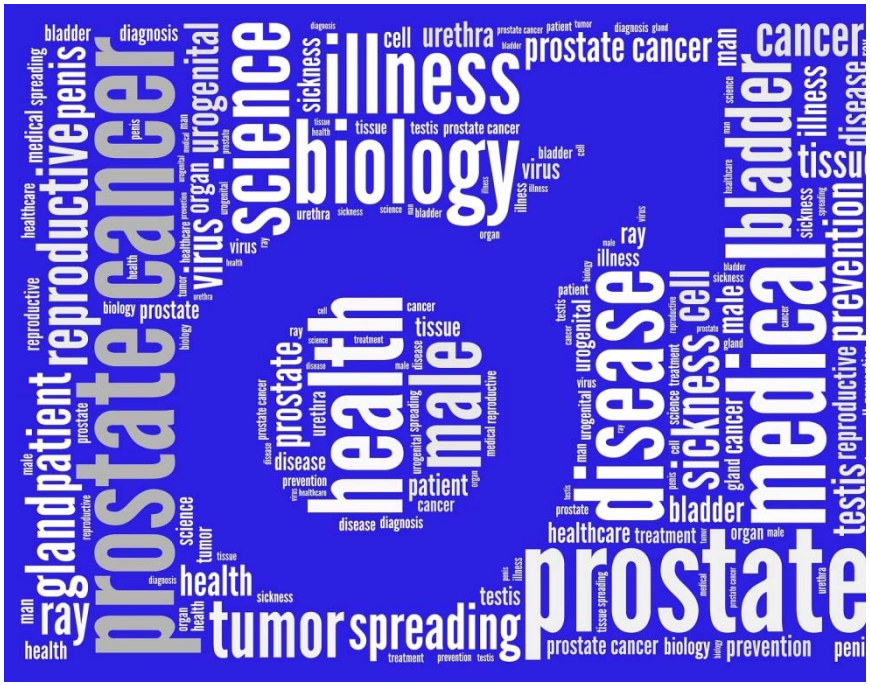
Federaal Kenniscentrum voor de Gezondheidszorg
Centre Fédéral d'Expertise des Soins de Santé
Belgian Health Care Knowledge Centre

SYNTHESIS

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



Belgian Health Care Knowledge Centre

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KCE REPORT 210Cs
GOOD CLINICAL PRACTICE

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2013 www.kce.fgov.be

COLOPHON

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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 patients' association 'Wij ook' and the Sickness Funds 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/2013/10.273/77

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 –Synthesis. Good Clinical Practice (GCP) Brussels: Belgian Health Care Knowledge Centre (KCE). 2013. KCE Reports 210Cs. D/2013/10.273/77.

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

FOREWORD

Most of us are familiar with the adage of Darwin's evolution theory: the species have evolved to what they are today thanks to the 'survival of the fittest', i.e. the survival of those with the highest reproductive success, generation after generation.

Mankind too, apparently blindly followed this pattern. Yet, especially for a species gifted with a strongly developed intelligence, 'fittest' can also, and not just to a limited extent, be translated into 'most fearful'. From an evolutionary point of view, we certainly seem to be endowed with a fair amount of risk aversion. On the whole, this family trait undoubtedly benefits our long-term progeny, but, more often than not, it also affects the decisions we take within the time horizon of our daily lives, much to the delight of the vendors of all kind of insurance products.

The combination of this risk aversion and our poor ability to properly deal with small probabilities only compounds the problem. Whether the odds of dying in a plane crash are 1 to 100 000 or 1 to 10 000 000 won't make a great deal of difference to someone suffering from a fear of flying. That same combination of characteristics also explains why neither patients nor physicians would readily adopt a 'wait and see' attitude (be it with a close monitoring of the evolution of the disease) when faced with a diagnosis of prostate cancer. Psychologically speaking, having to carry on with a prostate cancer time-bomb ticking away in one's body is nothing short of a challenge. From an intellectual point of view, as uncertainty is inherent to prognosis, it is difficult to get a clear overview of the odds and to then make rational choices based on these. The more as the projected risk is still pretty imprecise or uncertain. In that light, it is understandable that also physicians tend to 'play safe', often without being aware of their own bias.

Thus, the easiest solution is to follow one's own intuition and to have the tumour removed while it's not too late. But, meanwhile we learned that this is not necessarily in the patient's own best interest. Concomitantly, this also confronts us with a fairly underexposed quality-of-care aspect, i.e. the quality of the decision-making process favouring one treatment option over another.

