In a survey in 180 patients on AS since <10 years, 38% assume a collaborative role, 35% an active role and 27% a passive role.⁹ The age of men in this study had a significant impact on the role reported by men in treatment decision making. Younger men (under the age of 60 years) report that they wanted to be more involved in decision making compared to men older than 70 years. Otherwise, level of education, employment status, marital status, anxiety and length of time since diagnosis are not found to have a significant impact on the roles patients reported in treatment decision making.

- The major trend of an active role among younger men is confirmed by the survey of Sidana in 488 patients <50 years old.¹⁵ In this study, only 2% prefer a passive role in treatment decision making, 52.3% prefer a "Shared decision-making between physician and myself" while 45.8% prefer an "Informed decision made by myself based on information." Better educated men prefer "Informed decision-making" over "Shared decision-making" (< 0.011). An active role is preferred more by young patients who chose AS or radiation while shared decision-making is preferred more by surgery patients ($p < 0.0004$).¹⁵

Key Points

- **There are three categories of patients' role in the treatment decision-making.**
- **Younger men on active surveillance appear to be more active in the treatment decision making than older.**
- **The personal search for information on active surveillance is important but there are few publications on the resulting influence.**
- **The usefulness of informational material is highlighted by some authors.**



Table 2 – Patients' attitudes towards the disease, treatment priorities and role in the treatment decision in PCa according to the patients: literature review

Factors	Relation	Context	Level of evidence
Attitudes towards the disease			
Chance of cure/Treatment efficacy	- ¹⁵	488 patients < 50 years old of which 26 patients on AS	Low
	+ ²²	105 patients on AS	Low
Cancer not required aggressive treatment	+ ¹⁵	488 patients < 50 years old of which 26 patients on AS	Low
Fear/Anxiety about cancer progression	- ¹⁸	240 patients of which 99 on AS	Low
	- ¹⁹	198 patients choosing WW or AT	Low
	- ²⁰	60 AS discussed/102, 12 AS selected/102	Moderate
Uncertainty	- ¹⁸	240 patients of which 99 choosing AS	Low
Treatment priorities			
Avoid active treatment side effect	+ ⁹	180 patient on AS <10 years	Moderate
	+ ¹⁵	488 patients < 50 years old of which 26 patients on AS	Low
	+ ¹⁷	654 patients of which 37 on WW	Low
	+ ¹⁴	140 patients choosing EM or Surgery	Low
	+ ²³	167 patients of which 7 on WW	Low
Time needed to recover from treatment	+ ⁹	180 patient on AS <10 years	Moderate
Delay of treatment side effect	+ ¹⁸	240 patients of which 99 on AS	Low
Avoid surgery itself	+ ¹⁵	488 patients < 50 years old of which 26 patients on AS	Low
	+ ²²	105 patients on AS	Low
Need of prostate removed	- ¹⁵	488 patients < 50 years old of which 26 patients on AS	Low
	- ¹⁴	140 patients choosing EM or surgery	Low
Believe urologist spent more time	+ ⁹	180 patient on AS <10 years	Moderate
Role in the treatment decision making			
Personal search of alternative	+ ²²	105 patient on AS	Low
Internet search	+ ¹⁵	488 patients < 50 years old of which 26 on AS	Low
Active role in decision making	+ ¹⁵	488 patients < 50 years old of which 26 on AS	Low

AS = active surveillance; AT = active treatment; WW = watchful waiting; EM = expectant management. The signs +, 0 and – are used to present the results from the analysis. They are not related to the value of coefficient or tests (given the heterogeneity of the measures used). ‘++’ = factor mostly cited in favour of AS or WW; ‘+’ = factor cited in favour of AS or WW; ‘0’ = factor for which no association is found; ‘-’ = factor cited not in favour of the use of AS or WW; ‘+/-’ = factor which can be in favour and not in favour of AS or WW.



II. THE PHYSICIAN

The physician's recommendation is the **most influential** factor in the treatment decision-making process according to several authors.^{8,9,15,17-19,22}

This recommendation can be in favour of AS or WW when the physician gives his/her support to this option¹⁸ but it can also be in favour of an active treatment in the opposite case.¹⁵ In the patients' perception the recommendation can be influenced by the physician's specialization and by the site where the physicians work.

A. SPECIALIZATION

The urologists, radiotherapists or family doctors can all play a role in the treatment decision choice but this role appears to differ.

Urologists vs. radiotherapists

The physician specialized in one treatment option tends to favour this option:

- In a large cohort study of 85 088 men, higher rates of radiotherapy delivery are observed in men who were seen by both radiotherapists and urologists than by urologists only.²⁷
- In a survey on 167 patients of which 7 choosing WW, the strongest predictor of treatment is the specialization of the physician seen (radiation oncology vs urology) although it is not significant for the small groups of WW.²³
- In a sample of 654 patients recruited through radiotherapists or through urologists, the final treatment choice is related to the more represented specialization.¹⁷
- According to one study combining a survey of patients and urologists, urologists recommend less often AS in second opinion than in first opinion.²⁸
- Patients use the **reputation and publication records** of their specialists as an indicator of their expertise in the treatment of

prostate cancer: 'The more renowned and published the specialists, the easier it was for the men to follow the advice'.¹⁶

Family doctors

The family doctor's advice can have a positive impact on the patients' decision to opt for AS:⁹

- In a large cohort study of men >65 years old with nearly 17 000 men receiving expectant management, those seen by primary care physicians in addition of the specialist visit are more likely to be treated expectantly (and it is independent of patient age, co-morbidity status or type of specialist).²⁷
- The consensus between the family doctor and the urologist is one of the strongest influences in the treatment decision making according to interviews of 18 couples.²⁹

B. WORKSITE

The treatment pattern can vary markedly across **clinical sites** as shown in a large cohort study on 11 892 men in 36 clinical sites.¹¹ Explanations for the observed variation are speculative, reflecting variable physician training, experience and personal outcomes; payer mix, reimbursement patterns, and other financial incentives, local medico-legal environment and many other factors.¹¹

Key Points

- **The physician's recommendation is a paramount factor in the treatment of localised prostate cancer.**
- **The urologists and radiotherapists have a tendency to promote the treatment of their specialization.**
- **The family doctors appear to have a positive impact on the active surveillance choice.**
- **A variability of treatment pattern is noted across clinical sites but not clearly explained.**


Table 3 – Physicians' influence in the treatment decision-making process for PCa according to the patients: literature review

Factors	Relation	Context	Level of evidence
Physicians			
Specialist's opinion	++ ⁹	180 patients on AS since <10 years	Moderate
	++ ¹⁷	654 patients of which 37 on WW	Low
	++ ²²	105 patients on AS	Low
	+ ¹⁸	240 patients of which 99 choosing AS	Low
	+/- ¹⁵	488 patients < 50 years old of which 26 on AS	Low
	+/- ¹⁹	198 patients choosing WW or AT	Low
Specialist's reputation	+ ¹⁶	25 patients on AS <10 years	Moderate
Specialist's second opinion	+ ⁹	180 patient on AS <10 years	Moderate
Family physician advice	+ ²⁷	85 088 patients >65 years old of which 16 941 on EM	High
	+ ⁹	180 patients on AS <10 years	Moderate
	+ ²⁹	18 couples of which 1 on WW	Moderate
Practice site	+/- ¹¹	11892 patients of which 810 on WW	Moderate

AS = active surveillance; AT = active treatment; WW = watchful waiting; EM = expectant management. The signs +, 0 and – are used to present the results from the analysis. They are not related to the value of coefficient or tests (given the heterogeneity of the measures used). '++' = factor mostly cited in favour of AS or WW; '+' = factor cited in favour of AS or WW; '0' = factor for which no association is found; '-' = factor cited not in favour the use of AS or WW; '+/-' = factor which can be in favour and not in favour of AS or WW.



III. THE PATIENT'S SOCIAL NETWORK

Two categories of social influences are presented in this chapter: closely, the spouse or partner and more remote: family and friends.

Spouse/partner

The dynamic of the couple's relationship provides a contextual background against which treatment decisions are negotiated and made.³⁰ Spouses or partners assume in general a support role in the treatment decision-making process about prostate cancer.^{16, 31} But in the final moment of the treatment choice, spouses/partners leave generally the final decision to their husband.³¹

In particular with regard to the active surveillance option, four studies of which three from the same author give some precisions:

- The expectant management is rarely a first choice of spouse or partner. In a study with 18 couples, WW is viewed as 'doing nothing'.²⁹
- Some of spouses/partners put the patient **under pressure to seek active treatment**. This is particularly outlined in younger men of whom the spouses express their will to make their husbands have surgery according to a qualitative study of 25 patients on AS.¹⁶
- The advice from partners is more important for men assuming a **collaborative role in the decision-making process** (F=3.83, p=0.024) in a survey of 180 patients on AS.⁹
- The spouses' opinion comes **before other physician's opinion** (vs the first urologist's opinion) for 73 patients on AS.⁸

Family and friends

Although, in general, the family and the friends have an influence in the treatment decision making in prostate cancer,^{15,17} this influence is not outlined specifically for active surveillance by the selected studies:

- The family support is the most important of 10 reasons for electing AS for 54% of 105 patients on AS.²²
- According to one study on 50 men, those who chose WW, as well as those with other treatment, describe **considerable pressure** from family members, doctors or support groups, to seek **active treatment**.³²
- Advice from friends varied depending on whether the friends **have had any experience with PCa** and friends who had have a PCa suggest more often active treatment according to a qualitative study on 25 patients on AS.¹⁶
- Among the same 25 patients, several men prefer to keep the PCa diagnosis a **secret** and experience talking about having Pca as **uncomfortable**.¹⁶
- The anecdotal experience of family and friends is quoted in a survey of 21 patients, especially to decide 'what not to do'.³³

Key Points

- **The support of the spouse/partner in the decision process appears to be important even if they generally leave the final decision to the patient.**
- **The role of social support in the active surveillance option is barely outlined and results are not clear.**



Table 4 – Social sources of influence in the treatment decision-making process for PCa according to the patients: literature review

Factors	Relation	Context	Level of evidence
Spouse/Partner			
Advice from spouse/partner	+ ⁹	180 patients on AS < 10 years	Moderate
	+ ⁸	73 patients on AS < 10years	Moderate
	- ¹⁶	25 patients on AS < 10 years	Moderate
Family and friends			
Family very supportive	+ ²²	105 patients on AS	Low
Pressure of family	- ³²	50 men of which 4 on WW	Low
Experiences of men with PCa	- ¹⁶	25 patients on AS < 10 years	Moderate

AS = active surveillance; AT = active treatment; WW = watchful waiting; EM = expectant management. The signs +, 0 and – are used to present the results from the analysis. They are not related to the value of coefficient or tests (given the heterogeneity of the measures used). ‘++’ = factor mostly cited in favour of AS or WW; ‘+’ = factor cited in favour of AS or WW; ‘0’ = factor for which no association is found; ‘-’ = factor cited not in favour the use of AS or WW; ‘+/-’ = factor which can be in favour and not in favour of AS or WW.

3.1.4 Factors influencing the treatment decision-making process in PCa according to the physicians

Only 2 articles focused on urologists’ perception of the treatment decision-making process:

- **Patient preference for AS** is a reason quoted by 8 surveyed urologists for non-compliance with active treatment (AT).¹⁸ Patients having **comorbid conditions** is also quoted by the urologists to explain they prefer AS over AT.¹⁸
- When they are asked what factors most influenced their recommendations (list of 14 items), 25 urologists from academic clinics report more commonly **Gleason score and PSA** in the initial consultation versus stage, **patient preference**, and number of positive scores in the 2d opinion setting.²⁸ This survey show also that AS is less often proposed during 2d opinion session than initial session, even for men with low-risk disease.²⁸ For the author, it is not clear whether it is the patient or the urologist who focusses the conversation more heavily towards prostatectomy in the 2d opinion visit.²⁸

Key Points

- **There is a lack of good quality studies about the physician factors influencing the treatment decision-making process in PCa.**
- **According to the selected studies, patients’ preference, comorbidity and tumour characteristics are factors influencing the physician decision-making process.**

**Table 5 – Factors influencing the treatment decision-making process in PCa according to the physicians: literature review**

Factors	Influence	Context	Level of evidence
Physician perception			
Patient preference	+ ¹⁸	8 urologists	Low
Co-morbid conditions	+ ¹⁸	8 urologists	Low

The signs +, 0 and – are used to present the results from the analysis. They are not related to the value of coefficient or tests (given the heterogeneity of the measures used). ‘+’ = factor cited in favour of AS or WW; ‘0’ = factor for which no association is found; ‘-’ = factor cited not in favour the use of AS or WW; ‘+/-’ = factor which can be in favour and not in favour of AS or WW.

3.1.5 Conclusion regarding the search of literature

The literature search provides interesting information on the factors influencing the treatment decision in localised prostate cancer. The physicians’ recommendation appears to be the most influential in men with active surveillance. Among the other factors, older age at time of diagnosis, the presence of co-morbidity, the confidence to overcome the disease and the patients’ desire to avoid active treatment side effects are positively linked to active surveillance. On the contrary, the anxiety about cancer progression and the need of prostate removal are negative factors for active surveillance. The role of the patient in the decision making is particularly stressed in the context of localised prostate cancer, because of the lack of clear superiority between the different approaches.

Some limitations have to be mentioned regarding the literature search. First, the relative poor quality of the articles (selection bias, measure instruments not validated...) decreases the strength of the conclusion. Second, the confusion between the concepts of watchful waiting and active surveillance leads to inaccuracy. Third, the variability in age, co-morbidity conditions or settings hamper the generalization of the results. Finally, the literature provides more information on patients’ perception than on physicians’ perception about the factors influencing their treatment decision, despite the crucial role of the physicians.



3.2 Interviews with physicians

3.2.1 Description of achieved sample

22 physicians were interviewed: 16 urologists and 6 radiotherapists equally divided between Dutch (D) and French (F) speaking physicians. When looking at the type of hospital where they were active, a mixture was provided between physicians active in a general hospital, university hospital, private practice, or a combination of these hospital types. Six respondents had between 1 and 10 years experience, eight respondents had 10 to 20 years experience, and another eight had more than 20 years experience. All urologists are seeing patients with localized prostate cancer on a regular basis.

