



# A literature review to understand health literacy in men with prostate cancer on active surveillance

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**Background and Objective:** Active surveillance (AS) has been established as an important treatment option for patients with localised prostate cancer (PCa). Current evidence suggests that health literacy is an important facilitator or barrier to choosing and adhering to AS. We aim to understand how the level of health literacy has an impact on choosing and adhering to AS for PCa patients.

**Methods:** We performed a narrative literature review in accordance with the Narrative Review guidelines through the MEDLINE online database via PubMed using two different search strategies to identify the relevant literature. We looked at literature until August 2022. A narrative synthesis was performed to identify if there is any evidence on how studies report health literacy as an outcome in the AS population and if there are any interventions targeting health literacy.

**Key Content and Findings:** We identified 18 studies which looked at health literacy in the PCa context. Health literacy was measured in the context of comprehension of information of patients across PCa stages, decision making across PCa stages and quality of life (QoL) across PCa stages. Lower health literacy had a negative impact on the identified themes. Nine of the identified studies used validated health literacy measures. Interventions targeting health literacy have been used to improve health literacy with a positive impact across the patient journey.

**Conclusions:** Health literacy plays an important role in enabling men to take an active part in their treatment journey. In this review, we presented how health literacy is measured and which interventions targeting health literacy are implemented across PCa. These examples of interventions targeting health literacy should be studied further and translated into the AS setting to improve treatment decision making and adherence to AS.

**Keywords:** Health literacy; active surveillance (AS); prostate cancer (PCa); treatment decision making

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## Introduction

Prostate cancer (PCa) is the second most frequently diagnosed cancer in men and the 4<sup>th</sup> most frequent cancer overall. In 2020, 1.4 million cases were reported (1). In the UK, more than half of diagnoses are localised (cT1–T2, Grade Group 1–3) with generally good prognosis after treatment (2).

There are three main treatment options for men diagnosed with localised PCa: (I) surgery [i.e., radical prostatectomy (RP)]; (II) radiation, i.e., external beam radiation, brachytherapy (internal radiation) and radiation therapy; and (III) active surveillance (AS), i.e., active monitoring instead of immediate treatment. These different treatment options come with different side effects such as urinary incontinence, erectile dysfunction and bowel dysfunction (3). International guidelines recommend to use a shared decision making approach to identify the most suitable treatment approach for the individual patient (4). However, choosing monitoring (i.e., AS) over active treatment often seems to be a difficult choice for men with localised PCa, even though from an evidence-based medicine (EBM) perspective it is a safe option for localised PCa patients who meet certain criteria at the start of AS and during follow-up (4–7).

In 2018, Kinsella *et al.* identified in their mixed methods systematic review different factors that influence choice for and adherence to AS. These were found to be multifactorial and classified as: (I) patient characteristics; (II) tumour characteristics; (III) family and social support; (IV) provider; (V) healthcare organisation; and (VI) health policy. One of the highlighted facilitators in the “provider” theme was ‘Health literacy’, which can be described as an “individual’s capacity to access, understand, communicate, evaluate, utilize, and make decisions based on health information” (8). Kinsella *et al.* identified studies which highlighted health literacy (even though the studies itself did not specifically use the term or the concept “health literacy”) (9–12). Across the health care sector, the importance of health literacy in population health has been well-established, with poor health literacy associated with negative health outcomes, inadequate use of health services and increased occurrences of adverse events (13–15). In the AS setting, the education level of a patient has been described as particularly important to predict adherence (8).

We therefore aim to extend our understanding of health literacy by looking at whether there is any evidence on how studies report health literacy as an outcome in the AS

population. And if such studies are published, are there any which report interventions targeting health literacy then? We aim to answer the following two research questions: (I) “Is there evidence that health literacy has an impact on choosing and adhering to AS for PCa patients?”; (II) “What interventions targeting health literacy are currently being implemented across PCa?”. We present our work in accordance with the Narrative Review reporting checklist (available at <https://tau.amegroups.com/article/view/10.21037/tau-22-732/rc>).