The issue of prostate cancer all too poignantly illustrates that this is not a trivial matter, which is why KCE has decided to conduct an in-depth study on this topic. We hope that the result will prove to be an eye-opener for some or, at least, that it will clarify a familiar clinical issue. We even harbour hopes that this study will extend beyond localised prostate cancer alone and that, in general, it will further the empowerment of patients as fully fledged partners in their own health care.

Christian LÉONARD
Deputy general director

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General director

ABSTRACT

Active surveillance is one of the possible treatment options of localised prostate cancer, and consists of a close biochemical and histological monitoring with initiation of curative therapy in case of cancer progression.

Not immediately treating cancer, however, goes against the first instinct, which is to remove the tumour as soon as possible. How is this decision taken both by patients and doctors? This is what we wanted to know.

The aim of the present study is to describe how active surveillance is perceived by patients and by physicians and what factors affect the patients' acceptance of this type of management and the physicians' willingness to offer it. We performed a systematic literature search and complemented the information with a qualitative study, including interviews with 22 physicians (16 urologists and 6 radiotherapists) and interviews with 31 patients having chosen different kinds of treatment (14 with active surveillance). The results emphasize the dynamic nature of the treatment decision process involving several steps, each of which being influenced by several factors. Although the list of identified factors does not pretend to be exhaustive, it is very illustrative of the complexity of the decision-making process and of the paramount importance of the interaction between the patient, the physician and the patients' social network. Besides, even if respondents can see positive aspects of active surveillance, the barriers and fears remain substantial, both among patients and physicians. As to the latter, this study also demonstrates that patient-centred urologic care has to tap into other skills than medical knowledge and surgical dexterity. Bringing the patient to the best therapeutic option in terms of his own life situation and preferences also demands a lucid and skilful conduct of a shared decision-making process.

SYNTHESIS

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1. BACKGROUND AND METHODOLOGY

When confronted with prostate cancer, men are often bewildered by the number of treatment options. Moreover, none of these has been definitively proven to be superior to the others. In front of these uncertainties, the decision to opt for active surveillance is not an easy one, even if it is a valid option for patients with low-risk localised prostate cancer.[a]

The aim of the present study is to describe how active surveillance is perceived by patients and by physicians and what are the factors that affect patients' acceptance of this type of management and physicians' willingness to offer it.

We performed a systematic literature search and complemented the information with a qualitative study, including interviews with 22 physicians (16 urologists and 6 radiotherapists) and interviews with 31 patients having chosen different kinds of treatment (14 with active surveillance).

Individual semi-structured face-to-face interviews were chosen, as these allow to go sufficiently in-depth with each respondent, without them being influenced by the experience of others.

The physicians were recruited by means of an invitation letter sent out by the urologists' and radiotherapists' professional associations, or by telephone from Ipsos and KCE physicians' listing.

For the patients' recruitment, a broad arsenal of techniques was used: through the physicians who participated to the interviews, through general practitioners and urologists from the KCE network, by a message on the website of the Belgian Foundation Against Cancer and by messages in the magazines of a patients' organisation 'Wij ook' and of the Christian Sickness Fund.

We aimed at a relatively balanced distribution of age groups, of French and Dutch speaking patients, of geographical area of residence, and at an equal number of patients with active surveillance and patients with an active treatment. The recruitment process and the patient interview guide were approved by the Université catholique de Louvain (UCL) ethical committee. The methodology is described in more details in chapter 2 of the report.

[a] Mambourg F, Jonckheer P, Piérart J, Van Brabandt H. A national clinical practice guideline on the management of localised prostate cancer - part 1. Good Clinical Practice (GCP). Brussels: Belgian Health Care Knowledge Centre (KCE); 2012. KCE Reports 194C (D/2012/10.273/101) Available from: https://kce.fgov.be/sites/default/files/page_documents/KCE_194C_prostate_cancer_0.pdf

2. RESULTS

The literature review provided only a small number of good quality studies. Moreover, a majority of the retained studies (27/29) concerned only the patients' point of view in the treatment decision-making. The interviews of 22 Belgian physicians are thus particularly interesting and provided many factors not mentioned in the selected literature (chapter 2.3). As to the patient interviews, they confirm many results of the literature but bring some additional nuance, notably when confronted with the physicians' perception of the patient preferences.

2.1. The perception of active surveillance by patients and physicians

At the onset of the interview, the physicians and the patients were invited to state what they saw as advantages and disadvantages of active surveillance (Table 1). These elements cannot be considered to represent the whole perception of active surveillance by the patients and the physicians, and information collected further on during the interviews allowed us to better specify certain items. This is for instance the case with 'quality of life', which was mentioned to be preserved by active surveillance, but also threatened, if the patient experiences much anxiety due to uncertainty.