Table 6 – Distribution of the interviewed physicians according to the setting where they are active (n=22)

Type of physicians	General Hospital	University	Private Practice	General Hospital+ Private	University + Private	University + Private + General Hospital	Total
Urologists (D)	1	1	1	5			8
Urologists (F)	2	2		2	2		8
Radiotherapists (D)	2			1			3
Radiotherapists (F)	2					1	3



3.2.2 Physicians' perception of the active treatment options for localised prostate cancer

According to the interviewed urologists and radiotherapists, a localised prostate cancer is a disease which, if treated right and on time, is not lethal and can be cured. In their perception, some patient cases are crystal clear concerning which treatment options are best suitable. But the choice of treatment of localised prostate cancer can sometimes be a rather undefined process as there are often multiple therapy options for one patient case without clear impact regarding the chance of survival. A separate chapter considers active surveillance (see 3.2.3. Physicians' perception of active surveillance for localised prostate cancer).

This chapter reflects the interviewed physicians' perceptions which do not always correspond to objective, accurate, up-to-date scientific knowledge.

The usual treatments for localised prostate cancer are **prostatectomy**, **external radiation** (which can be, if necessary, combined with hormone therapy), **brachytherapy** and **active surveillance**. Some centres in Belgium also offer or refer to the **HIFU** (high intensity focused ultrasound) **therapy**. This treatment, however, is not yet widely accepted as a legitimate treatment among urologists in Belgium. **Hormone therapy** on its own is seen as a palliative treatment and not a curative treatment by all interviewed urologists.

Hormone therapy can be started when the prostate cancer is metastatic and no longer localised or used in combination with external radiation therapy or brachytherapy.

As each treatment has the pros and cons which can be assessed differently by each physicians, controversy persists on which treatment is most appropriate to execute. A summary of the physicians' declarations is presented below. More details are available on demand.

3.2.2.1 Prostatectomy

According to the interviewed urologists, prostatectomy is still the most common procedure to deal with localised prostate cancer although other therapies such as radiation and active surveillance have gained importance during the last years. Surgery is especially popular to implement in **'younger' patients below 60 who still have a life expectancy of more than 10 years** and with **physically fit patients** who will recover more quickly and have a better chance to retain continence and avoid erectile dysfunctions. Besides that, younger patients have a tendency to suffer from more aggressive tumours than older patients which makes the choice of a prostatectomy a 'safer choice' as you are **sure to remove the complete tumour**. A prostatectomy is also a good first treatment option for patients as it **keeps the window open for other treatments** should there be a recurrence.

3.2.2.2 External radiation (sometimes combined with hormone therapy)

Interviewed urologists agree that external radiation is a good option for **people who are not able to endure surgery** (often people **older than 70 years**), or choose to not have a surgery (due to the **fear of impotence and incontinence**). External radiation can sometimes be perceived as not practical, as it demands a huge time-investment of a patient: he has to come to the hospital to receive his radiation during several weeks. Radiotherapists state that there has been a big technological revolution in the field of radiotherapy which has made external radiation more effective and less toxic. In the future, radiotherapists expect a growing importance of external radiotherapy in treating patients with a localised prostate cancer. However, if a patient has recurrence, treating him with a prostatectomy after already being treated with external radiation is not an option since there will be too many adhesions of different organs where the physician has to perform this surgery.



3.2.2.3 *Brachytherapy (sometimes combined with hormone therapy)*

Brachytherapy has gained **more popularity over the last years**. Small radioactive particles are placed inside the prostate. Brachytherapy is executed by the radiotherapist, together with the urologist. It is considered by the interviewees as having fewer side effects than prostatectomy and external radiation and can be executed in day clinic. Brachytherapy is a therapy option **for rather small tumours** (T1 and T2).

3.2.2.4 *HIFU*

HIFU uses ultrasound waves generated by a rectal probe to produce intense heat, destroying prostate tissue while preserving surrounding tissue. HIFU is seen as an experimental treatment that still needs to prove its worth. There are not many centres offering HIFU. The advantages of HIFU according to HIFU advocates are the fact that it is not very invasive and the patient can go home after one day. Besides that, the HIFU technique allows precise aiming in the prostate and is supposed to lead to only a low chance of side effects such as impotence and incontinence.

3.2.3 *Physicians' perception of active surveillance for localised prostate cancer*

Active surveillance is something that is most often dealt with by urologists and therefore radiotherapists do not often play an important role in active surveillance. Radiotherapists only talk about active surveillance as something they know from urologists.

Over the last years, active surveillance has become a real treatment option for localised prostate cancer. Not all physicians make a clear distinction between AS and WW. It is **therefore important to closely see how each specialist implements what he calls 'active surveillance'**. What urologist X calls 'active surveillance' could actually be what urologist Y calls 'watchful waiting'.

Specialists who distinguish between active surveillance and watchful waiting state that with active surveillance, the tumour is monitored and a curative treatment is started if the tumour evolves. With watchful waiting, a curative treatment is never implemented. Watchful waiting is offered to patients who have a low life expectancy because the side effects of a curative treatment will be too much to cope with. Active surveillance is

reserved for people who are still eligible to endure a curative treatment if necessary (when the tumour evolves). When a patient becomes unfit for a curative treatment, he can evolve from active surveillance to watchful waiting.

3.2.3.1 *Advantages of active surveillance*

The big advantage of active surveillance for interviewed physicians is the fact that this option is **completely non-invasive** (except for the biopsies). Patients do not have to deal with **side effects** of a treatment and retain their **quality of life**.

Another advantage of active surveillance is the elimination of (unnecessary) costly treatments. This creates an enormous **cost reduction** for patients and for society as a whole.

3.2.3.2 *Disadvantages of active surveillance*

According to interviewed physicians, there are several barriers regarding active surveillance:

- One does nothing about a potentially fatal condition although there is still a chance for full recovery. Waiting too long can have fatal consequences, the tumour can become metastatic. **The fear of discovering a tumour which turns out to be more aggressive than previously estimated** is also related to the fear for litigation by **unhappy patients** who blame their physicians.

'Het grootste nadeel is eigenlijk het oncologische risico dat wordt gelopen. Dat men effectief op een tumor zit te kijken en zit te wachten tot hij eventueel wel metastatisch is geworden. Dat is het grootste nadeel en bij mijn weten bestaan er op dat vlak nog geen goede testen om te weten wat de biologische activiteit van een tumor is. (Urologist, General Hospital, 25 years experience)

- Moreover, there are **no reliable parameters to estimate the evolution of the tumour**:
 - **The PSA value is not very reliable, it can only be seen as a sort of 'warning sign' that there could be something wrong.**

- A badly differentiated and aggressive tumour hardly produces any PSA, so it is possible to have a low PSA value and a very aggressive carcinoma.
- Another marker, the PCA3 marker is still very expensive and not often used by specialists.
- **The Gleason score is based on estimation**, made by an anatomical-pathologist. These estimations sometimes vary between different anatomical-pathologist which makes the Gleason score somewhat imperfect.
- **There is often no relationship between the complaints of the patient and the evolution of the tumour.** A tumour can grow and become aggressive while the patients does not experience more physical complaints. It is therefore very dangerous if a patient fails his follow-up appointments of the active surveillance programme.

'Les deux traitements qu'on pratique le plus fréquemment, c'est un traitement chirurgical, ou un traitement de surveillance active. Mais on a été un petit peu bloqué par quelques mauvaises surprises de patients qui avaient été initialement mis en surveillance active et donc, on a plutôt tendance, si le patient est jeune, à proposer une chirurgie. Rien que cette année-ci, on a eu cinq patients qui étaient sous surveillance active et qu'on a finalement, au bout d'un an, décidé d'opérer vu l'évolutivité de la maladie. Et on s'est retrouvé avec des tumeurs vraiment très agressives. Donc, on est en train de revoir un petit peu les critères et ce qui me dérange principalement c'est que les critères sur lesquels sont basés la surveillance active sont des critères qui, par définition, sont imparfaits: le PSA et les biopsies de prostate' (Urologist, University Hospital, 7 years experience)

- Important **improvements** are expected in the (near) future as a better marker than PSA, able to determine the aggressiveness of a cancer and improvement of imaging techniques to better detect the exact location and aggressiveness of a tumour, making the choice for active surveillance less risky.

- Active surveillance is **less profitable** for a physician compared to any other treatment option. It takes more time while it generates less money. Even explaining and convincing a patient for active surveillance is more time consuming and more difficult than convincing a patient to perform any other treatment option.

'Soms moeten we het aandurven om te zeggen van: we gaan niets doen. Maar dat zijn moeilijke gesprekken met de patiënt, en dan moet je ze strikt opvolgen. Die actieve opvolging is iets dat we nog te weinig doen. Dat ligt ook niet zo gemakkelijk in de dagdagelijkse praktijk. Het valt soms heel moeilijk. Het is een lange consultatie, en om het heel cru te zeggen: het is makkelijker om als uroloog iemand te overtuigen om wel een operatie te hebben dan om geen operatie te hebben, met een halve consultatie zet je hem gewoon op de boek en doe je een radicale prostatectomie. Dat is cru maar daar komt het wel op neer. Om te zeggen: ik wil je niet opereren, dan moet je al langer gaan praten met de patiënt om hem te overtuigen dat dit het beste is.' (Urologist, University Hospital, 15 years experience)

'Quand vous faites de la surveillance active, c'est que déjà vous êtes obligé de passer un moment à expliquer au patient qu'il a quelque chose, que ce n'est pas grave, qu'on pense qu'il va bien évoluer et que dans son cas, dans 70 % des cas dans 5 à 7 ans, il ne va rien se passer. Et la majorité va mourir d'autre chose, de maladie cardiaque etc. C'est toujours délicat de dire à quelqu'un vous n'allez pas mourir de ça mais rassurez-vous, vous allez mourir d'autre chose !' (Urologist, General Hospital, 40 years experience)

- Active surveillance is **less credible** than other treatment options, notably than 'surgery' which is still the number one option: According to physicians, there are patients who will never accept that they **are not directly given a 'curative' treatment**. Still having a tumour which is not treated but only monitored can cause an unbearable anxiety for certain patients.



*‘Een patiënt 77 jaar heeft een verhoogde PSA, maar het is niet dat het van 2 naar 20 is gegaan, een geleidelijke stijging waarvan ik voel dat het belangrijk is dat we diagnose hebben. Dan doe je een biopsie en dan blijkt het een beperkt gelokaliseerd prostaatacarcinoom te zijn, dan zeg ik tegen de mensen van ‘kijk: ik denk niet dat ik het opereer of ga behandelen.’ Maar dat is niet eenvoudig om aan de mensen uit te leggen. Zeker met die oudere generatie. Met de nieuwere generatie heb ik de indruk dat ze er meer voor open staan. **Die ouderen denken nog van: kanker, dat moet eruit, ten koste van alles.** Maar ja, goed. Dat is moeilijk om die idee-fixe bij die oudere generatie, en dan bedoel ik 70-75 plus, dat eruit te krijgen. Het feit is ook dat die mensen al veel vrienden hebben zien sterven aan kanker. Mensen gooien ook alle kankers op één hoop. Of dat nu maag of prostaatkanker is, kanker is kanker. En die mensen moeten constant naar begrafenissen gaan. Ik zie dat ook bij mijn eigen moeder. En die slaan dan in paniek.’ (Urologist, General Hospital, 5 years experience)*

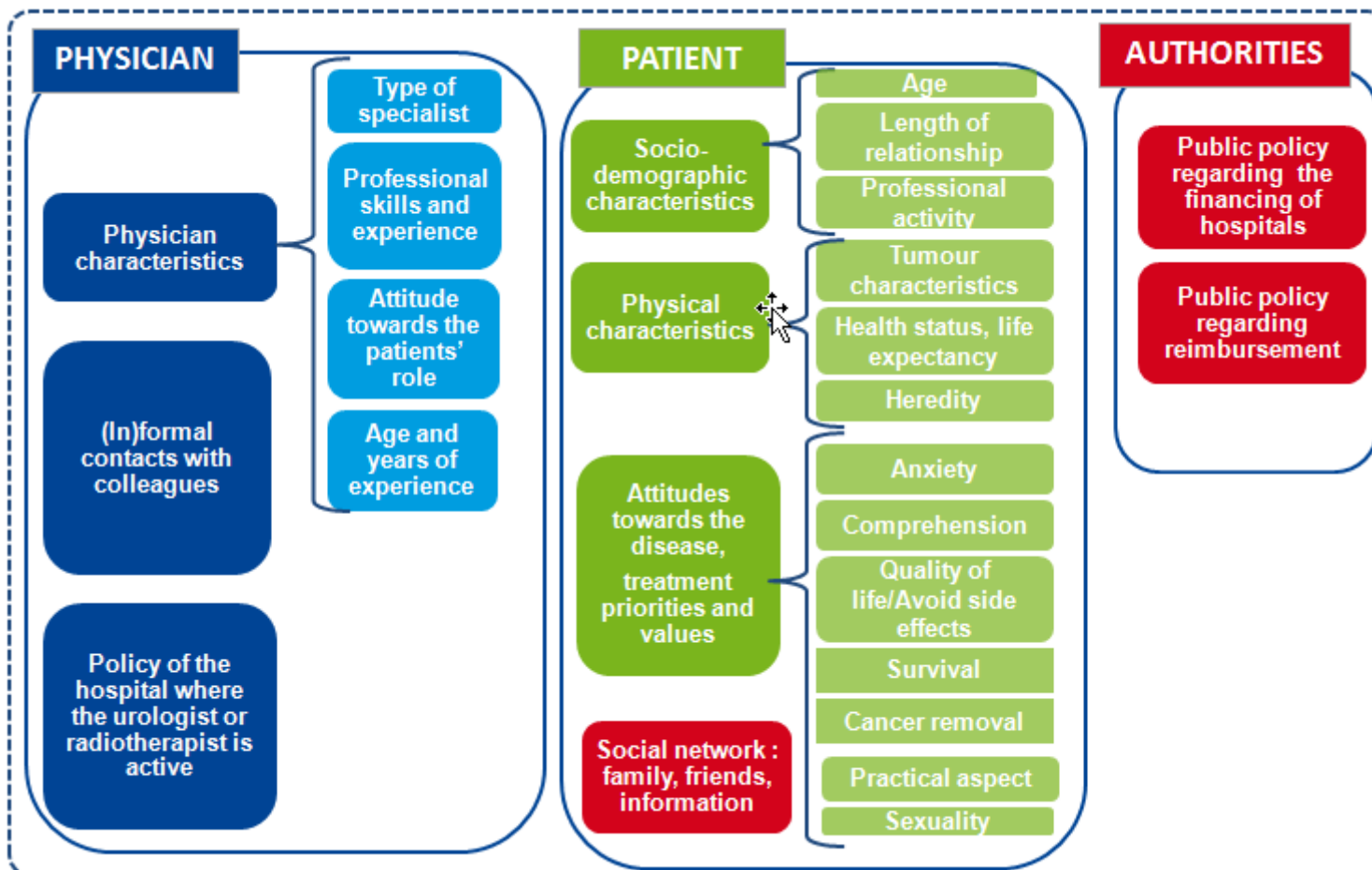
3.2.4 Factors influencing the treatment decision-making process in localised PCa according to the interviewed physicians

From the interviews with physicians we can deduce that the therapy choice is influenced by three interfering main pillars: the patient, the physician and the public authorities. Each pillar can be subdivided into several aspects influencing the treatment choice (Figure 2).