## Methods

We performed a literature review in accordance with narrative review guidelines using the MEDLINE online database via PubMed (16) (*Table 1*). Firstly, we reviewed the current literature on men diagnosed with localised PCa who chose AS as a treatment in the context of health literacy. Secondly, we reviewed the literature on health literacy and PCa overall, to identify what lessons can be learned from other treatment settings.

These two searches and analyses were then combined to (I) identify how health literacy can be measured and (II) what interventions targeting health literacy (i.e., interventions which support patients in their treatment journey) support patients in treatment decision making and adherence to AS.

We used two searches to enable us to answer the two research questions.

### Search strategy

Firstly, we used the search terms: “active surveillance” AND “health literacy”. The inclusion criteria for the first search were based on:

- ❖ Patients (male) aged older than 18 years diagnosed with a low grade PCa where AS can be proposed as a treatment option;
- ❖ English language;
- ❖ Quantitative papers where health literacy was assessed with a patient reported outcome measure (PROM) or quantitative survey;
- ❖ Qualitative papers where health literacy was explored for patients to access, understand, appraise information about AS to make decisions about choosing or adhering to AS.
- ❖ As part of our second literature search, we used the search terms: (“low health literacy” OR “mental

**Table 1** Search strategy summary

Items	Specification
Date of search	20.08.2022
Databases and other sources searched	MEDLINE via PubMed
Search terms used	Search 1: “active surveillance” AND “health literacy” Search 2: (“low health literacy” OR “mental health literacy” OR “literacy”) AND “prostate cancer”
Timeframe	Open ended-present (20.08.2022)
Inclusion and exclusion criteria	Search 1: <ul style="list-style-type: none"> <li>• Patients aged older than 18 years diagnosed with a low-grade PCa where AS can be proposed as an option</li> <li>• English language</li> <li>• Quantitative papers where health literacy was assessed with a validated tool</li> <li>• Qualitative papers where health literacy is explored for patients to access, understand, appraise information about AS to make decisions about choosing or adhering to AS</li> </ul> Search 2: <ul style="list-style-type: none"> <li>• Men aged older than 18 years diagnosed with prostate cancer</li> <li>• English language</li> <li>• Quantitative papers where health literacy was assessed with a validated tool</li> <li>• Qualitative papers where health literacy is explored for patients to access, understand, appraise information about treatment decision making</li> </ul> For both searches, we excluded: <ul style="list-style-type: none"> <li>• Case reports, review papers, conference proceedings, opinion pieces, editorials, letters to the editor, dissertations/theses, book chapters, protocols</li> </ul>
Selection process	One reviewer (KB) extracted data from the included studies which were checked for accuracy by a second reviewer (LDFV)

PCa, prostate cancer; AS, active surveillance.

health literacy” OR “literacy”) AND “prostate cancer”. We included papers which focused on:

- ❖ Men aged older than 18 years diagnosed with PCa;
- ❖ English language;
- ❖ Quantitative papers where health literacy was assessed with a PROM or quantitative survey;
- ❖ Qualitative papers where health literacy is explored for patients to access, understand, appraise information about treatment decision making.

For both searches, we excluded:

- ❖ Systematic reviews, narrative reviews, case reports, review papers, conference proceedings, opinion pieces, editorials, letters to the editor, dissertations/theses, book chapters, protocols.

The timeframe for the first search was from 2015 (year first manuscript on health literacy and AS was published) until August 2022 and from 1989 to August 2022 for the