Some differences between the physicians and the patients are particularly interesting:

- Physicians stress the absence of side effects as an advantage of active surveillance, while from the patient side, the burden of regular biopsies was cited as a disadvantage.
- The patient's confidence in the cancer monitoring is counterbalanced by the lack of reliable parameters of disease evolution mentioned by the physicians.
- The fact that active surveillance is financially not very rewarding for the physician is never quoted by the patients.

2.2. Factors 'pro' and 'contra' active surveillance

- The combination of literature study and qualitative research methods (individual face to face interviews) allowed us to identify a wide array of factors intervening in the eventual treatment decision. Again, these results do not pretend to be exhaustive but very likely provide a good overview of the different dimensions or categories of factors at stake. Moreover, they show that some factors cannot be put clearly in the pro or contra active surveillance category (Table 2).

Table 1 – Advantages and disadvantages of active surveillance according to the physicians and the patients

	Physicians	Patients
Advantages	• No side effects • Quality of life preserved	• No worry because the cancer is monitored • Quality of life preserved
Disadvantages	• Risk of cancer being more aggressive than initially diagnosed • Lack of reliable parameters of disease evolution • Less profitable • Not really credible as an option because the cancer is not removed despite its risk	• Uncertainties • Need for several biopsies (unpleasant)

Sources: physician and patient interviews

Table 2 – Summary of factors influencing the treatment decision

Dimension	Pro active surveillance	Unclear whether always pro or contra active surveillance	Contra active surveillance
Patient's socio-demographic characteristics	Older age Professionally active High socio-economic status		Long-standing relationship Having (young) children
Patient's physical characteristics	Co-morbidity Lower tumour grade Life expectancy <10y	Life expectancy ≥10y	Higher grade of localised prostate cancer
Patient's attitude towards the disease, preferences and values	Confidence to overcome the disease Belief that tumour is not aggressive Concerns about side effects Importance attached to sexuality Wish of less interruption of professional activities	Importance attached to quality of life	Anxiety Perception of better chance of cure with active treatment Importance attached to survival Perceived need of having cancer removed Lack of comprehension of the disease
Patient's role in the decision-making	Personal active search of information	Tendency to follow the physician's recommendation Taking up an active role in decision making	
Physician's characteristics		Age	'Hyper' specialization Fee for service payment
Physician's experience	Experience of side effects with invasive treatment		Bad experiences with active surveillance
Physician's attitudes	Confidence in active surveillance	Reputation Wanting the best for his patient Communication skills Openness to patient's role in the decision	
Dimension	Pro active surveillance	Unclear whether always pro or contra active surveillance	Contra active surveillance
Physician's work environment		Influence of key opinion leader Decision involving a multidisciplinary team	
Policy of the hospital	Active patient information policy		Investment in technologies
Patient's social network		Attitude of the family Having peers with medical background	Attitude of the spouse