The interaction between which kind of patient meets which kind of physician results in specific treatment decision outcomes, whereas the public authorities influence treatment decisions in a more general way.



Figure 2 - Factors influencing treatment choice of patients regarding localised prostate cancer identified from interviews with physicians





I. THE PHYSICIAN

Three categories of determinants can be described within the pillar 'physician': the characteristics of the physician himself but also the network of his colleagues and his work environment.

A. PHYSICIANS' CHARACTERISTICS

The interviews provide information on 4 types of physicians' characteristics: the physician's specialization, his professional skills and experience, his attitude towards the patients' role in the decision and the physician's age.

Specialization: urologist or radiotherapist

Urologists tend to function as gatekeepers regarding the therapy choice. Patients are more likely to first visit an urologist rather than a radiotherapist because general practitioners are more likely to refer a patient with an increased PSA level to an urologist. In general, radiotherapists are only consulted when the therapy choice is already made by the urologists.

'In België is het nog steeds zo dat patiënten meestal via de huisarts komen. De huisarts stelt een afwijking vast in het labo, of de patiënt heeft urinaire klachten, dat hij moeilijker kan plassen, dat er dan op die manier iets aan het licht komt. Dan is het toch de reflex om de patiënt onmiddellijk naar de uroloog te sturen voor de echografie en voor de biopsie. De ingangspoort is de uroloog.' (Radiotherapist, General Hospital, 23 years experience)

According to radiotherapists, this strongly influences the number of executions of each treatment type:

- Radiotherapists sometimes express the feeling that urologists tend to promote the treatment option which they can execute themselves. This can be done because someone is an advocate of his own abilities (each physician will first think about what he can do for the patient and treatment options) or because of more economical reasons.
- Radiotherapists refer to an American study which showed that patients often choose the treatment offered by the first physician they have consulted. This could, according to them, explain the high amount of

prostatectomies as the patient often first (or only) sees an urologist in Belgium.

'Hoe sterk is de heelkundige approach in de verf gezet? Of hoe sterk heeft de uroloog een radiotherapiebehandeling toegelicht als therapeutisch alternatief? Dat ligt dan minder voor de hand omdat dat je vakgebied verlaat. Er is een soort bias, dat is ook de reden dat er nog zoveel wordt geopereerd hé. Uiteindelijk, statistisch gezien zou je misschien op 1/3 opereren, 1/3 bestralen en 1/3 brachy moeten uitkomen en dat is nu niet het geval.' (Radiotherapist, General Hospital, 23 years experience)

Professional skills and experience

Not all specialists are skilled in the same way. They differ in terms of technical expertise, in the way they work, in previous experience with treatments.

- Some physicians (urologists or radiotherapists) can have a lot of experience in executing a **new technical procedure** as robot assisted surgeries, brachytherapy, HIFU therapy and external radiation while others do not. This can lead to two situations:
 - When a physician is specialized in a certain treatment, he will automatically receive patients asking for this specific treatment.
 - A physician with a certain technical specialization can, in case where several options are possible, advise his specialty treatment more readily because he is convinced of the benefits of this treatment.

'Ik denk dat ik het kan verwoorden onder de vorm van een Duitse professor die het eens op een internationaal congres heeft gezegd: 'Het komt er niet op aan hoe je gelokaliseerde prostaatkanker behandelt, je moet de dingen doen waar je ervaring in hebt, en de techniek gebruiken waar je ervaring in hebt.' Ik heb veel meer ervaring in de open chirurgie.' (Urologist, General Hospital and Private Practice, 23 years experience)



- **The assessment of the tumour severity in combination with patient characteristics** varies among physicians and influences treatment decisions. Physicians can have different attitudes towards how and when one should actively treat prostate cancer:
 - Life expectancy can be differently assessed by different physicians.
 - The way biopsies are taken can vary: at random biopsies versus guided biopsies.
 - A biopsy is not always processed for further examination after seeing a patient with a suspicious PSA level, notably because the physician does not think it is very urgent or dangerous. This is often because of the low life expectancy of the patient. The suspicious PSA level could be due to a prostate cancer but in some cases, it is not worth searching and treating the prostate cancer. The prostate cancer will probably never get the chance to evolve and become lethal. Physicians do not want patients with low life expectancy to worry about 'having cancer' when in reality it probably will never pose a life-threatening problem.
- **Previous good or bad experiences with treatments** can also influence the choice of treatment for specific patient cases. There are for example urologists who have had some bad experiences with active surveillance after actively promoting it for a while with a broad patient target group (younger patients). These patients suffered from a more aggressive growing tumour than previously estimated and needed surgery within the first year of the active surveillance. These bad experiences have led to the fact that these urologists now choose to be more restrictive than in the past (when selecting patients for active surveillance). They will only offer active surveillance to older patients and will choose for more aggressive treatment options when dealing with younger patients.

Physician's attitudes towards the patients' role in the treatment decision

The role the patient plays in the treatment decision varies between different urologists or radiotherapists. One promotes a high patient autonomy when possible; another has a more paternalist view as 'physicians know best'.

- High patient autonomy: the patient plays an active role in the therapy choice. A patient needs to be fully convinced of his therapy. He also needs to be fully aware of the risks, side effects and prospects of each option.
- Paternalist view: urologists' argue that with their expert knowledge they are best positioned to make the final decision regarding the choice of therapy.

These different attitudes can lead to different scenarios. For example, in front of a patient who insists on having surgery despite the physician's advice, one follows the patient in his choice, while another refuses to perform a prostatectomy. This can have two different outcomes: the patient adapts his opinion and follows the specialist or he goes for a second or third opinion, in search of a specialist, willing to execute the prostatectomy.

Age and years of experience

Age and years of experience with treating localised prostate cancer influence urologists' attitudes towards active surveillance. But urologists disagree about the direction of this influence. It can be noted that there is an age-effect and generation-effect. Older urologists prefer to give weight to the age-effect, while younger urologists tend to favour the idea of the generation-effect.

- **Older urologists** focus on the role of age in their own and younger colleagues' treatment decisions:
 - That time has made them more conservative regarding surgery and/or radiation. By ageing themselves, they are now more capable of identifying themselves with patients with this condition. This has made them more empathically involved.
 - Experience has given them the chance to see the negative side of prostatectomies.
 - Younger urologists are often viewed by their older colleagues as more willing to operate as they want to train their surgery skills and prove themselves as good surgeons.
 - Younger urologists are perceived as more driven by economic reasons and thus less pro active surveillance; because they are paid for service, they are likely to perform more surgeries. This makes them less willing to choose for active surveillance.

'Vous savez ce que l'on dit parfois c'est que le choix entre tel ou tel traitement par le médecin dépend du nombre d'enfants qu'il a, si c'est une famille qui lui coûte cher.... C'est une caricature, je sais, mais inconsciemment, ça joue parfois un rôle.' (Urologist, General Hospital and University Hospital, 15 years experience)

- However, **younger physicians** focus on differences between generations of physicians when comparing themselves to older colleagues:
 - They are educated with the fact that active surveillance is a valuable treatment option besides surgery and radiation, while older physicians are more rigid in preferring the older, more established treatment options.
 - They perceive older physicians as not trained and educated with the idea of active surveillance and they tend doing what they have always done (which in many cases is executing prostatectomies).
 - As experienced senior physicians are often remunerated by payment modalities other than fee for service, it does not matter whether or not they execute 10 or 100 prostatectomies.

Key Points

- **According to the interviewed physicians, several physician characteristics are negatively linked to active surveillance:**
 - **Role of gatekeepers assumed by the urologists regarding the therapy choice (with bias towards prostatectomy)**
 - **Expertise in one technical procedure: each specialist has the tendency to offer the treatment option in which he is most experienced**
 - **Previous bad experience with active surveillance**
 - **Fee-for-service payment**
 - **Need of gaining experience/skills as a surgeon**
 - **Older physicians less trained in active surveillance**
- **The factors positively related to active surveillance are few:**

- **Trend to become more conservative with age (older physicians identifying themselves with patients).**
- **Experiences with negative side effects of prostatectomy.**
- **Younger physicians more open to AS during their training.**
- **The physicians' attitude towards the patient's role in treatment decision can lead to several situations (pro or contra AS).**

B. PHYSICIANS' COLLEAGUES

Two issues are highlighted by the interviewed physicians concerning the relation with their colleagues: the influence of the key opinion leader and the role of the multidisciplinary team meeting (MOC - COM)^c.

Key opinion leaders

The type of urologist one becomes over the years is influenced by the environment where a physician is educated and shaped. Closely working together with key opinion leaders can influence the treatment decisions physicians make. When a young urologist works in the same unit together with a senior urologist (who heavily defends and promotes active surveillance), he is more likely to consider active surveillance. If the same urologists would work together with a key opinion leader who is a pioneer regarding robot assisted surgery, he is more likely to follow the path of robot assisted surgery.

'Le choix d'un traitement se fait en fonction du patron chez qui tu as été formé. Par exemple, moi j'ai été formé par X qui a tendance à pousser plus pour la surveillance active. C'est pour ça que je parle des générations, mon père qui est urologue aussi, il n'a pas été formé sur la surveillance active. Donc la surveillance active n'est pas un premier réflexe. Tandis qu'ici, tous ceux qui sont sortis de ma génération, ont été formés à penser à l'option surveillance active, c'est une option à mettre en parallèle, sur le même niveau que la chirurgie, la brachythérapie et la radiothérapie. Au même niveau. Donc, si j'avais

^c Multidisciplinary team meetings (MOC — COM) have been implemented in many countries as the predominant model of cancer care to ensure that all patients receive timely diagnosis and treatment, that patient management is evidence based, and that there is continuity of care.³⁴



un patron qui était pro chirurgical et qui opérerait tout le monde, j'aurais probablement eu les mêmes réflexes.' (Urologist, Private Practice and University Hospital, 7 years experience)

Multidisciplinary team meeting

The multidisciplinary team meetings (MOC-COM) where all patients are being discussed together with urologists, radiotherapists, anatomical pathologists, oncologists and sometimes a general practitioner can be a great help to make a treatment decision. The organization of the MOC-COM meetings is only a relatively recent evolution (since 2003) and the impact of the attitude of urologists towards these meetings should not be underestimated:

- An open attitude towards the opinion of colleagues and other specialists can determine whether different treatment options will be considered.
- A more negative attitude towards the MOC-COM and the interference of other colleagues can make the meetings a moment of one-way communication where a specialist notifies his colleagues what he is going to do in a certain patient case. There is little or no space for discussion.

'Le COM, ça se passe bien, c'est-à-dire que l'on discute de tous les cas en présence du radiothérapeute, des oncologues, d'autres urologues, du pathologiste. Tous ensemble, on discute des différentes options et on regarde ce qui convient le mieux au patient. Tout dépend ainsi des caractéristiques que vous avez. C'est-à-dire que si vous avez quelqu'un qui impose son idée en disant: c'est mon patient, je décide de ce que je fais et je n'ai pas envie de vous écouter, voilà, OK, la messe est dite.' (Urologist, University Hospital, 7 years experience)

- The ways multidisciplinary meetings are organized and the different physicians attending these meetings can make a treatment decision shift in favour of or against active surveillance: **if an urologist is working in an environment which does not strongly focus on active surveillance, the MOC-COM meetings will be less supportive towards having a high number of patients in active surveillance.** This may result in an urologist who (sometimes unconsciously) complies with his environment and will less emphasize the option of active surveillance in the treatment offer towards patients.

Key Points

- **The relation with the colleagues, key opinion leaders and the multidisciplinary team meetings can influence the physician's recommendations in both ways: in favour of or against active surveillance.**

C. POLICY OF THE HOSPITAL

The policy of the hospital where a physician is active can also play a role in the treatment choice:

- A university hospital or a big hospital makes it possible for a physician to **'hyper'specialize** in one kind of treatment compared with a peripheral hospital.
- The hospital has to make a **choice in its investment**. If a hospital for example has recently invested in new external radiation technology, which can treat localised prostate cancer, it will not also invest in another treatment type for localised prostate cancer (such as a Da Vinci robot or brachy therapy).
- The **investments** hospitals have done (in material for a certain kind of treatment) **need to be recovered**. The availability of a robot to perform a robot assisted surgery may for example push a physician to perform more prostatectomies because this robot is an investment and there needs to be a return on investment. Someone working in a hospital which has heavily invested in a robot will be **less eager to choose for active surveillance** when he could also operate with the robot.

‘Si je peux être très honnête, je pense que le danger est plus grand lorsque certains urologues prennent eux-mêmes la décision ! Je pense que c’est plus réel comme danger. Par exemple, je pense à certains urologues qui ont un robot et qui justement ont pour mission de la direction que le robot fonctionne au maximum. Je pense également à des centres, je ne vais pas citer le nom des centres mais ce sont souvent même des centres universitaires, qui ont une radiothérapie externe dont l’installation est très chère et qui ont pour mission de faire travailler cette radiothérapie externe. Cela existe également, c’est moins connu mais cela existe, c’est très réel.’ (Urologist, University Hospital, 26 years experience)

- Some hospitals foresee different **measures to help, inform and guide patients** in their decision-making process. For example, they enroll a specialist nurse to talk with patients after their consultation with the physician. Some hospitals provide patients brochures or even an iPad tool about prostate cancer. These measures can also influence the decision-making process.