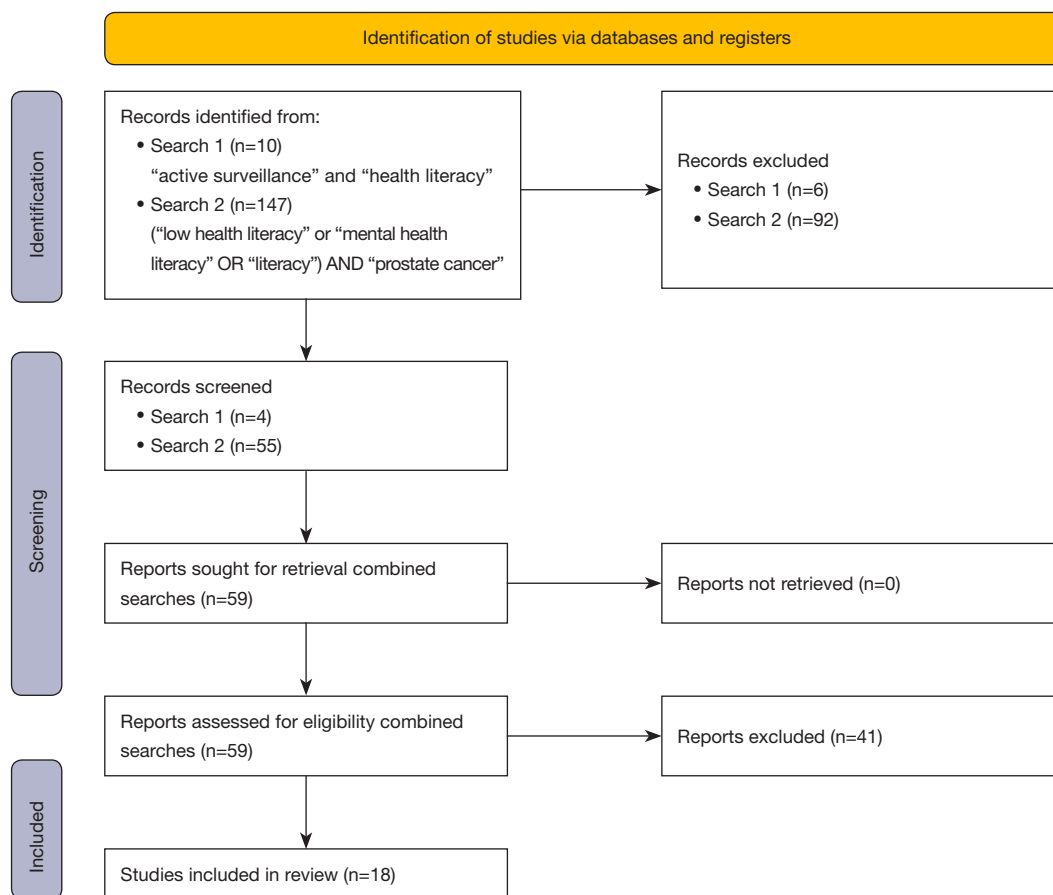
second search (see *Figure 1* for details). One reviewer (KB) extracted data from the included studies which were checked for accuracy by a second reviewer (LDFV).

#### **Data extraction**

Data on study characteristics (i.e., author, year, country study undertaken, setting, design, aims/objectives, health literacy measure used, outcomes) were collected. We furthermore highlighted the aims/objectives of the included studies, the health literacy measurement used and the primary outcome of the study.

#### **Analysis**

To enable us to better understand health literacy as an outcome, we wanted to understand how the included



**Figure 1** Flow diagram representing the selection process of studies via databases and registers. For clarity, the duplication of articles have been removed in the PRISMA table (1 article), however, 1 duplicate article is included in the description of the article for transparency.

studies measured health literacy as a patient reported outcome (PRO). We then grouped those using a thematic analysis approach and highlighted the PROMs which have been used to assess the PROs. Finally, we report the interventions targeting health literacy which aim to improve health literacy across PCa.

## Results

For the first search, we identified 10 studies focused on AS and PCa, of which five met our inclusion criteria; four after abstract and one after full text screening. For the second search, we identified 148 studies and included 56 for abstract text screening and ultimately included 17 studies which met our inclusion criteria. Combining these two searches then resulted in 18 unique eligible studies.

Most of the studies were observational studies, with two randomised controlled trials (RCTs), one mixed method

and one qualitative study. The studies were conducted in Canada (n=2), Denmark (n=1), Germany (n=1), Sweden (n=1) and United States (n=13). The identified studies were looking at health literacy across stages (n=5), in the screening (n=3), diagnostic (n=5), AS (n=1), localised PCa (n=3), advanced PCa (n=1) and survivorship setting (n=1) (see *Table 2*).