Sources: literature review, patient and physician interviews

2.3. Particularities of physician and patient points of view

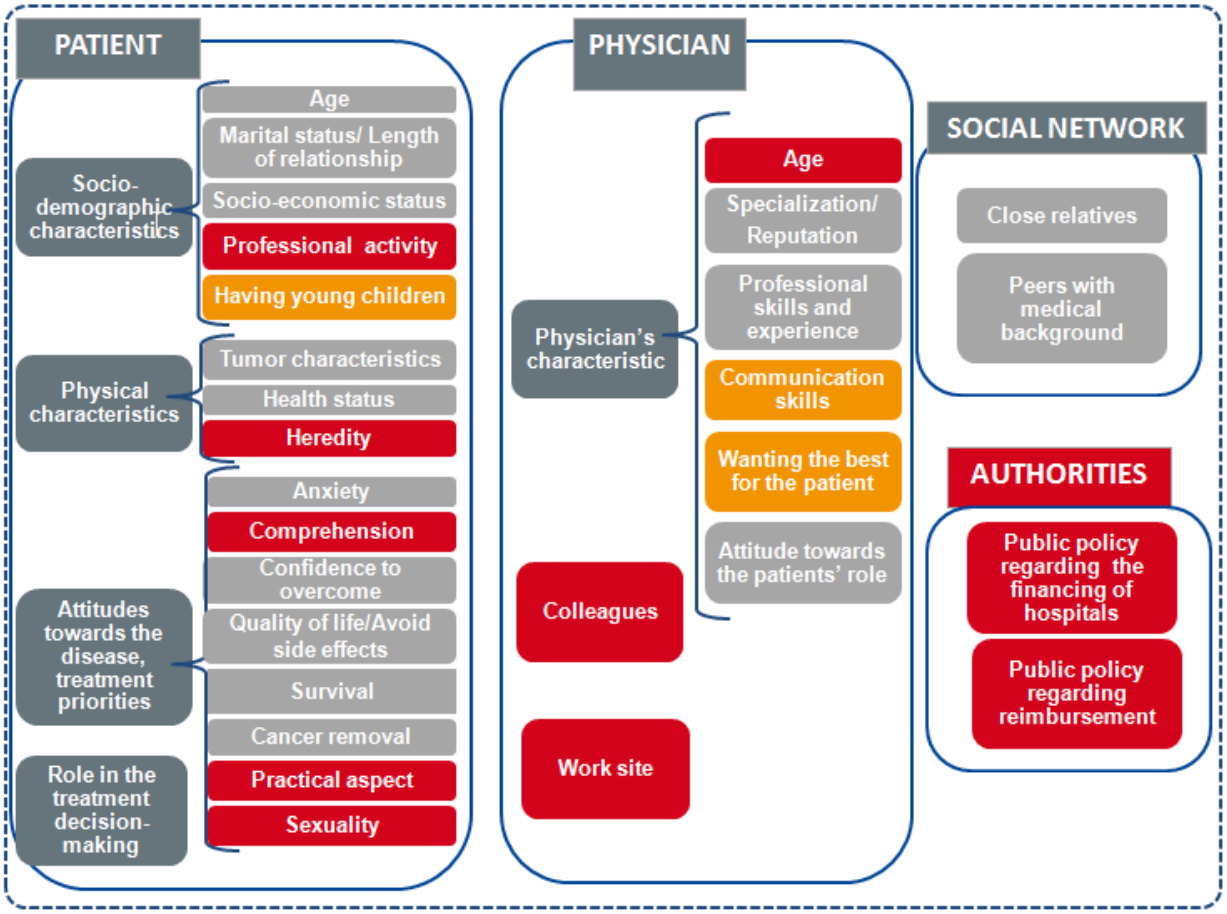
As shown in Figure 1, there are many factors quoted by the interviewed physicians that were not mentioned in the selected literature:

- They take into account the patient's professional status and consider that active surveillance would interfere less with the patient's professional duties or career than more invasive treatment options.
- They mention an uncertainty about the weight that should be attributed to family antecedents or heredity in the decision-making.
- They wish for a patient's 'good attitude' and comprehension of the disease to qualify for active surveillance as a treatment option. But meanwhile, their appraisal of the patient's attitude can be inadequate, especially since the treatment decision is a dynamic process, and the patient attitudes can change over time.
- They attach a certain importance to the patient's sexuality. However, the prevalence of some stereotypes could reveal that they consider sexuality to be important for only particular patients (as tribal chiefs or young men).
- They acknowlegde the influence of the patient's social network (spouse, family, contacts with medical background), but also consider it as not easy to manage.
- They highlight the influence of their own training, experience and age. With respect to the latter, most physicians think it has an influence, but they have very divergent views on the direction of this influence: some young physicians think their older colleagues are rather pro, others think the opposite, and exactly the same picture is seen in the perception by the older of the younger.
- They mention the role of key opinion leaders, enable to shape a physician's basic attitudes during his initial training.
- They quote that open discussions in the multidisciplinary team can be of great help in making a treatment decision. However, the multidisciplinary team can also be the place where an urologist imposes his decision.
- They underline the influence of hospital policies at two levels. On the one hand, there can be some pressure for return on investment for certain devices/medical technologies (e.g. a surgical robot). On the other hand, the overall strategy with regard to patient information and informed consent is a help.
- They evoke also the context of the health insurance system and the public policies: fee for service payments do not favour active surveillance, which is perceived as time-consuming and not very rewarding financially.
- They emphasize the uncertain reliability of PSA and biopsies to document tumour progression and, hence, the fear to miss a more aggressive condition or to detect it too late.

Concerning the patients' point of view, the following findings from the interviews bring some additional nuance to the elements found in the literature:

- Patients did not mention their age as a factor pro or contra active surveillance but consider the fact of having young children as a reason against active surveillance.
- They highlight the importance of patient-centred care and appreciate when they sense in their physician a genuine concern for finding the best solution for them.
- They stress the importance of the physician's communication skills and empathy.

Figure 1 – Factors influencing treatment choice regarding localised prostate cancer identified from literature, patients and physicians interviews



In grey = factors mentioned in the literature and in patients or physicians interviews; in red = factors quoted in physicians interviews only; in orange = factors quoted in patients interviews only

2.4. Steps to active surveillance

The treatment decision is the result of a dynamic process wherein both the different characteristics and profiles of patients and physicians play a role. We found several milestones that have to be passed to reach to active surveillance, and many factors that can influence each of them.