Key Points

- **The policy of the hospital where a physician is active can also play a role in the treatment choice:**
 - **The investment in some technologies can be unfavourable to active surveillance.**
 - **The use of measures informing the patients on prostate cancer such as a brochure, encounter with a nurse or iPad tool can help the patient to decide for or against active surveillance.**

II. THE PATIENT AS PERCEIVED BY THE PHYSICIANS

According to the interviewed physicians, prostate cancer treatment should be tailored to the patient. The quoted factors can be classified in four categories: the socio-demographic characteristics of the patient, his physical characteristics, preferences and social support resources.

*‘Het belangrijkste dat mensen moeten onthouden is dat het **een behandeling op maat van de patiënt moet zijn**. Je kan geen twee patiënten met een gelokaliseerd prostaatacarcinoom vergelijken. **Alles is afhankelijk van de patiënt zelf**. Van de uitgebreidheid van de kwaadaardigheid, van de PSA, van de agressiviteit, van zijn voorgeschiedenis, van zijn partner, van zijn comorbiditeit...’ (Urologist, General Hospital, 5 years experience)*

A. SOCIO-DEMOGRAPHIC CHARACTERISTICS

From the physicians’ accounts, three socio-demographic characteristics affecting treatment decisions are identified: age, partner relationship and professional status.

- **Age** is self-evidently linked to patients’ physical condition and life expectancy, which are treated below (see section 3.2.4.8. Health status and life expectancy)
- Patients in a long-lasting **partner relationship** are more confident about dealing with the side effects of invasive treatments (as incontinence and/ or erectile dysfunctions). Otherwise, for patients in a more recent (open or covered) relationship with (often) a younger person, being able to remain sexually active can be very important. In that case invasive treatments are less likely.
- The fact of being **professionally active** is also mentioned by physicians as a factor withholding patients from invasive treatments:
 - Younger men, who are still professionally active, often prefer active surveillance as they are not willing to cope with the side effects of other treatments (risk of incontinence, need for a period of radiation appointments...). These side effects hinder their professional career.

- Nevertheless, younger men often suffer from more aggressive tumours which need to be treated more radically and younger men can better endure surgery.

Key points

- **Age alone is insufficient to define a treatment recommendation.**
- **A long partner relationship allows the patient to be more confident that he will be able to handle the side effects of an invasive treatment.**
- **To be professionally active can influence patients towards active surveillance since there are less side effects that can threaten their professional career than with other more invasive treatments.**

B. PHYSICAL CHARACTERISTICS

Tumour characteristics

The tumour characteristics play a key role in the treatment decision. Urologists base themselves mainly on the stage of the tumour (T1, T2 or T3), the PSA value and the Gleason score.

Active surveillance is considered as a good option for tumours with a low Gleason score and low PSA value. With active surveillance (over)treatment can be avoided. But doubtful cases can be differently interpreted by different urologists. This doubt occurs because the criteria for the classification are subject to interpretation (see also disadvantage of AS in chapter 3.2.3.2):

- The PSA value has to be low but also stable. If the **PSA value** does not stabilize, physicians do not often accept a patient into active surveillance.
- According to one view, active surveillance is only acceptable for patients with a Gleason up to 3 or 4; according to another view, active surveillance can be accepted also for patients with a Gleason score of 7, which is constituted of a 3+4 score (but not a 4+3 score).

The position of the tumour can also play a role as a tumour located in the periphery of the prostate has more chance of breaking out to other organs and becoming metastatic than a more centrally placed tumour.

'De exacte locatie van de tumor speelt een rol: gaat het om een centraal gelegen letseltje of ligt het heel periferisch, misschien al tegen het kapsel? Dit speelt mee bij de beslissing. Iemand met een groot prostaatadenoom waarin een klein centraal gelegen tumortje zit dat je toevallig hebt kunnen biopsieren is een ander verhaal dan hetzelfde tumortje bij dezelfde persoon, maar helemaal perifeer gelegen, helemaal lateraal tegen de neurovasculaire bundel in het prostaatkapsel.' (Urologist, General hospital, 25 years experience)

Other characteristics are the size of the prostate since a large prostate can for example exclude the option of brachytherapy.

Health status and life expectancy

Age is not a sufficient factor to make a treatment decision. There are perfectly fit 72 year old patients, able to endure surgery, while this will be less obvious for a 58 year old obese patient who already had other health issues. The **physical condition** of the patient and the presence of **co-morbidity** are thus crucial. If someone already had a cardiac arrest, a stroke, suffered from another cancer, is diabetic or already had surgery in the abdominal area will impact on which treatment will be most adequate for a patient.

'Il ne faut pas opérer juste la carte d'identité! Il y a des patients qui ont 65 ans et qui ont l'air d'en avoir 10 de plus. Et l'inverse aussi. Ce n'est pas que l'âge, c'est aussi comment il est physiquement.' (Urologist, General Hospital and Private Practice, 7 years experience)

- **The general level of fitness of the patient** often determines whether or not a patient will be candidate for surgery or radiation but the influence on active surveillance is unclear: one physician sees the ideal patient for active surveillance as somebody who is not fit for surgery anymore while another will also offer active surveillance to patients who could be eligible for surgery.
- **The estimated life expectancy** is considered as very important in the decision: an invasive therapy needs to be worth the side effects that patients risk to endure. It is, however, not always possible to give an accurate estimation of life expectancy. Also the role life expectancy plays in considering active surveillance is ambivalent: one physician only chooses to offer active surveillance to patients who have a life

expectancy of less than 10 years, knowing that he will not have to treat these patients (this can be more interpreted as watchful waiting); another chooses for active surveillance with patients who have a life expectancy larger than 10 years. The goal is then to temporarily avoid complications and side effects of surgery but accepting that in the future, if the tumour evolves, a surgery can become necessary.

Heredity

When a close relative suffered from an aggressive prostate cancer, two physicians' attitudes exist: one is cautious and does not offer active surveillance while another doubts the direct link between prostate cancer and **heredity**.

'Een familiale medische voorgeschiedenis speelt toch ook een rol om te bepalen of iemand al dan niet kandidaat is voor actieve opvolging. Als we weten dat prostaatkanker al enkele malen in de familie is voorgekomen denk ik dat in het algemeen de neiging groot zal zijn om eerder voor een invasieve optie te kiezen. Of dat echt 100% wetenschappelijk onderbouwd is, is mij niet duidelijk.' (Urologist, General Hospital, 7 years experience)

Key points

- **Tumour characteristics determine the physicians' recommendations but there is room for different interpretations, hence variation exists between physicians.**
- **Although the general level of fitness and estimated life expectancy play an important role in physicians' recommendations, no rules can be deduced: active surveillance appears to be proposed to both fit and unfit men, to men with life expectancy <10 years as well as to men with higher life expectancy. However, a confusion between watchful waiting and active surveillance is possible.**
- **The impact of heredity or family history of prostate cancer on the treatment differs between physicians.**

C. PATIENTS' ATTITUDES TOWARDS THE DISEASE, TREATMENT PRIORITIES AND VALUES

Several patients' attitudes towards the disease and patients' treatment priorities are mentioned by the interviewed physicians. Some of them were already described in the literature (see section 3.1.3) but others are additional.

Patients' attitudes towards the disease: anxiety versus confidence

The attitude of a patient towards the diagnosis of prostate cancer can range from very anxious to very confident. Physicians emphasise patients' attitudes to be very important in the treatment decision-making process. A patient can be a perfect candidate for surgery or active surveillance in terms of tumour and physical characteristics but might refuse the proposed treatment because of anxiousness. Active surveillance might be understood as having no treatment at all or doing nothing to overcome or cure the disease. Absence of active treatments scares some patients, hence they refuse active surveillance.

'Er zijn al patiënten geweest waar ik actieve opvolging aan heb voorgesteld en die patiënten worden zot: 'het is kwaadaardig, je moet dat opereren'. Dan moet je echt veel moeite doen om dat uit te leggen aan die mensen en dan krijg je een week later telefoon van die mensen hun huisarts dat die mensen thuis in volle paniek zitten en denken dat we hen laten doodgaan. Het is niet eenvoudig.' (Urologist, General Hospital, 5 years experience)

Comprehension of the disease and successful coping strategies are important preconditions to choose active surveillance. Besides a full understanding of his situation, a patient in an active surveillance programme should also be able not to worry too much about the fact that there still remains an untreated cancer inside the body. He needs to be able to approach his disease in a calm and serene manner.

- Physicians report that the **comprehension and management of the disease** can be viewed separately from the general intelligence of a patient. Some patients can perfectly understand their situation without necessarily having a high IQ, while other, very intelligent patients will not accept active surveillance because this will cause too much stress.



- If a physician estimates that a person is not able to fully understand his current situation, active surveillance will not be a good option, and often not promoted actively. Physicians report that they often have patients with a physical profile to offer active surveillance to but who do not have the 'right attitude' to deal with active surveillance, and thus refuse this option. In order to choose for active surveillance patients need to be fully convinced.
- Moreover, because physicians need to be able to **communicate properly** with a patient choosing active surveillance, they often do not offer this option to patients who do not master English, Dutch or French.

Patients' treatment priorities

Question is which treatment is most likely to restore the patients' embodied sense of control. According to the physicians, some patients prioritise their concern about side effects of the treatment (e.g. incontinence or impotence) which threaten their normal functioning in all aspects of daily life. Others evaluate the risk of side effects to be less important than the risk of dying or of keeping the cancer inside the body. The practical consideration of the treatment can also influence the choice since they can threaten some patient's priorities.

- Patients with a strong focus on **quality of life** will be more likely to be worried about the **side effects** (incontinence and impotence) and to avoid an invasive surgery, hence to choose active surveillance.
 - For example, physicians mention having patients who prefer active surveillance over surgery because they do not want to take the risk of having to give up their sexual capabilities. This is especially the case for men in a new relationship (with a younger woman).
 - For those who are especially stressed by the **threat to their life**, active surveillance does not offer enough guaranties to make sure that a bad evolution of the tumour is discovered before it becomes lethal. Active surveillance would hence induce stress and therefore threaten their quality of life.
- Some people cannot cope with the idea of having a cancer. They want this **cancer removed** as soon as possible, even if the tumour is very small and indolent and it is unlikely to be life threatening. This is not in favour of active surveillance.
 - According to the physicians, there is a contradiction between the ideal patient profile for surgery and the willingness of this patient to have surgery. Older people are often more keen on having their prostate removed when the label 'cancer' is placed upon their condition. The automatic reflex of these people is to have the cancer removed in order to survive. Younger patients seem to better understand their situation in a nuanced way. They are more likely to postpone a surgery. But at the same time younger patients often suffer from more aggressive tumours, where surgery is more advised.
 - The way a person deals with **practical considerations** also influences the therapy choice: the number of days in the hospital, days absent from work, appointments for radiation, etc. are perceived as barriers. For example, a patient can choose for brachytherapy because then he only has to come to the hospital for the surgery and the follow up. He will, compared to external radiation, not have to come to the hospital during a certain period. Besides that, sometimes patients choose to do nothing about their localised prostate cancer because they are not willing to deal with the obligations that come along with choosing for a certain therapy.
 - For active surveillance, physicians indicate that a patient needs to be **motivated enough** to respect his appointments and endure several biopsies over time.



Patients' values: Importance of masculinity and sexuality

Values define what is desirable and the best way to attain this. They refer to shared preferences within a group of people regarding life goals or behaviour in general. One value emerges from the physicians' interview: the cultural importance attached to masculinity and sexuality.

The importance of embodiment in relation to health and illness, as well as the importance and meanings of masculinity vary between groups or cultures. Depending on patients' ideas on masculinity, the prospect of losing sexual capabilities will have a different meaning and impact on status within the group and identity.

'Vous avez aussi des contingences culturelles: on soigne beaucoup de gens non belges qui sont africains, chefs de tribu, qui sont entre guillemets, je ne vais pas dire chef de harem, cela ne se dit plus mais cela se fait encore ! Et qui ont besoin pour être culturellement et administrativement toujours chef, de rester sexuellement actifs, ça fait partie de la culture!' (Radiotherapist, General Hospital, 32 years experience)

However, this stereotypical cultural vision of physicians reported above can also reflect the underestimation by the physicians of the importance of these questions for other patients (e.g. older patients) than patients seen as 'African tribal chief'.

Key points

- **The attitude of a patient towards the diagnosis of prostate cancer can range from very anxious (unfavourable to AS) to very confident (more positive to AS); urologists as well as radiotherapists think active surveillance is only suitable for patients with a good mind-set and comprehension of their disease.**
- **In their treatment choice some patients prioritise their concern about side effects which threaten their normal functioning. Others evaluate the risk of side effects to be less important than the risk of dying. Patients with a strong focus on quality of life will be more likely to avoid an invasive surgery, hence to choose active surveillance, while the others are more likely to prefer active treatment (e.g. prostatectomy).**

- **Some practical considerations related to active treatment can be arguments to choose active surveillance.**
- **The cultural importance attached to masculinity and sexuality appears to be a factor taken into account by the physicians but the stereotypical cultural vision reported can also reflect an underestimation of these questions.**

D. PATIENTS' SOCIAL NETWORK

A patient's social network provides him with emotional and informational support. Emotional support is about the provision of empathy and caring, while informational support often comes in the form of advice, sharing of experiences and knowledge. From the interviews it seems that physicians are attentive to patients' social network and especially close family members.

Partners

Physicians acknowledge that the partner needs to be involved and informed about the disease, the treatment options and their consequences, since she or he has a role to play in the formation of patients' treatment preferences. Moreover, the treatment also affects the partner.

'Ik heb heel graag dat partners of dochters of gelijk wie meekomen. Voor de behandeling van prostaatkwaadaardigheid is het belangrijk omdat de behandeling niet alleen interfereert met de persoon zelf, maar ook met het familiale en seksuele leven. Het is ook belangrijk dat de partner op voorhand weet van: 'goed, als mijn man incontinent is, wat kunnen we daaraan doen? We gaan naar de kinesist, hoe lang gaat dat duren,...' Ook wat erecties betreft. Dat heeft een impact op beiden. En als mannen altijd alleen hier bij mij zitten dan vraag ik soms of ze een partner hebben. 'Dat is niet mijn zaak, maar wil ze eens meekomen?' Ik vraag daar actief naar.' (Urologist, General Hospital, 5 years experience)'

However, the influence of the partner regarding AS is not clearly mentioned by the physicians.