### *PROs and PROMs linked to health literacy*

We identified three themes linked to outcomes measured in papers assessing health literacy in men with PCa on AS: comprehension of information, decision making, quality of life (QoL) (see *Table 2*).

### **Comprehension of information of patients across PCa stages**

Five studies were measuring outcomes linked to

Table 2 Using PROM measures

Authors	Study	Country	Stage	Aim	Validated	Outcome measure	Outcome coded	Outcome described
Jamieson SC, <i>et al.</i> , 2022, (17)	Observational study	United States	Screening	Association between self-reported health literacy and the likelihood of PSA screening	Y	2016 BRFSS	Decision making	The primary exposure was self-reported health literacy, and the primary outcome was whether patients underwent prior PSA testing. They saw a positive association between self-reported health literacy and the likelihood of PSA screening
Nguyen DD, <i>et al.</i> , 2021, (18)	Observational study	United States	Screening	To understand association between self-reported health literacy and the likelihood of PSA screening	Y	2016 BRFSS	Decision making	Self-reported PSA screening within the past year with a link to health literacy. They identified that men who reported higher levels of health literacy were found to have higher levels of screening
Joyce DD, <i>et al.</i> , 2020, (19)	Observational study	United States	Across all stages	To measure Health literacy linked to PCa knowledge	Y	REALM-R, BHLS	Comprehension of information	Health literacy linked to PCa knowledge in an African community. They identified lower health literacy among African American men, and lower prostate-related knowledge in those with poor health literacy
Haack M, <i>et al.</i> , 2020, (20)	Observational study	Germany	Across all stages	Understand if specific aspects of health literacy are associated QoL and fear of progression in men with PCa	N	Communication skills, guideline awareness, and knowledge in several domains: PCa, health care system, own physical condition, dealing with health problems	QoL	Health literacy link to fear of progression- where they identified that some aspects of HL may have a positive and some a negative influence on men with PC. Men should not be overwhelmed by a recommendation for self-observation or by promotion of PC knowledge
Seaton CL, <i>et al.</i> , 2020, (21)	Observational study	Canada	Across all stages	To explore whether sociodemographic and health factors were related to men's health literacy scores	N	The HLQ (44-item)	Comprehension of information	The looked at Health literacy & Education and identified that the level of education was positively associated with health literacy scores
Kayser L, <i>et al.</i> , 2015, (22)	Observational study	Denmark	Localised (AS setting)	Explore whether the scores of and verbal responses to a Health Literacy Questionnaire can be used to identify individuals in need of information and support and to reveal differences in perception and understanding in health-related situations within couples	N	Nine-domain HQL	Comprehension of information	Health literacy patient vs. spouse (use of a framework to explore health literacy in eight couples where the men were on active surveillance for PCa progression) They identified that the HLQ used as a dialogue tool maybe an adjunct to assist healthcare providers to understand the need for support and information of men with prostate cancer on active surveillance and the dynamics within couples
Mazor KM, <i>et al.</i> , 2016, (23)	Observational study	United States	Diagnosis	To describe patients' questions when faced with cancer prevention and screening decisions and to explore differences in question-asking as a function of health literacy with respect to spoken information (health literacy-listening)	N	CMLT-Listening	Comprehension of information/ treatment decision making	They looked at the understanding of risks/benefits, procedure details, personalizing information, additional information, decision making and credibility and concluded that lack of comprehension of prostate health terminology is pronounced in this patient population and may be widespread. This lack of comprehension potentially limits the ability of patients to participate in informed decision-making
Wang DS, <i>et al.</i> , 2013, (24)	Observational study	United States	Diagnosis	It is hypothesized that predominantly lower literacy patients would demonstrate a severe lack of comprehension of PCa terms, thus validating the findings of a previous single-institution study	N	A previously developed survey was used to evaluate understanding of terms related to urinary, bowel, and sexual function	Comprehension of information	Understanding of bowel, sexual and urinary function. They concluded that lack of comprehension of prostate health terminology is pronounced in this patient population and may be widespread. This lack of comprehension potentially limits the ability of patients to participate in informed decision-making
Song L, <i>et al.</i> , 2012, (25)	Observational study	United States	Localised	The authors examined the relation between HRQOL and health literacy among men with PCa	Y	REALM and HRQOL using the Short Form-12 General Health Survey (SF12)	QoL	The study looked at HRQOL and health literacy. They identified that men with low health literacy levels were more vulnerable to mental distress than those with higher health literacy levels, but physical well-being was no different
Best AL, <i>et al.</i> , 2017, (13)	Mixed methods	United States	Across all stages	To explore the implications of applying Nutbeam's multidimensional health literacy framework to men's understanding of PCA information	Y	Cloze tests and the Shortened Test of Functional Health Literacy in Adults	Comprehension of information	Comprehension of information. Despite having satisfactory literacy test scores, results from interviews and focus groups revealed participants' limited understanding and misconceptions about PCa risk
Bennett CL, <i>et al.</i> , 1998, (26)	Observational study	United States	Advanced stage	To evaluate the association of poor literacy skills with higher rates of presentation of advanced stages of PCa among low-income black and white men who received care in equal-access medical systems	Y	REALM	Health service/ treatment decision making	Health literacy was measured and it was concluded that low literacy significant barrier to the diagnosis of early-stage prostate cancer among low-income white and black men