2.4.1. Patient eligibility for active surveillance

The first milestone on the active surveillance pathway is certainly the eligibility for this option. It depends mainly on the patient's age, physical condition and tumour characteristics as mentioned in 2012 in the KCE clinical practice guideline on the management of localised prostate cancer[b]:

- In patients with low-risk localised prostate cancer, eligible and opting for a strategy with curative intent, active surveillance should be considered as a management option, taking into account patient preferences and health conditions related to urinary, sexual, and bowel function.(Strong recommendation, low level of evidence)
- In case the individual life expectancy becomes <10 year or after reaching the age of 80, or in case of the development of significant co-morbidity, it is recommended to stop active surveillance and to offer watchful waiting with palliative intent.

These factors appear at first sight as being objective. However, the physicians interviewed expressed various views on how active surveillance eligibility should be determined, in terms of severity of the tumour or life expectancy, and they asked for more elaborate criteria to guarantee the validity of the diagnosis.

[b] Mambourg F, Jonckheer P, Piérart J, Van Brabandt H. A national clinical practice guideline on the management of localised prostate cancer - part 1. Good Clinical Practice (GCP). Brussels: Belgian Health Care Knowledge Centre (KCE); 2012. KCE Reports 194C (D/2012/10.273/101) Available from: https://kce.fgov.be/sites/default/files/page_documents/KCE_194C_prostate_cancer_0.pdf

2.4.2. Physician attitude towards active surveillance

The physician's attitude is another milestone of paramount importance: a patient will hardly ever opt for active surveillance unless at least one physician encountered was in favour. Manifestly, not all physicians are. According to the patient interviews, some physicians have a clear preference for active treatment and provide biased information, favouring their own expertise and skills. The attitude pro or contra active surveillance is depending upon several factors, including the physician's age, career stage, experience, colleagues, and the hospital policy.

2.4.3. Patient conviction regarding active surveillance

In order to opt for active surveillance (AS), the patient has to be convinced that this is a valid option for him. This is a third milestone. It can result from several situations:

- AS is proposed by the physician and it is in harmony with the patient's personal preferences.
- AS is proposed by the physician and the patient trusts this physician; this confidence is related to physician characteristics such as reputation, communication skills, expression of wanting the best for his patients, etc.
- AS is not proposed by the physican but the patient plays an active role and finds information from other sources. He asks a second (or a third) physician's opinion, he takes the opinion of his general practitioner, he discusses with his family and friends, etc.

The two main elements influencing a patient's treatment preference are: (a) his attitude towards the disease and (b) his treatment priorities. Some patients absolutely want an invasive treatment and are prepared to accept the risks this brings about. In this case, opting for active surveillance would require that the physician changes the patient's mind. Physicians perceive this as a challenging and time-consuming task.

2.5. Interactions between the different factors and the milestones

If we put together the factors influencing the treatment decision at each of the milestones, we can deduce four types of dynamic processes (Compliance, Hesitation, A priori preference for aggressive approach and, A priori preference for conservative approach). Each process results from the combination of certain patient attitudes, a specific role in the decision-making, the influence of the social network, and the encounter with a certain physician. The four dynamic processes described here characterise the 31 patients interviewed, but this does not mean that there are no other possible dynamic processes.

All of these processes start with patients eligible for active surveillance. A quote coming from the patients' interviews is provided as an example of each type.

Table 3 – Description of four types of dynamic processes for the treatment decision in localised prostate cancer

	Compliance	Hesitation	A priori preference for aggressive approach	A priori preference for conservative approach
Physician's attitude towards AS	The first physician has to be in favour of AS.	At least one physician has to be in favour of AS and has to have the necessary skills to convince.	Even if the first physician is pro AS, the patient will be likely not to choose it.	If the first physician is convinced by active surveillance and has good communication skills, the decision is taken quicker.
Patient's attitude towards the disease, treatment preference	**Confidence to overcome the disease if he follows his physician** This patient is rather confident that he will overcome and/or manage the disease if the physician has given positive signals. He does not express preferences.	**Anxiety** This patient does not know what he wants, but does not want to give control to the physician either.	**Survival** This patient wants to survive and fights his disease at whatever price. He has a pro-active attitude towards his disease: it is something which has to be and shall be overcome. Being negative about the situation will not help; it will even make the situation worse. Side effects of treatment are not of primordial importance, survival is most important.	**Preservation** The priority is the preservation of bodily control, capacities and normal functioning by avoiding incapacitating side-effects of active treatment.
Role in the treatment decision	**Passive** This patient believes the physician knows best and is confident about his expert knowledge. He only visits 1 physician and follows the treatment advised. The physician himself is often not chosen upon his personal preference, but is the one to whom his general practitioner has referred him. When he is given several treatment options, the patient asks the physician 'what he recommends', or 'would do in his situation'. This patient does little or no own	**Active** This patient is less likely to trust a physician immediately. He fears that the specialist has a hidden agenda: e.g. wanting to make money, wanting to skill himself with a new technique, wanting to promote a certain technique. He dislikes physicians who work very routinely and miss the provision of custom-made medical care. Thus, this patient often consults several physicians before making a final decision. He does also a lot of research about the condition. By seeking a lot of information, he often feels he has become a real 'prostate expert'	**Active** The physician has to match the patient's preferences; if not the patient goes to another physician. He wants to feel understood by his physician, tries to find a physician who can be trusted and often explicitly seeks a physician who has a very good reputation. He also actively searches for information to fully understand his situation. In addition, he is looking for practical support (tips, advice, names of good physicians, etc).	**Active** The patient's preferences must match with the physician's suggestions. If not, he goes to another physician for a second opinion to verify the first treatment offer, or to verify why a certain treatment option was not offered to him. He also searches information from several sources: friends, internet, etc.