Family, friends, relatives

Physicians mention that **experiences** of friends or relatives who have suffered from cancer (not specifically prostate cancer) can shape a patient's attitudes towards his disease and treatment preferences. If people have lost friends or relatives due to a cancer, they are likely to be more inclined to opt for a radical approach, even if their cancer is not aggressive.

'Wanneer er iets gebeurt in de familie, bv iemand die doodgaat van longkanker, dan is het bij mensen vaak direct paniek, van: ik heb ook kanker, en ik ben nog niet behandeld. Je moet er goed mee babbelen en goed informeren. (Urologist, University Hospital, 15 years experience)

If the patients' social network is characterised by more **nuanced perceptions** regarding the specificities of localised prostate cancer (knowing that there is no urgency and a radical treatment is not always necessary, positive experiences with active surveillance, etc.) patients will better understand and appreciate the option of active surveillance.

Information

The information a patient already has gathered influences the treatment decision-making process. **The internet** is for example quoted to be a source of information which can induce **false hopes or unnecessary worries to a patient**. Physicians often need to take time to refute what patients have read on the internet. They have to inform their patients about their specific tumour situation and the correct facts about their possible treatment options. However, it is also considered as a **good source to gain insights** in the patients' personal situation.

Key points

- **The role of the partner is recognised by the physicians and needs to be considered when a treatment choice is being made. However, the impact of the partner's influence (pro or contra AS) is not quoted.**
- **Family members and friends, especially if they have experienced cancer themselves, may refrain a patient from choosing AS, while more nuanced well-informed opinions represented in the patient's network may encourage him towards AS.**

- **Information found on the internet can induce false hopes or unnecessary worries to patients but can also help for the discussion.**

III THE PUBLIC AUTHORITIES

The way healthcare is organized and financed in a country can determine therapeutic strategies. How specialists are paid, how hospitals are funded and which treatments are reimbursed appear to play an important role according to the interviewed physicians.

The way specialists are paid

Physicians report that the way healthcare is organized in Belgium can stimulate physicians to execute more procedures. It is notably because the amount of money that a department receives depends on upon the number of treated patients.

'Het Belgisch systeem van vergoeding van artsen zit zo ook in mekaar hé. Het is prestatiegericht. Je wordt gefinancierd in functie van het aantal patiënten dat je in behandeling hebt genomen. Dus als de uroloog de patiënt doorverwijst naar de radiotherapeut, dan kan hij voor die patiënt geen behandeling aanrekenen. Dus het is omgekeerd ook. Dat speelt ook mee hé.' (Radiotherapist, General Hospital, 23 years experience)

Hospital financing

The public authorities can guide the policy of hospitals by the way they are financed. Hospitals cannot heavily invest in all treatment options. That is why the authorities force hospitals to choose a certain specialization for treating localised prostate cancer (e.g. invest in a robot, a HIFU device, brachytherapy or state of the art external radiation).



Reimbursement

The public authorities can also guide the way treatments are offered by physicians and chosen by patients by setting out in which way they are reimbursed by the National Institute for Health and Disability Insurance (RIZIV-INAMI). Therapies are only eligible for refund under specific indications. Other therapies are not yet eligible for refund which makes them more costly for patients. For example HIFU is not (yet) reimbursed. This causes hospitals not to invest in the HIFU procedure.

'Brachy kent een enorm groot succes in de Verenigde Staten, omdat daar de kostprijs van een hospitalisatie bijzonder hoog is. De heelkundige benadering is daar gigantisch qua kost, terwijl dat een brachy therapie in de prostaat, een one day procedure is. De patiënt komt 's morgens binnen, gaat onder narcose en gaat dan 's avonds buiten hé. Wij doen hier wel nog een overnachting. Er is ook geen intensieve zorg nodig, complicaties zijn er bijna niet, geen bloedingen of infecties of dergelijke... dat is allemaal veel geringer vergeleken met de klassieke heelkunde.

Bij uitwendige bestraling is de behandelingsduur een belangrijke factor. De patiënt moet zich gedurende zeven of acht weken dagelijks verplaatsen. In dit land is dat natuurlijk een heel relatief gegeven. Er zijn 25 bestralingscentra in België, wat heel veel is, maar in bv Scandinavische landen, of de US, of Canada, moeten de mensen voor een bestraling twee maanden op hotel. Dit kan hier op zich wel een praktische barrière zijn, maar minder dan in andere landen...

Vandaar dat in dergelijke landen de brachy therapie zo'n succes kent. De patiënt moet zich maar één keer verplaatsen en heeft zijn therapie in één keer gehad en mag terug naar huis.' (Radiotherapist, General Hospital, 23 years experience)

Key points

- **Three factors of the public policy are mentioned as determinants of physicians' treatment decision (payment of specialists, hospital financing and, reimbursement of technology). None of them are unambiguously in favour of or against AS.**

3.2.5 Assessment of patient eligibility and implementation of active surveillance

One physician appears rather confident towards AS while another has a more controlling attitude. Two questions emerge: Which patients do physicians find eligible for active surveillance and how do physicians implement active surveillance.

These 2 questions combined with the 2 attitudes (confident vs. controlling) allow to distinguishing 4 types of physicians:

Table 6 – Description of four types of physicians according to their attitudes towards active surveillance

	Patients eligibility	Implementation	Remarks
Physician Type 1	Controlling Attitude	Controlling Attitude	<p>This type of physician prefers a very strict patient profile for active surveillance (lower life expectancy and/or Gleason lower than 6 or even 4 or 5, max 2 positive biopsies). Once a patient is offered active surveillance, he is very strictly followed, with screening, PSA measurement, proactive biopsy and proactive imaging.</p> <p>If a patient does not show up on his appointment, these physicians are likely to be actively involved or control routinely the fact that a patient missed his appointment.</p> <p><i>‘La surveillance active, je dirais que ça représente peut-être 2 ou 3 % des patients, pas plus. Tout ça parce qu’effectivement, ce sont des cas encore bien sélectionnés. On ne va pas faire de la surveillance active pour n’importe qui. On a encore eu ici dernièrement un patient à qui on avait proposé une surveillance active, pour lequel le PSA a progressé, pour lequel on a refait des biopsies qui ont montré effectivement que la maladie avait évolué durant ce temps de surveillance, qui a subi une prostatectomie radicale et pour lequel le résultat anatomo-pathologique définitif a montré que c’était une tumeur qui dépassait la capsule donc, franchement, on a peut-être perdu un peu de temps, on aurait pu l’opérer plus tôt et encore pouvoir arriver dans le temps. Mais là, on a dépassé. C’est un risque malgré tout. Quand on dit surveillance active, ça veut dire que le patient doit effectivement tous les six mois subir de nouveau une série de biopsies, contrôle de PSA tous les trois mois, c’est astreignant. C’est pour cela que cela ne doit pas être réservé à n’importe qui. Ça dépend de la compliance, de la volonté du patient aussi.’</i> (Urologist, General Hospital, University Hospital and Private Practice, 20 years experience)</p>
Physician Type 2	Confident Attitude	Controlling Attitude	<p>These physicians accept a broader set of patient profiles into the active surveillance treatment (even younger patients who are physically fit to have surgery or patients with a Gleason score up to 7), and they follow a strict active surveillance implementation.</p> <p>If a patient does not show up on his appointment, these physicians are most likely to be actively involved or control routinely the fact that a patient missed his appointment.</p> <p><i>‘Oui, je suis pro surveillance active, quand je peux, je le fais. Même chez des patients jeunes chez qui certains de mes collègues auraient déjà opéré d’office... Moi, je pratique la surveillance active mais en prévenant le patient qu’il va se faire opérer mais ce n’est pas obligé de le faire dans l’immédiat. Donc, comme cela, on gagne un peu de temps, un ou deux ans sans troubles érectiles chez les patients qui ont 55,60 ans et qui sont encore capables d’avoir beaucoup d’érection. Je leur dis, on va essayer de gagner encore un an, deux ans si on peut mais je leur dis : vous allez être opérés ! Mais pas tout de suite. Il y en a certains chez qui ça passe.’</i></p>
Physician Type 3	Confident Attitude	Confident Attitude	<p>These physicians can accept a broader set of patient profiles into the active surveillance treatment (younger patients or patients with a Gleason score up to 7) and they are likely to mainly follow PSA values (every 6 months, or for one year). When PSA values remain stable these physicians often do not feel the need to take a</p>

			<p>biopsy or imaging.</p> <p>If a patient fails to show up, these physicians are less likely to undertake any action, it is seen as the sole responsibility of the patient.</p> <p>We did not find any physicians in our study who fit in this theoretical description.</p>
Physician Type 4	Controlling Attitude	Confident Attitude	<p>This type of physicians set strict standards for patients who can step into an active surveillance programme. After being fully screened, the follow up of the PSA value can be sufficient as long as this value stays stable.</p> <p>If a patient fails to show up, some physicians will not undertake any action, it is seen as the sole responsibility of the patient.</p> <p><i>'In de praktijk bespreek ik de opvolging met de patiënt en zijn partner. Waarom dat volgens mij, rekening houdend met zijn parameters, verantwoord is. En dan zal ik vragen in geval van een goed tot matig gedifferentieerde tumor om dat één keer per jaar op te volgen. Ik denk ook dat het niet nodig is om die mensen te frequent op te volgen, omdat ze anders met een prostaatobsessie gaan rondlopen en dat kan ook niet de bedoeling zijn van een conservatieve houding. Ik probeer die mensen gerust te stellen. Je hebt soms mensen die zeggen: 'een jaar is toch lang? Mag ik niet om de zes maanden komen?' Dat mag gerust. Ze zijn altijd welkom, maar ik zeg er bij: 'als een tumor nu plots veranderingen zou beginnen vertonen die op termijn schadelijk zouden kunnen zijn, als we daar binnen een jaar bij zijn dan zijn we nog op tijd denk ik.'</i> (Urologist, General Hospital, 25 years experience)</p>

This table shows that a 'patient X' with 'characteristics Y' can be offered different treatment options, depending on which doctor he encounters. Some may offer him the option of active surveillance, while others may only offer surgery or radiation. Even when active surveillance is offered, there can still be differences regarding the way the active surveillance is implemented: will he be strictly followed, with screening, PSA measurement, proactive biopsy and proactive imaging? Or will a simple PSA follow up be sufficient?

3.2.6 Conclusion regarding the physicians' interviews

According to the interviewed urologists and radiotherapists, a localised prostate cancer is a disease which, if treated right and on time, is not lethal and can be cured. But the choice of treatment of localised prostate cancer can be a rather undefined process as there are often multiple therapy options for one patient case without clear impact regarding the chance of survival.

Over the last years, active surveillance has become a real treatment option for localised prostate cancer. However, some physicians appear reluctant to offer it as they often cannot be sure about the correct phase and evolution of the tumour. The lack of reliable parameters to estimate the evolution of the tumour is a crucial barrier for active surveillance and a demand for better markers is expressed.



The physicians' interviews confirm several determinants described in the literature regarding the treatment choice in localised prostate cancer. This is the case of the tumour characteristics, the age and physical status of the patients, their attitudes towards the disease (anxiety versus confidence), their treatment priorities, the expertise and experiences of the physicians...

Three elements are more noteworthy. Firstly, active surveillance is disadvantaged by economical reasons linked to the fee-for-service financing mechanism or the pressure of the hospital to make cost-effective investments. Secondly, the multidisciplinary team (MOC-COM) can be a great help to make a treatment decision although it cannot prevent the predominance of one particular option. Thirdly, the importance of the social networks is acknowledged by the physicians but considered not easy to manage.

Concerning the limitation of the physicians' interviews, although the sample has tried to cover all the different attitudes and opinions of specialists concerned by prostate cancer, the risk that some attitudes are over or under represented cannot be excluded. The sample size is small and the physicians were recruited on a voluntary basis. Besides that, there can be a socially desired answer-bias in the answers of the physicians: Since the interviewer asked for and focused on 'active surveillance', physicians could have been more positive than they are in practice regarding active surveillance (the ideal patient profile, the number of patients they have in active surveillance, the future of active surveillance according to them) and the way they implement active surveillance (controlling vs. confident).

3.3 Interviews with patients

3.3.1 Description of achieved sample

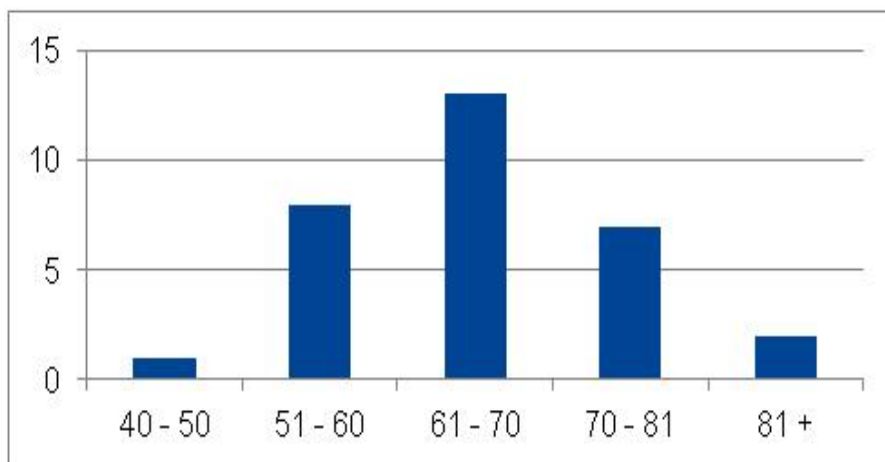
31 patients were recruited with varying therapy options for localised prostate cancer: 19 Dutch speaking patients and 12 French speaking patients (Table 7). The age of the patients varied between 49 and 82 years. Most patients were between 61 and 70 years old (Figure 3) and most patients have chosen their treatment option since less than one year.