PROM, patient reported outcome measure; PSA, prostate-specific antigen; PCa, prostate cancer; QoL, quality of life; HRQOL, health-related quality of life; PCA, prostate cancer; Y, yes; N, no; BRFSS, Behavioural Risk Factor Surveillance System; REALM-R, the revised Rapid Estimate of Adult Literacy in Medicine; BHLS, the Brief Health Literacy Screen; HLQ, the Health Literacy Questionnaire (long and short form); CMLT-Listening, the Cancer Message Literacy Test-Listening; REALM, the Rapid Estimate of Adult Literacy in Medicine; PC, prostate cancer.

comprehension of information, such as comprehension of PCa knowledge and terms to identify additional support needs, comprehension of health-related situations within couples where one partner is on AS, and comprehension of information linked to sociodemographic factors (19,21,22,24,27). Joyce *et al.* identified lower prostate related knowledge in men with poor health literacy (19). Seaton *et al.* also found a positive association between level of education and health literacy (21). Wang *et al.* and Friedman *et al.* identified that lack of comprehension might be widespread across the PCa population and may have an impact on shared decision making as well as understanding the need of PCa screening (24,27).

### Decision making across PCa stages

Four studies looked at outcomes linked to decision making (17,18,23,26). The studies assessed the association between health literacy and the likelihood of participating in prostate-specific antigen (PSA) screening, health literacy and the way people ask questions about treatment decision and health literacy and late presentation. All four studies identified that higher health literacy levels have a positive association with the likelihood of PSA screening and early diagnosis (17,18,23,26).

### QoL across PCa stages

Two studies looked at health literacy and QoL, such as fear of progression linked to health literacy and overall health-related QoL and health literacy for men with localised PCa (20,25). Haack *et al.* identified that better QoL was statistically significantly associated with communication skills, knowledge of dealing with health problems, and knowledge of own physical condition (20). Song *et al.* concluded that higher health literacy levels were significantly associated with better mental well-being (25).

### PROMs

Nine of the identified studies used validated health literacy measures such as: the 2016 Behavioural Risk Factor Surveillance System (BRFSS) (17,18), the Swedish Functional Health Literacy Scale (FHL) (28), the Swedish Communicative and Critical Health Literacy Scale (CCHL) (28), the revised Rapid Estimate of Adult Literacy in Medicine (REALM-R) (19,25,26,29), the Brief Health Literacy Screen (BHLS) (19), the Health Literacy Questionnaire (HLQ) (long and short form) (21,22) and the Cancer Message Literacy Test-Listening (CMLT-

Listening) (23). However, two studies also used non-validated measures, such as self-developed surveys on PCa (20,24) (see *Table 3* for details).