	research about prostate cancer and its treatments (this would only confuse him or confront him with (too) negative prospects). His only sources of information are his general practitioner and his specialist.	(knows almost as much as specialists but just is not able to execute treatments). However, because there remains a taboo regarding localised prostate cancer, he seeks information online or in books.		
Patient's use of social factors	**In isolation** Prostate cancer is something a patient has to deal with alone, it is a rather personal issue. He does not want to burden his environment with his situation. He often only talks about the disease with his wife, his children, close relatives, and one or two close friends.	**In isolation, fear of stigma** This patient does not talk to many people from his network about his condition. He considers that the localised prostate cancer is a rather personal issue and he is afraid of receiving a label being 'someone with cancer'. Sometimes, he asks his partner or close relatives to search information (on internet for example).	**Intensely and openly used** This patient sees no problem in discussing localised prostate cancer with friends and family. For him, communicating can help the decision-making process. He can talk to others to receive tips, advice, names of good physicians, support. He will also be happy to be of help for others who have prostate cancer.	**Actively and openly used** This patient is used to communicate with peers about the condition and the way he is dealing with the whole situation. He looks for emotional and informational support (experience of others, reassurance, comfort).
Result: patient's final attitude towards active surveillance	If this patient encounters a physician who offers active surveillance, this option is likely to be followed. These patients will not doubt the choice for active surveillance **if the physician himself has not placed any question marks with this treatment**. When the physician offers and explains the possibility of active surveillance as 'the best' option, this patient is glad that invasive surgery or radiation is not necessary and the side effects (impotence and incontinence) can be avoided. But if this option was not offered by the first urologist they encountered, they will not be aware of the possibility of AS.	A hesitator can choose for active surveillance, but often has psychological coping difficulties. It is very difficult for him to make 'the right' decision. This patient always consults several specialists before making a treatment choice. When active surveillance is offered as the first treatment choice, he will go for a second opinion.	This patient with a combative attitude will be less eager to choose for active surveillance: he wants to fight and overcome the disease. He does not want to take the risk that the tumour evolves and becomes metastatic. He will be more likely to choose for a more invasive treatment if this guarantees a better chance of survival. Risks of side effects (hence, decrease in the quality of life) are of less importance.	As he attaches a lot of importance to his quality of life, this patient compares all the side effects of the different treatment options and will not quickly choose for the radical prostatectomy. If he encounters a physician who offers active surveillance, this option is likely to be followed; if not, especially if he has doubts about his physician, he will consult other physicians and social networks. He then can be convinced by active surveillance.