Table 7 – Description of the interviewed patients: therapy choice and language

Treatment type	Dutch speaking	French speaking
Active surveillance	8	6
<ul style="list-style-type: none"> One patient was more in a watchful waiting shedule and is now on a hormone therapy. One person who is scheduled for a HIFU treatment was already more than one year in active surveillance. 		
Prostatectomy	2	2
<ul style="list-style-type: none"> Of which 2 respondents had to receive radiation therapy afterwards. 		
Robot assisted prostatectomy	2	1
<ul style="list-style-type: none"> Of which 1 respondent had to receive radiation therapy afterwards. 		
External radiation	3	2
Brachytherapy	1	1
HIFU	3	0



Figure 3 – Distribution of the patients' age



3.3.2 Patients' perception of the active treatment options for localised prostate cancer

The interviewed patients summed up several positive and negative aspects for each treatment option. The positive and negative aspects can be mentioned by people who have endured this treatment but can also be the perception of people who have had another treatment. Active surveillance is discussed under a separate heading (see section 3.3.3. Patients' perception of active surveillance for localised prostate cancer).

This chapter reflects the patients' perceptions of reality which do not always correspond to objective knowledge.

3.3.2.1 Open prostatectomy

The open prostatectomy combines removal of the tumour, a large amount of expertise since it is a well established technique and it leaves open the opportunity to be treated with radiation in the case of recurrence. Compared with robot assisted surgery, the open way allows the physician to base himself on the realistic vision instead of the image on a screen which could introduce bias.

Concerning the negative aspects of the open prostatectomy, patients stress the general risks of surgery (narcoses, blood loss, etc) and the probability of severe side effects (incontinence and impotence). This leads to a long recovery time, the need to buy incontinence material, the need for rehabilitation and visits to the physiotherapist. Open prostatectomy is also more invasive than robot assisted prostatectomy and any other therapy. Moreover, having surgery could turn out to be redundant in case of very indolent tumour.

3.3.2.2 Robot assisted prostatectomy

The robot surgery is perceived as 'state of the art'. Compared to open prostatectomy, there is a bigger chance of smaller side effects regarding erectile dysfunctions and incontinence problems as urologists have the ability to work more nerve-sparing; recovery time can also be shorter and the patient leaves the hospital more quickly.

But robot assisted prostatectomy has also negative aspects. It can be viewed as a field in which one needs to build expertise and the link between the surgeon and the patient is less straightforward compared to open prostatectomy. In addition, a technical error can cause great problems and the image on screen can be biased so that residues of tumour tissue remain unnoticed.

3.3.2.3 External radiation

According to the patients, radiation has made an enormous evolution, which makes that physicians are today able to work more focalised. External radiation is less invasive than surgery and can have fewer side effects. Patients think potency is better preserved than with a prostatectomy.

Several problems are mentioned by patients as the risk of remained residues of the cancer, incontinence and impotence, damage to other tissues in the area (bowels), suffering and feeling sick, loss of hair or skin affection. Radiation can raise practical problems as it demands a series of treatments. Patients state also that treating prostate cancer with radiation is not efficient.

3.3.2.4 Brachytherapy

Brachytherapy is perceived as less invasive and is reported to have fewer side effects compared with a prostatectomy. After a brachytherapy, a patient can leave the hospital after one day.

However, having radioactive particles in the body can cause distress especially when a patient hears there is a possibility that he will urinate them out and that he needs to keep these 'radioactive grains' in a special box to prevent contact with other humans. Brachytherapy can also cause a feeling of fatigue as long as the seeds remain radioactive and can be followed by impotence and incontinence.

3.3.2.5 HIFU

HIFU can act very focalised and is less invasive compared to prostatectomy and brachytherapy. It is sometimes perceived as something 'new' and 'state of the art' by patients. It is related to a smaller recovery time and fewer side effects compared to other treatments. Moreover, all other therapy options remain open after having HIFU.

But HIFU is an expensive treatment type, which is not refunded by most insurance companies and is not yet accepted by all urologists as a 'common procedure' which can raise doubts about the effectiveness.

Sometimes a 'TURP'^d procedure is needed before HIFU can be executed. This makes HIFU somewhat inconvenient.

3.3.3 Patients' perception of active surveillance for localised prostate cancer

The sample represents a mix of patients in active surveillance or who were offered active surveillance but refused it or even patients who were never offered active surveillance by their urologist. This chapter examines how and under which conditions patients choose or refrain from choosing active surveillance.

3.3.3.1 Advantages of active surveillance

A positive aspect of active surveillance is the preservation of the **quality of life**. This can be attractive either for older patients who fear to suffer from a general deterioration after having endured surgery, or for younger patients who now do not have to worry about incontinence and impotence.

With active surveillance, there is also no need to worry because the **cancer is being monitored**.

3.3.3.2 Disadvantages of active surveillance

Active surveillance can put patients under a **psychological pressure**. There is doubt about the exact size of the tumour, and its aggressiveness. Moreover, the tumour remains untreated, so there is the risk that a bad evolution of the tumour is discovered too late.

'De psychologische belasting is voor mij het zwaarste punt van heel de actieve opvolging. Ik vind dat zwaar. Ik weet niet hoe dat met andere mensen is, ik ben nu volop bezig met welke behandeling ik zal kiezen wanneer mijn toestand zou evolueren.' (Active surveillance, 63 years old)

^d The transurethral resection of the prostate (TURP) is a surgical procedure that removes portions of the prostate gland through the penis.



This **uncertainty** is clearly mentioned by the patients who were offered active surveillance, but have chosen another more invasive therapy: they refuse to live with a tumour inside their body (even if this tumour is very small) which could evolve and become metastatic. It is a risk they are not willing to take.

'Ik weet dat er een grote kans is dat ik daar niet aan zal sterven, maar ik wil dat risico niet nemen. Ik wil nog een jaar of tien, vijftien leven. Ik wil dat risico niet nemen van: er misschien 1 kans op 3 dat ik ervan dood ga. Ik ben nu nog in een goede fysieke staat en heb geen andere ziektes daarom konden ze mij nu nog opereren, zodat ik er zeker niet van zal sterven.' (Prostatectomy, 69 years old)

'Je préférais être opéré que d'être dans l'inconnu' (Prostatectomy, 71 years old)

Another negative aspect of active surveillance is the need to endure **several biopsies** over the years, which patients find an unpleasant experience and can cause inflammation. Older patients who are in active surveillance, whose PSA value remained stable for some time, may ask their physician to postpone the biopsy as it is not a pleasant experience. The digital rectal examination is also mentioned as a small inconvenience of active surveillance. However, it does not weigh up to the inconvenience caused by an active treatment.'

'Le désavantage, ça pourrait être la biopsie, je suis d'accord. Première biopsie, c'est logique. Deuxième biopsie, à la limite, on contrôle. La troisième... J'ai pensé qu'on allait quand-même exciter cette glande et cela m'inquiétait un peu, savoir si on n'allait pas réveiller le chat qui dort. C'est comme ça que Matisse a dit elle-même « ça suffit maintenant, c'est quand-même une invasion.' (Active surveillance, 74 years old)

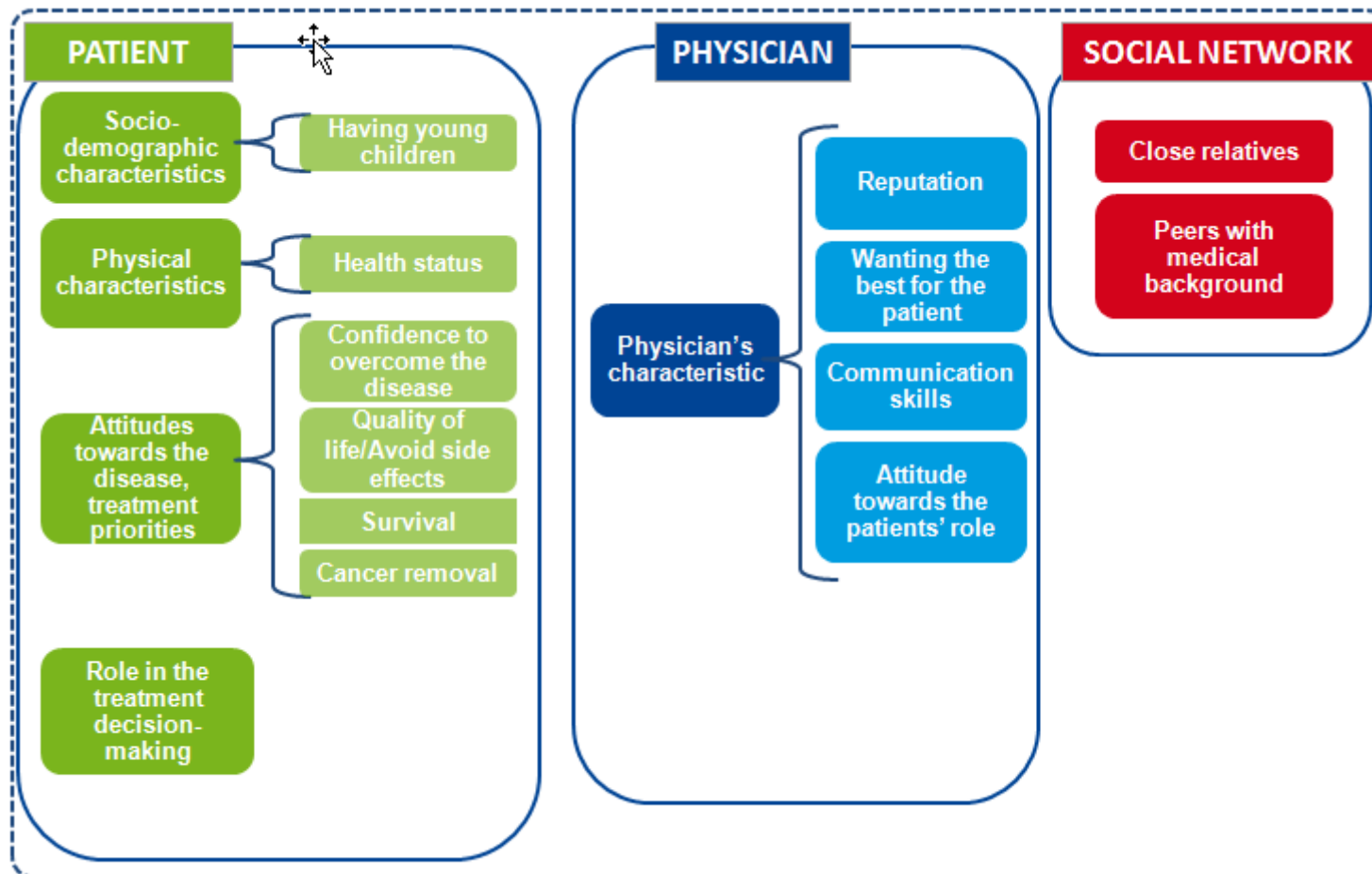
3.3.4 Factors influencing the treatment decision-making process in localised PCa according to the interviewed patients

After the staging of the cancer (when the cancer turns out to be localised), patients have to choose a therapy. This is influenced by several determinants which can be grouped into 3 main pillars: the patient, the physician and the social network. Each pillar can be subdivided into several aspects that individually influence the treatment choice (Figure 4).

The interplay between patient characteristics, how the physician is appreciated and what the physician proposes will make whether or not a patient accepts the treatment. If there is no acceptance, a second opinion will be sought. It is important to note that the decision-making process is not always a straightforward process. It can take some time (and several consultations) before a decision is made.



Figure 4 – Factors influencing treatment choice of patients regarding localised prostate cancer identified from interviews with patients





I THE PATIENT

The patients mentioned several factors that influence their treatment decision. These factors are classified in the same four categories used in the previous chapter presenting the main ideas from the interviews with physicians (see section 3.2.4.): the patients' socio-demographic characteristics, their physical characteristics, their attitudes towards the disease and treatment preferences, and the role of informational and emotional support provided by the patients' social network.

A. SOCIO-DEMOGRAPHIC CHARACTERISTICS

Only one socio-demographic characteristic was mentioned during interviews with patients: the presence of (young) children in the household. Patients with (young) children tend to prioritize survival, hence choose an invasive treatment as they do not want to leave their children behind without a father.

'Je ne peux pas me permettre de laisser mes enfants sans père' (Prostatectomy, 59 years old)

Age, marital status, and professional status were mentioned by the physicians but not in interviews with patients.

Key points

- **Fatherhood pushes patients towards active treatments.**

B. PHYSICAL CHARACTERISTICS

From the two physical characteristics described in the literature and mentioned in the physicians' interviews (the influence of their physical condition and the tumour characteristics), patients only mention the first.

When all treatment options are being presented, patients appear to make a first evaluation in terms of what they expect their body can cope with. They make this estimation, together with, or independent from their specialist.

- For example, patients who have already had surgery in the abdominal area state they were not keen on having a radical prostatectomy. Because of the side effects of previous procedures, they choose radiation therapy.

- Younger patients might choose surgery because they estimate to be physically able to cope with the burden of surgery.

Key points

- **The patients are aware that their physical condition plays a role in the treatment decision. However, the impact on the decision for or against active surveillance is not mentioned.**

C. PATIENTS' ATTITUDES TOWARDS THE DISEASE, TREATMENT PRIORITIES AND VALUES

The attitudes towards the disease reported by the patients are similar to the attitudes identified by the physicians (anxiety versus feelings of confidence), as well as the corresponding opposition in priorities (on the one hand preservation of bodily control by avoiding incapacitating side effects of surgery and on the other hand survival as main concern).

- Patients can have a **very confident, relativistic and self-assured attitude** towards the disease and do not perceive the disease as a threat to their life and/or feel confident to overcome the disease.
 - In general, patients who choose for active surveillance remain very calm under the circumstances. They do not panic when they hear the word 'cancer' and will not choose for an invasive treatment 'just to be sure'.

'De meeste mensen krijgen het vroeg of laat maar gaan er daarom nog niet van dood. Dus op zich vond ik het niet zo alarmerend. Het is niet aangenaam natuurlijk.' (Active surveillance and then HIFU, 59 years old)

'Je n'ai pas l'impression de vivre au bord d'un volcan. Ça pourrait, mais il faut être réaliste, voir le pour et le contre.' (Active surveillance, 74 years old)

- The consequences of a radical prostatectomy or radiation therapy are known by patients. **Avoiding side effects** is the main argument used by patients to choose active surveillance. With active surveillance, the door for a more invasive therapy remains open, but as long as a more invasive therapy is not necessary, patients win years with a **higher quality of life**.