### Interventions linked to health literacy

We identified interventions targeting health literacy across all stages of PCa; however, none were targeting men on AS.

### Health literacy & screening setting

We reviewed one RCT aiming to understand if a simple information leaflet on screening options in PCa would encourage patients to talk to their doctor (i.e., primary outcome). Around 48.4% of participants in the intervention group reported discussing PCa during their appointment vs the control group were only 37.3% mentioned PCa. Therefore, Kripalani *et al.* suggested that handing out information leaflets about screening and overall PCa might increase PSA test orders as well as a discussion of PCa with the clinician (30).

### Health literacy & diagnosis setting

Three studies looked at how to best support patients during diagnosis in their decision-making (29,31,32). One study used video presentations to educate men on their cancer pathology reports and diagnosis and evaluated whether there was a change of understanding of the diagnosis and therefore health literacy. Ninety-five percent of the participants found it helpful and agreed that the video increased their understanding (31). The second study evaluated knowledge, level of satisfaction, and treatment preferences of men after participation in a Compact Disc Read-Only Memory (CD-ROM) shared decision-making program which focused on educating patients regarding their PCa and health care knowledge. The REALM PROM was used to measure success. They concluded that two thirds of patients were able to select their preferred treatment option based on the intervention, however, lower health literacy scores also indicated that patients may have a lower understanding of the shared decision making program and therefore with this population it seemed less successful (29). The third study used a video-based education tool emphasising narrated animations to improve the understanding of key terms related to PCa such as urinary, bowel, and sexual function. Using the tool, Wang *et al.* saw improvements of the understanding of participants of the terminology used in PCa [i.e., incontinence (from 14% to 50%), rectum (from 27% to 45%), and impotence (from 58% to 84%)] (32).

Table 3 Supportive care intervention

Authors	Study	Country	Stage	Intervention	Aim	Validated	Outcome measure	Outcome
Kripalani S, <i>et al.</i> , 2007, (30)	RCT	United States	Screening	Patient education handout	Understand if a handout simply encouraging patients to talk to their doctor about PCa. They then examined the effects of two low-literacy interventions on the frequency of PCa discussion and screening	N	Patients received a patient education handout on PCa screening, a handout simply encouraging patients to talk to their doctor about PCa, or a control handout	Patient-reported discussion of PCa with the physician, and chart review to determine prostate specific antigen test orders and performance of digital rectal examination
Khanchandani AT, <i>et al.</i> , 2022, (31)	Observational study	United States	Diagnosis	Video presentations	Give patients insight into their respective cancer pathology reports and diagnoses	N	Patients then watched their respective diagnosis video in their clinic exam room + survey (containing information about demographics, use of a patient portal to access health information, confidence of filling out medical forms to help to establish baseline health literacy, evaluate participants' understanding of the role of the pathologist and the health information contained within their medical record concerning their respective diagnosis)	Assessing change in health literacy after intervention
Kim SP, <i>et al.</i> , 2001, (29)	Observational study	United States	Diagnosis	CD-ROM shared decision-making program	The objectives of the study were to evaluate (I) knowledge, level of satisfaction, and treatment preferences and intentions of men newly diagnosed with PCa after participation in a CD-ROM shared decision-making program; and (II) the relationship between PCa knowledge and health literacy	Y	REALM	Health literacy
Wang DS, <i>et al.</i> , 2015, (32)	Observational study	United States	Diagnosis	Video-based education tool	It was hypothesized that a video-based educational tool would significantly improve the understanding of key terms related to prostate health in a predominantly lower literacy population	N	A software application was developed to serve as a video-based educational tool emphasizing narrated animations to promote understanding of terms related to urinary, bowel, and sexual function	Improvement of health literacy
Sundberg K, <i>et al.</i> , 2021, (28)	Observational study	Sweden	Localized prostate cancer scheduled for curative radiotherapy	App for symptom management	Compare Health literacy and self-care ability in men with PCa undergoing radiotherapy that used an app for symptom management with a control group	Y	FHL, CCHL	Outcomes were Functional Health Literacy, Communicative and Critical Health Literacy and Appraisal of Self-Care Agency
Oliffe JL, <i>et al.</i> , 2011, (33)	Qualitative study	Canada	Across all stages	PCa support groups	We describe the connections between PCa support groups and men's health literacy and consumer orientation to health care services	N	Interviews	Explorative
Marziliano A, <i>et al.</i> , 2022, (34)	RCT	United States	Survivorship	PC survivorship website	Improve health literacy for survivors on informational that addresses physical, emotional, interpersonal, and practical concerns relevant for PCa survivors	N	Health literacy was assessed using a 3-item screen for health literacy instrument: "How often do you have someone help you read hospital materials?", "How confident are you filling out medical forms by yourself?", and "How often do you have problems learning about your medical condition because of difficulty understanding written information?"	Exploration of personal characteristics associated with use of the instrument