Quotes	*'De dokter had van zichzelf de instelling om niet direct te overdrijven met de behandeling, hij was zeker niet paniekerig. Hij stelde wel wat gerust, in de stijl van 'lig daar niet teveel van wakker, het zal allemaal niet zo een vaart lopen'. Dus dan volg je gewoon zijn mening hé.' (First active surveillance, than Hifu, 59 years old).* *''Le docteur me dit voici ce que je vous propose et moi je dis d'accord. Moi, je ne suis pas médecin. Dès l'instant où vous avez confiance en quelqu'un, et bien c'est tout, vous faites ce qu'il vous propose. Je ne vois pas au nom de quoi j'aurais dit: non je ne suis pas d'accord. Avec la manière dont on me l'a présenté, cela m'a convenu.' (Active surveillance, 65 years old).*	*'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).* *'Ik zit nu in die opvolging, maar ik heb het enkel tegen mijn vrouw gezegd, ik praat er met niemand anders over. Misschien vertel ik het wel nog tegen mijn zonen.' (Active surveillance, 65 years old).*	*'Het moet altijd wit of zwart zijn bij mij, niet grijs, want dan speel je met je leven. Daarom had ik ook gezegd van: mijn vader is prostaatpatiënt geweest, en dat was echt agressief. Daarom zei ik dat ik het volledig onder controle wil houden.' (Prostatectomy, 53 years old).*	*'Ik koos ervoor om te wachten omdat opgenomen worden in een ziekenhuis niet aangenaam is hé. Als je iets kan uitstellen dan doe je dat hé, ook wel met het idee dat ik zo nog wel zes, zeven jaar zou verder kunnen. Niemand zit te wachten op gelijk welke ingreep hé. Elk jaar dat je wint zonder ingreep is mooi meegenomen.' (Active surveillance, 60 years old).* *'J'ai 56 ans… J'ai encore, théoriquement, pas mal d'années devant moi. Je me suis dit, que ça tombait dans l'année où j'estime que je peux obtenir les meilleurs résultats que je peux sportivement. J'ai dit « Ecoutez, ok, je veux bien réfléchir à tout ça mais je ne le fais pas en fin d'année ». Il m'a dit que ce n'était pas urgent, que fin d'année c'était toujours bon. Moi j'ai envie de vivre ma vie et de réaliser mes objectifs quoi.' (Active surveillance, 56 years old).*
When will they choose for AS?	If the physician says so	After several consultations with different specialists After an intense search for information	**They will probably not choose for active surveillance.**	After making a well considered decision by searching information and consulting a second or third opinion
Crucial factors	Physician's conviction	Physician's communication skills Social factors	Patient's preferences Social factors	Patient's preferences Physician's communication skills

2.6. Next steps

Although the four processes described above cannot fully catch the reality, they have the merit to show the complexity and dynamics of the decision-making process and the interaction of the different factors at stake. They also indicate ways for improving this process, making it more balanced, transparent, objective and patient-centred.

- To decrease the reluctance of certain physicians to opt for active surveillance:
  - A better dissemination and implementation of the guidelines on the management of prostate cancer (a.o. the KCE guideline published in 2012), along with continued education of physicians about AS;
  - Adjustments in the financing mechanisms so as to minimize incentives in favour of certain types of therapy;
  - An improvement of the knowledge of diagnostic and follow-up criteria enabling physicians to take less 'risky' decisions. Being able to better define whether or not a tumour will evolve aggressively or rather stay indolent will help specialists to recommend or choose with more self-assurance for active surveillance.
- To avoid a dominant influence of one single physician, and to ensure that the patient receives a balanced perspective on the risks and benefits of all therapeutic options:
  - Availability of accurate, standardised and accessible informational material about all treatment options, empowering the patient to make a well informed, personal decision.
  - A systematic well organised multidisciplinary consultation for every patient, with the aim of discussing the most appropriate therapeutic options to propose to the patient.
  - The implication of the general practitioner in the decision-making process.
- To manage the emotional distress of the patient facing a diagnosis of prostate cancer:
  - Priority should be given to an effective and caring communication between the physician and the patient. Specific training to develop the physicians communication skills in the context of this type of difficult shared decision-making situations could be useful.
  - The role of the spouse or partner could be reinforced, notably by involving them more actively in the decision-making process and in the AS clinical follow-up.
  - Social support (e.g. through peer-support groups) could be promoted as well as, in certain cases, counseling services, especially for men in whom the idea of having a cancer that is not being 'actively' treated generates too much anxiety.

2.7. Limitations of this study

This report had not the ambition of performing an in-depth, theoretically driven sociological analysis, but aimed at describing the variation in physician and patient attitudes towards and experiences with active surveillance. Due to the methods used, it had to face a number of limitations that can be summarized as follows:

- The literature review provided only a small number of good quality studies. Moreover, the variability in age, co-morbidity conditions or settings hampers the generalization of the results.
- Both in the litterature and in the perception of the physicians, there is a certain degree of confusion between watchful waiting and active surveillance, leading to inaccuracy in the conclusions.
- Due to the small sample size and the voluntary participation, probably not all prevailing attitudes and opinions of specialists dealing with localised prostate cancer could be covered or represented in a fully balanced way.
- In this type of interviews, there is always a risk that respondents give socially desired answers, which do not necessarily match actual day to day practice. This applies both to the patients and to the physicians. For the latter, the fact that the interview guide adressed all treatment options and not only active surveillance should have reduced this risk.
- We did not succeed in acquiring an exact 50/50 divide between Dutch and French speaking patients. Social class was not considered as a quotum in the recruitment.
- A part of the patient 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.
- As all patients volunteered to participate, a selection bias is possible. However, it is unclear if this selection bias is in favour or not to active surveillance.