- Older patients can choose active surveillance, because they do not want to endure the side effects of a treatment. The positive aspects of the treatment do not weigh up to the negative aspects.

'Je suis déjà depuis quatre ans sous surveillance active et ce sont quatre ans sans effets secondaires d'une opération.' (Active surveillance, 74 years old)

- Even people who are fit to endure surgery can choose for active surveillance because they do not want to deal with the side effects of more invasive treatments.
- Attaching high importance to masculinity, the **preservation of sexual fitness** is also mentioned by patients as a reason to prefer a less invasive treatment.

'L'aspect de sexualité compte aussi. Je ne suis pas obsédé, mais on m'avait fait sous-entendre que c'était jeune pour se faire opérer quand j'avais 58 ans... Mon copain a maintenant un souci de ce côté-là, je sais bien que ce n'est pas toujours gai quoi. Sa femme dit 'ok' mais elle a parfois envie quoi. Si malgré tout, ça fait partie de la vie quand-même, on n'est pas des moines. Il faut dire ce qui est, c'est un facteur important.' (Brachytherapy, 62 years old)

'Hij zei iets van mijn prostaat weg te nemen. Ik zei tegen de dokter: je mag doen wat je wilt, maar van mijn kloten blijf je af.' (Radiation therapy, 81 years old)

- Other patients are more ready to accept some risks as long as **survival** is guaranteed.

'Het slechte nieuws was dat ze iets gevonden hadden en het kwaadaardig was. Op dat moment heb ik drie keer moeten slikken. Ja, dat doet je wel iets, dat pakt je, het is in één keer aan mij, het was in één keer dichterbij. Zolang dat je er zelf niet mee te maken krijgt heb je daar geen idee van. Maar in één keer ben jij het, en dat is een grote impact. Zeker naar mijn gezin toe, ik heb toen gebeld naar mijn vrouw en we zaten samen te huilen. Allez ik heb mijn pa zien sterven en prostaatanker heeft toen een grote rol gespeeld, die was nog maar 56' (Robot assisted prostatectomy, 49 years old)

- Patients who cannot imagine living with a **cancer inside**, want to remove it and prefer invasive therapy.

Key points

- **The attitudes towards the disease reported by the patients are similar to the attitudes identified by the physicians.**
- **Feelings of confidence and preservation of bodily control by avoiding incapacitating side effects of active treatment make active surveillance more likely.**
- **Conversely, patients preferring survival and cancer removal are more attracted by active treatment.**

D. PATIENTS' ROLE IN THE TREATMENT DECISION MAKING

The patients' interviews allow distinguishing two categories of patients related to the role in deciding on their treatment:

- **Passive patients** do not question the physician's recommendation and do not feel the need to gather additional information.

'Veel informatie heb ik daar niet over opgezocht. Je moet toch afwachten hoe alles draait en keert. Ik heb gelaten mijn lot ondergaan, ik zal het zo zeggen. Ik heb gewoon laten doen wat de dokter zei dat hij ging doen' (Radiation, 81 years old)

- **Active patients** take the treatment decision after a broad investigation and gathering of information from multiple sources. They value their personal autonomy and bodily control. They take the lead in the decision-making process. They take a critical stance towards physicians.

'Ik heb al een stuk of 6/7 urologen geraadpleegd in binnen- en buitenland. Spijtig genoeg is er minder expertise in België. Vooral op beeldvorming. Veel mensen doen gewoon wat de dokter zegt, veel oudere mensen luisteren en volgen 'mr dokter' blind maar dat is niet aan mij besteed. Ik zit momenteel in een programma van actieve opvolging maar wil mijn opties weten voor wanneer er toch iets zou moeten gebeuren.' (Active surveillance, 63 years old)



The active or passive role is related to the **confidence** patients have in **their physician** and the correspondence between the physicians' proposal and patients' preferences. The need to feel a '**connection**' with a physician is explicitly mentioned. If there is a connection, patients are more likely to trust the physician and follow his advice. Patients lacking trust in a specialist are likely to opt for a second opinion.

'Waarom nog naar een andere dokter gaan als alles al zonneklaar is? Het is kanker en het moet geopereerd worden.' (Prostatectomy, 65 years old)

'Ik heb al een stuk of 6/7 urologen geraadpleegd in binnen- en buitenland. Spijtig genoeg is er minder expertise in België. Vooral op beeldvorming. Veel mensen doen gewoon wat de dokter zegt, veel oudere mensen luisteren en volgen 'mr dokter' blind maar dat is niet aan mij besteed. Ik zit momenteel in een programma van actieve opvolging maar wil mijn opties weten voor wanneer er toch iets zou moeten gebeuren.' (Active surveillance, 63 years old)

'Ik heb een heel goed gesprek gehad met de uroloog. Dat was een klik. Dat ging beter als met de vorige uroloog. Die vorige was zo kortaf. Ik kon er niet goed mee praten, dat was er ook precies een fabriek. Bij die dokter in X had ik een heel goede klik. Ik voel hier dat ik geen nummer ben, wat ik bij de eerste uroloog wel was. Ik voel dat ik nu goed gekozen heb. De eerste dokter zei: binnenkomen, biopsie onder narcose, en dan mag je ervan uit gaan dat we de prostaat drastisch gaan verwijderen. En dan dacht ik 'hola, nu ga ik eens horen op een ander.' (HIFU, 63 years old)

The **confidence in the general practitioner** can also play a role in the patient's acceptance of the referred specialist and shapes the active or passive role that patients play. If they do not trust their family doctor, they take the matter in own hands and use other channels to find a specialist.

'Mijn huisarts heeft me doorverwezen. Die zei dat professor X de beste is waar ik kon gaan, ik vertrouw mijn huisarts hierop.' (Active surveillance, 65 years old)

'Mijn vorige huisarts denkt dat hij alles zelf kan genezen, hij begon bij mij een rectaal toucher te doen. Hij moet dat niet doen hé, das iets

voor de uroloog. Ik ben dan veranderd van huisarts (Robot assisted prostatectomy, 67 years old)

The **internet** can be used to form a judgment about the side effects of treatments through patient reviews, scientific, semi-scientific or popular literature and forums. For example:

- Patients can have discovered the HIFU treatment by searching for information about treating localised prostate cancer.
- They can decide to not to have a prostatectomy because of what they read online.
- They can find support for their choice for a robot assisted prostatectomy, because they have read negative stories about being treated with radiation or through an open procedure.
- Patients can seek an expert in the treatment option they prefer, so they can consult him (for a second opinion).

'Het internet is een goudmijn qua informatie. Ik heb informatica gedaan en industriële automatisatie. Ik zei tegen de professor: 'Ik kan misschien niet opereren, maar ik weet er wel alles van.' Via internet kan je alles te weten komen.' (Prostatectomy, 53 years old)

- Still patients can avoid the internet because of the negative tone of voice and worst case scenarios described on the web.

'Non, on m'avait dit de ne surtout pas aller lire sur internet parce qu'on y lit des idioties. J'ai déjà regardé des forums et on serait malade rien que de les lire.' (Brachytherapy, 62 years old)

Books, popular magazines, television programmes or DVD's can also guide them in their treatment decision.

'Je me souviens qu'à l'époque, il y a eu une émission à la télévision autour de l'appareil de radiothérapie qui est installé à X dans lequel on disait que c'était le nec le plus ultra est donc là, je me suis senti vraiment en confiance. Je me suis dit que là, on avait fait le bon choix, ça a renforcé la confiance que j'avais déjà au départ. C'est vrai qu'à travers les médias, cela peut être important de voir des gens qui témoignent. Cette mission c'était avant la radiothérapie.' (Prostatectomy and radiation, 61 years old)

'Mijn geluk is geweest dat ik een collega beeldhouwer heb, die ook prostaatkanker heeft en naar X gaat naar zijn uroloog. Daar lagen in de wachtzaal DVD's over prostaatkanker. Hij heeft die DVD meegebracht, ik heb die 2 keer gezien en ik was gerust. Alles staat daar zo duidelijk in, zonder doekjes om te winden. De grote geruststelling voor mij is dat ze op de DVD, met statistieken zeggen dat eens je 71 bent, de kans op overlijden door prostaatkanker heel klein is. De meeste mannen, 80%, krijgt prostaatkanker. De meesten zullen sterven van iets anders als je het op late leeftijd krijgt. Op de DVD leggen ze ook alle verschillende therapieën uit. Ik vind dat alle mannen die prostaatkanker krijgen de kans zouden moeten krijgen om die DVD te zien of minstens die info zouden moeten krijgen. Dan weet je ineens wat er kan gebeuren, welke mogelijkheden er zijn. Dat vind ik zo geweldig hé. Ik heb die al aan verschillende mensen laten zien. Ik voel me echt gelukkig dat ik die DVD toevallig gekregen heb.' (Active surveillance, 74 years old)

Both the active and passive attitudes can lead to active surveillance:

- In general, patients who have chosen active surveillance have an active way of dealing with their disease when they make their treatment decision. They want to fully understand their situation and will not hesitate to go for a second opinion. So when a specialist only offers them one invasive treatment option, they will first validate this offer by consulting another specialist.

Na die punctie moest ik terug op consultatie. Tijdens dat gesprek gaf hij mij enkel een boekje over hormoontherapie. Ik had eigenlijk niet de kans om te vragen wat er juist allemaal mogelijk was, die man was daar wat aan het zwansen met zijn personeel en hij zei: 'Als je die hormoontherapie ondergaat zal je gecastreerd zijn hé man, gecastreerd.' Dat was een echte bullebak, die heeft me niet meer gezien. Ik heb het tegen de huisarts gezegd, stuur er niemand meer naartoe. Moest ik daar gebleven zijn had ik die hormoontherapie gehad en was ik gecastreerd. Met alle gevolgen van dien. Hij heeft me niets anders voorgesteld.' (Active surveillance, 74 years old)

- However, there are also patients in active surveillance with a more passive attitude, who have just followed the treatment decision of the first specialist they have encountered.

'Je n'ai pas été voir un autre médecin, pour un second avis lorsque j'ai eu ce diagnostic. Je le savais et donc, c'était un point réglé pour moi.' (Active surveillance, 76 years old)

Key points

- **Patients can take an active or passive role in deciding on their treatment. The active patient takes the treatment decision after a broad investigation and gathering of information from multiple sources. Passive patients do not question the physician's recommendation and do not feel the need to gather additional information.**
- **Confidence in physicians but also correspondence between the physician's proposal and the patient's preferences facilitate a passive role.**
- **Both the active and passive attitudes can lead to active surveillance.**

II. THE PHYSICIANS AS PERCEIVED BY THE PATIENT

The perceived physician's profile is an element intervening in the trajectory towards a treatment decision. The evaluation of a physician's qualities should turn out positive in order to build a relation of mutual understanding and trust.

Patients use several evaluation criteria in their assessment of their physician's profile: his reputation, his expression of wanting the best solution for his patient, his communication skills and, his attitude towards patient's autonomy in the decision-making process.

Physician's reputation

Patients can explicitly seek a specialist with a good reputation. They verify with their general practitioner, and/or with peers and/or seek information on the internet to know about a specialist's reputation.

'J'avais lu dans le Télémoustique, que le Professeur X c'était une sommité en la matière. Si on ne part pas confiant avec ça, c'est jamais ! Ca m'a rassuré.' (Brachytherapy, 62 years old)

'De dokter heeft ook mijn pa geopereerd, dus ik wist wie die mens is. Het is een vakman. Iemand die duidelijk communiceert in mensentaal en niet rond de pot draait. Hij is misschien een beetje cru, maar dat is goed als je dat kan plaatsen, en ik kan dat plaatsen. Dat is een luxe denk ik.' (Robot assisted prostatectomy, 49 years old)

If for example, a patient directly goes to a university hospital, he will often not go to another hospital to have a second opinion, because he believes to be already in the hands of 'the best'.

'Ik ben doorsnee een voorstander om direct naar een academisch ziekenhuis te gaan, de summums zitten in een academisch ziekenhuis hé. In theorie heeft dat mijn voorkeur. Ik heb eens 6 maand in een ziekenhuis gelegen dus ik ken er wel wat van.' (HIFU, 68 years old)

Patients appreciate especially the following characteristics:

- Providing clear explanations
- Being friendly and very professional
- Skilled and renowned as an outstanding master of a certain technique.

'Dokter X is de enige in België die werkt met het HIFU systeem, dus hij is echt de kenner op dit vlak.' (HIFU, 68 years old)

- Investigating every possible option in order to offer a solution tailored to the patient's profile and needs, instead of performing a routine procedure.

Once a relationship of mutual understanding is established, compliance with the physician's advice becomes more likely.

Physician's expression of wanting the best solution for his patient

Patients want to be treated as human beings and appreciate it when a physician takes an empathic stance and time to build a relationship of mutual understanding regarding localised prostate cancer and the characteristics of the disease. If patients feel a physician is doing his very best, takes time and is highly involved to find the best suitable option, they will not think about consulting another physician.

Patients report differences between physicians in the amount and type of information provided. One received complete information about all treatment options and the risks of side effects; another had the impression that not every treatment option got an equal share of attention; still another received little information and was just offered one treatment, favouring the physician's own speciality or the treatment he is most experienced in.

'Het enige waar de eerste dokter over sprak was een operatie.' (Active surveillance, 73 years old)

'Andere artsen spraken niet van HIFU, dat vind ik wel een beetje raar. Maar dat is gewoon omdat hun winkel dit niet aanbiedt denk ik.' (HIFU, 52 years old)

According to the interviewed patients, not every physician is an advocate of active surveillance. Some do not offer active surveillance on a regular basis to candidate patients. So when these patients do not opt for a second opinion, the option of active surveillance will never be presented to them.

'Actieve opvolging? Wat is dat juist? Daar heb ik niks van vernomen' (Brachytherapy, 58 years old)

'De eerste twee specialisten spraken niet van actieve opvolging, het was pas bij de derde dat me dit is aangeboden.' (Active surveillance, 73 years old)

'Ik mocht zelf kiezen of ik een operatie of bestraling wou, actieve opvolging ken ik niet nee.' (Radiation therapy, 63 years old)

Patients who choose for active surveillance have the feeling they are in the hands of a physician who is ahead of the pack regarding the evolutions of the medical field. They perceive their physician to be somebody who will not just operate everybody but only when necessary.

'Dokter X denkt niet aan zijn portemonnee. Ik weet nu dat hij hoger aangeschreven staat dan de andere specialisten die ik eerst heb geconsulteerd en toch vraagt hij maar 30 euro per consultatie terwijl ik bij de andere twee telkens minstens 60 euro kwijt was. Hier in West-Vlaanderen heb ik het gevoel dat ze iets te graag de robot laten werken.' (Active surveillance, 73 years old)

When physicians clearly state that active surveillance is ‘the best option’, they improve the likelihood that the patient accepts this treatment compared to when a physician only briefly highlights the existence of active surveillance besides the other more invasive options.

‘Het is nog niet nodig om iets te doen zei de dokter, dus dan ga ik daar zelf niet om vragen. Je laat je niet voor u plezier opereren hé. Ik zit goed bij de actieve opvolging.’ (Active surveillance, 65 years old)

‘D’abord je me suis dit: allez, je ne vais pas continuer à vivre avec cette bombe à retardement, je vais aller m’inscrire à la radiothérapie. Et je suis allé donc chez le radiothérapeute avec tous les papiers, les examens etc. Et à la lecture de ce que j’avais comme symptômes et de ce que je lui disais, le radiothérapeute m’a dit: ‘écoutez, il faut mettre dans la balance la radiothérapie et la guérison qui n’est pas à 100 %. Vous aurez peut-être des problèmes après, des séquelles de la radiothérapie. Cela peut infecter les intestins, l’érection, des problèmes de vessie, incontinence. Et donc, dans votre cas, étant donné le peu de symptômes que vous avez et étant donné les résultats de la biopsie, il m’a dit: moi, je vous conseille la surveillance active.’ Et il m’a dit à ce moment-là : avec votre âge et l’état dans lequel vous êtes, faites plus attention en traversant la rue, vous avez plus de risques de mourir de ça.’ (Active Surveillance, 77 years old)

Physicians’ communication skills

The physician needs to be able to gain trust as patients attach a high importance to the way a physician communicates with his patients. He has to show **empathy** and to be able to reassure the patients.

Regarding active surveillance, the patients quoted they need to be reassured about:

- Active surveillance does not mean that nothing is being done
- Active surveillance is a viable option
- There is no need to rush to invasive treatments when a patient has an indolent cancer. The option of more invasive treatments remains open if a tumour seems to evolve.

‘Ik kwam op zijn bureau en dat was daar geen drukdoenerij. Ik had de indruk dat hij tijd had voor mij. Terwijl die andere dokters dat duidelijk niet hadden. Actieve opvolging is volgens hem een goede keuze, en als blijkt dat er toch een evolutie is, kan er nog ingegrepen worden. Deze dokter leek me het meest solidair met mijn situatie, maar daarnaast ook het meest bekwaam, een topkerel.’ (Active surveillance, 73 years old)

Physicians who reassure their patients about their situation create openness towards active surveillance. When a physician uses the term ‘cancer’, patients will be likely to choose for a more radical approach. But when a physician succeeds in creating a frame of understanding that clarifies that prostate cancer is a slowly developing disease and that for the moment the situation is not yet worrying, patients will be more likely to understand that active surveillance might be interesting for them.

‘De professor noemde mijn situatie eigenlijk de naam ‘kanker’ niet waard dus tot zolang de situatie zo blijft laat ik me gewoon opvolgen.’ (Active surveillance, 65 years old)

Physicians’ attitude towards patient’s autonomy in treatment decisions

According to the patients, some physicians appear to have a personal treatment preference from the start, leaving no space for patient preferences. They seem to identify themselves as an authority in the field; hence the one who knows what is best. If active surveillance is not on their list, it will not be discussed with the patient either.

‘Zonder dat ik het wist had die dokter al een operatie dag gepland voor mij, dat ben ik te weten gekomen toen ik voor een second opinion ging bij iemand anders. Mijn huisarts had ook een papier ontvangen van hem waar in stond dat de patiënt alle opties te horen had gekregen en akkoord is met een operatie. Ik viel bijna van mijn stoel. Het is niet omdat hij enkel over die optie spreekt, dat ik dat ga doen hé.’ (Active surveillance, 73 years old)



At the other side of the spectrum, physicians take a neutral stance, explain all treatment options with all their advantages and disadvantages and leave the treatment decision up to the patients, allowing patients to build their preferences in an autonomous way.

'De dokter heeft alle mogelijkheden perfect uit de doeken gedaan, bij alles heeft hij de voor en nadelen opgenoemd. Ik kon vrij kiezen wat ik wou.' (Robot assisted prostatectomy, 49 years old)

'L'urologue professeur X m'a proposé les deux, brachy et prostatectomy. Il ne m'a pas gardé dans son giron pour m'opérer. Et j'ai dit que je voulais au moins parler avec le professeur Y pour voir ce qu'il proposait. Et lui m'a dit que je prenais la bonne décision. Lui, il opère aussi.' (Brachytherapy, 62 years old)

However, all patients do not want to be autonomous. They can feel not capable of making an informed choice. They need a strong guidance by their physician since 'doctors know best', it is their profession and they are trained to provide the best solution.

Key points

- **From the patient interviews several evaluation criteria used by patients in their assessment of their physician's profile are identified:**
 - his reputation,
 - his empathic expression of wanting the best solution for his patient,
 - his communication skills,
 - his attitude towards patient's autonomy in the decision-making process.
- **Some physicians are perceived as pro one therapy option, leaving no space for patient's preferences; others are neutral and open to the patient's autonomy.**
- **All patients do not want to be autonomous; they can feel not capable of making an informed choice.**

III. THE SOCIAL SUPPORT AND THE SOCIAL NETWORK

The use and availability of social support and its role in the treatment decision vary between patients. According to the patients' interviews, two categories of patients can be defined: the users of individual strategy and the users of open strategy. This chapter presents the definition of both categories and the influence of social support.

The reason to seek social support can be emotional or instrumental: one wants to cope with the diagnosis in isolation; another seeks the support of others.

Individual coping strategy, no need for social support

Patients with an individual strategy do not often talk about their condition. They wait to inform people about having prostate cancer until for example the treatment is chosen or planned. They try to manage their situation alone, or within the small social circle of close family members (their partner and/or children). Those who search isolation do not want to burden others with their problems, feel ashamed or fear stigma. They perceive the reaction of others to the diagnosis in a negative way.

'Als koppel spreek je er met de dokter over, maar over de prostaat wordt er thuis niet zoveel gepraat, ook met andere mensen wordt er amper iets gezegd. Nee, het leven gaat gewoon door. Misschien is het ook omdat we al zoveel zijn tegengekomen.' (External radiation, 63 years old)

'Mijn kinderen weten niet dat ik prostaatanker heb. Mijn jongste zoon is nu 35 jaar. Ik heb het alleen tegen mijn vrouw gezegd, maar we spreken er niet veel over. Misschien vertel ik hen het ooit, als ze er naar vragen, het is toch wel een onderwerp waar ik niet graag over spreek.' (Active surveillance, 60 years old)

'Als ze horen dat je kanker hebt... je zit achter een muur hé. Jij staat aan de ene kant en zij aan de andere kant, en ze vermijden je. Ik heb ook kanker gehad aan mijn maag, en ik heb toen gezien dat er veel vrienden schrik krijgen wanneer ze zoiets horen.' (External radiation, 63 years old)

Open coping strategy, active search for social support and information

Patients who actively seek support communicate openly about their condition, their therapy choice and the consequences of their therapy choice with friends, family, partner and peers.

'C'est vrai que j'en ai parlé avec mon compagnon, j'en ai parlé avec des amis aussi. J'avais envie d'en discuter. On a parlé souvent, peut-être bien tous les jours avec les clientes. Oui jusqu'à mon opération quand même. Et par après, même encore maintenant, les clientes demandent comment cela va. Oui, cela fait partie du métier que je fais. Quand on coiffe une personne, cela dure quelquefois 1h et on a le temps de parler. Et souvent, on rentre dans l'intimité des clients et fatalement, on parle de choses dont on n'aurait peut-être pas le temps de parler dans une boutique. Oui, cela m'a aidé.' (Prostatectomy and radiation, 61 years old)

'Ik heb het direct aan mijn vrienden verteld, ook in mijn stamcafé. Volgens mij is dat één van de redenen dat ik het zo goed kan verwerken. Er zijn mensen zoals mijn vader, niemand mocht in de tijd iets weten over zijn operatie, maar dan denk ik 'hoe meer je je opsluit hoe geïsoleerder je geraakt'. Dan zal je het pas in je hoofd steken.' (Prostatectomy, 53 years old)

The open strategy can be a source of information and reassurance. Peers give advice about which specialist to consult and this can influence with which specialist a patient ends up. People with a more extended social network will be able to hear more stories about different options which can influence their view on dealing with prostate cancer.

'De man van een vriendin van mijn vrouw vertelde me dat hij ook voor prostaatkanker behandeld was. Die sprak over HIFU, dat was iets nieuws, ik ben dan naar zijn dokter eens gaan horen wat dat juist is.' (HIFU, 68 years old)

'Ik heb toch al wat vrienden horen klagen over een operatie, dat boezemt me wel angst in.' (Brachytherapy, 58 years old) *'Ik ken een mens die nog zonder robot geopereerd is, en die is niet meer incontinent, die is in orde. En daar trek je je aan op; 'als dat lukt voor*

hem, moet dat voor mij ook lukken.' (Robot assisted prostatectomy, 49 years old)

The definition of the social circle of significant others varies from limited to the partner and close family members to a broader network of (close) friends but also internet (e.g. forums).

Close relatives

Patients report stories of a close relative who also suffered from prostate cancer. They followed the battle with the disease from close by.

'J'ai un oncle qui avait eu une brachy à X, il y a plusieurs années, qui m'avait dit de ne pas m'inquiéter.' (Brachytherapy, 62 years old)

'Het eerste dat hij zei was we dat we ook even konden afwachten, dat was het eerste dat hij aanhaalde. En ik heb direct gezegd dat ik dat niet wil. Dat is voor mij een doodsstek. Ik heb mijn vader zien doodgaan van niets te doen. Dus dat was voor mij duidelijk, niets doen, dat is voor mij verkeerd.' (Robot assisted prostatectomy, 49 years old)

The relatives can help the patient in his search of information

Ce n'était pas catastrophique, non, je n'ai pas eu un choc. Non pas vraiment. Bon, c'est inquiétant évidemment. Je ne l'ai pas pris à la légère non plus puisque je continue à suivre ça. Surtout que dans mon idée, je savais qu'il y avait des solutions. Je me suis surtout documenté par Internet. Et j'ai aussi un exemple dans ma famille, un homme qui a eu le cancer de la prostate et lui, il ne s'en est pas inquiété du tout.' (Active surveillance, 76 years old)

'Ik ben maar tot mijn 17 jaar naar school gegaan, zo ging dat in die tijd. Mijn kinderen zijn langer naar school gegaan en die kennen ook meer van internet en die hebben me dan wel wat ondersteund.' (HIFU, 63 years old)

'Ik kan ten eerste niet goed overweg met computers. Mijn vrouw wel, zij moet dan alles gaan instellen dat ik het kan lezen. Maar het is ook altijd meer reclame dan wat anders. Ik richt me liever op die twee specialisten die ik gesproken heb. Mijn huisdokter is er ook nog. Ik richt me liever tot hen.' (HIFU, 68 years old)



Peers with a medical background can also be a source of information and guidance.

'De optie voor bestraling heb ik nagevraagd in X, omdat ik daar een vriendin heb die daar oncoloog is. Zij vertelde me van: 'ja, straling ok, maar dat is niet evident. Er zijn dingen die beschadigd worden daarnaast.' En daarom heb ik gekozen voor de gewone manuele verwijdering.' (Prostatectomy, 53 years old)

'Mijn vriendin is een laborante dus zij kent er ook wel wat van, ik heb mijn privé dokter thuis zitten, zij weet ook wie de betere urologen zijn, dat is zo hé, eens je in dat wereldje zit. Het is op haar aanraden dat we naar X zijn gegaan.' (Active surveillance, 65 years old)

Key points

- **The use and availability of social support and its role in the treatment decision varies between patients:**
 - **Patients with an individual coping strategy have no need for social support**
 - **Patients with an open coping strategy actively search for social support and information**

3.3.5 Conclusion regarding the patients' interviews

The patients' interviews confirm the conclusion of the literature review: the most influencing factor in the treatment decision is the physician's recommendation. If the physician informs patients about active surveillance, and offers it to patients as a viable option, patients are more likely to opt for this treatment type. However, it appears also that not all physicians support active surveillance since we met patients who never heard about that or did not remember that. It is particularly important for patients assuming a passive role in the decision making. If a patient takes an active role, he can do a broad investigation, search information from multiple sources and talk to peers. Even when active surveillance is not offered to him, he can opt for a second opinion and choose it.

The other factors influencing the treatment decision mentioned by the patients are also similar to those found in the literature and the physicians' interviews: physical conditions, attitudes towards the disease (anxiety versus confidence), treatment priorities (preservation of bodily control by avoiding incapacitating side effects versus survival and cancer removal). Regarding the social network, one kind of patients has an individual coping strategy where only close relatives are aware of the disease while another kind is open, searching actively for social support and information.

Two needed actions can be deduced from the patients' interviews: Provide complete and accurate information of all treatment options in localised prostate cancer and ensure a support to reduce the psychosocial pressure felt by patients choosing active surveillance.

Considering the limitations of the patients' interviews, the difficulty of the recruitment of the patients has to be mentioned. This results in an unequal regional distribution between Dutch and French speaking patients. As all patients volunteered to participate, a selection bias is possible. However, it is undetermined whether this selection bias favours active surveillance or not. A part of the patients' recruitment was conducted via the specialists. Although we did not observe major differences between respondents recruited this way and respondents recruited freely, specialists could have filtered the recruitment consciously or unconsciously. Finally, the risk of socially desired answers exists which leads patients to appear more favourable towards active surveillance than they really are. The fact that half of the patients have not chosen this option and that the questions concerned all the options should reduce this risk.



4 DISCUSSION/SYNTHESIS

For the discussion, conclusions and recommendations of this report, the reader can consult the synthesis on the KCE Website.



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