3. CONCLUSIONS

The three sources of data used in this study provided us with more insight in the factors intervening in the decision-making process. Although this list of factors does not pretend to be exhaustive, it is very illustrative of the complexity of the process and of the paramount importance of the interaction between the patient, the physician and the patients' social network. Clearly, there is more in it than simply giving the correct information to the patient.

For patients to choose for active surveillance, several conditions need to be fulfilled. First, there is of course access to complete information. But equally important, he must encounter at least one physician convinced of the validity of this option and able to reassure the patient. Moreover, the patient needs to have confidence or at least manageable anxiety, and he is supposed to be open to other options than maximizing the chances of 'survival at whatever price'. The importance of the social network in the decision-making and the subsequent coping should not be underestimated either.

Patients take an ambivalent stance towards the more active medical solutions: on the one hand medicalisation increases their sense of control over the disease, hence their body, but on the other hand medicalisation decreases their personal control since new uncertainties or risks, if not new impairments are introduced by the medical intervention. Following the latter reasoning, a largely demedicalised approach such as active surveillance enhances bodily control. The treatment decision also depends on how risks are perceived, hence on how they are presented to the patient, and which risks predominate for the patient (and the physician): the risks linked to the disease or the risks or harms introduced by the medical intervention.

According to most interviewed physicians, the decision making in the treatment of localised prostate cancer has already taken great steps forward. In their perception the decision to perform a radical prostatectomy is far less automatic than, say, 10-20 years ago, as radiotherapy got a significant development over the last decades, but also due to the rising awareness of a potential overutilization of surgery. There has certainly been a shift in perception in favour of active surveillance. But, as clearly demonstrated in this study, the barriers and fears remain substantial, both among patients and physicians. As to the latter, what this study also demonstrates is that good urologic care has to tap other skills than medical knowledge and surgical dexterity. Bringing the patient to the best therapeutic option taking into account his life situation and preferences also demands a lucid and skilful conduct of a shared decision-making process.

RECOMMENDATIONS[c]

To the Minister of Public Health and Social Affairs, after advice of the competent bodies

- ***The financing modalities*** **of all treatment options for prostate cancer should be revised in order to reduce the financial disincentives of the conservative and potentially time consuming option.**

To the involved physicians and the hospital managers

- **Patients should receive the diagnosis during a well-organised *consultation of diagnosis announcement* and should get the opportunity to discuss the therapeutic options during following encounters. Associated with the multidisciplinary team meeting (MTD), two services exist for 'long consultations with the patient' which can be used for this purpose:**
  - **350232 if this long consultation is carried out by the treating recognised general practitioner**
  - **350254-350265 if this consultation, according to the decision in the MTD, is carried out by the specialist who participated in the MTD.**
- **Patients should receive complete, accurate and timely *informational material*, in an easily understandable format, offering them a balanced perspective on the risks and benefits of all therapeutic options.**
- **Patients should receive the *opportunity to discuss* their treatment in an open and respectful way, and be empowered by the development of a sense of control and meaning.**
- **Before offering a choice between active surveillance and active treatment, an assessment should be undertaken during a *multidisciplinary team meeting* (MDT) including:**
  - **the patient's overall health status, his individual life expectancy and comorbidities**
  - **the quality of the biopsy and tumour characteristics (including the risk category)**

To the Scientific Associations of Doctors and the National Council for Quality Promotion

- **The dissemination and implementation of the *available evidence-based guidelines* on the management of prostate cancer should be actively supported, o.a. by presentations in congresses, integration in the continued medical education, publications.**

[c] The KCE has sole responsibility for the recommendations.

- **There is a need to develop and disseminate *informational material, training modules and, decision support tools* both for physicians and for patients about the treatment options for prostate cancer. This should be done in collaboration with the *patient organisations and sickness funds*.**

To the universities and organisers of continued medical education

- **The *physicians' communication skills* should be further developed in order:**
  - **to deal adequately with the whole person and not only the disease and with the emotional distress of the patient confronted with the diagnosis of cancer;**
  - **to become more skilled in the conduct of a shared decision-making;**
  - **to better acknowledge the role of the spouse or partner, and always consider involving them in the decision-making process.**
- ***Education* is needed about the currently available *marquers and imaging techniques* improving the reliability and precision of the diagnosis and disease progression monitoring.**

Research agenda

- **There is a need to reach more *standardisation in active surveillance*, to be consolidated into protocols for clinical use.**
- **Further research is required into *prognostic indicators* which should enable physicians to identify an aggressive tumour with accuracy, and reduce the uncertainty as to the most appropriate therapeutic choices.**