RCT, randomised control trial; CD-ROM, Compact Disc Read-Only Memory; PCa, prostate cancer; PC, prostate cancer; N, no; Y, yes; REALM, the Rapid Estimate of Adult Literacy in Medicine; FHL, the Swedish Functional Health Literacy Scale; CCHL, the Swedish Communicative and Critical Health Literacy Scale.

### Health literacy & localised PCa

One study introduced an app for symptom management for men with localised PCa scheduled for curative RT. They evaluated self-care ability and health literacy and used the FHL and the Communicative and Critical Health Literacy and Appraisal of Self-Care Agency (CCHL) tool. They reported improvement of the intervention group such as “ability to select information needed from a variety of information sources”, “ability to determine the information credible”, and “being able to plan and decide what to do to improve health” (28).

### Health literacy across PCa stages

A Canadian qualitative study looked at men’s health literacy and consumer-oriented healthcare as well as the link with PCa support groups. They used an explorative approach in their qualitative study. They defined key findings of success of their study as patients’ ability to understand their rights, responsibility, to compare diverse health products and services in making decisions across the PCa journey (33).

### Health literacy & survivorship

In the field of survivorship, one study looked at improving health literacy for survivors using a PCa survivorship website. They measured their outcomes using a 3-item PROM (described in *Table 3*). The study’s success was limited since education, income, health literacy, blunting style of coping, self-efficacy, and treatment type were not found to be associated with the intervention (34).

## Discussion

Our mixed methods review identified that there is currently limited evidence on health literacy in the context of choosing and adhering to AS for men with localised PCa. However, health literacy seems to have an impact on screening, treatment decision making, late diagnosis and survivorship across stages of PCa, as identified in our study. Identified studies looked at decision making of patients, comprehension of information and QoL linked to health literacy and show the negative impact of low health literacy. None of the identified studies looked at interventions targeting health literacy for choosing and adhering to AS, which might be linked to the fact that most studies have been conducted in the US (n=13) and potentially lower the relevance of some of the studies in a

global setting.

Validated health literacy measures are increasingly used to measure health literacy in the PCa population. Especially BRFSS, CCHL, FHL, REALM, HLQ are PROMs which are used. However, when interventions targeting health literacy are introduced, validated measurements are less used, with only two out of seven studies reporting on a health literacy PROM. Many different interventions targeting health literacy are proposed across PCa to support men in their treatment journey: websites, videos, graphics and apps seem to have a positive impact on health literacy of patients (28-34).

The increased importance of measuring health literacy is also shown in 2021 when Murphy *et al.* published the results of their RCT in favourable-risk PCa patients. The study looked at the impact of genomic tests on treatment decision making in a predominantly African population (i.e., ENACT trial). The goal of the RCT is not to understand health literacy, however it seems to have an important impact on their outcomes as one of the main indirect findings of the ENACT trial showed that men with low health literacy were less likely to choose AS compared to men with high health literacy (35).

Across cancer care, Holden *et al.* performed a mixed methods systematic review where they demonstrated the role and consequences of health literacy in an oncology setting. They concluded that treatment decision making is closely linked to health literacy, similarly as shown/we present here. Nevertheless, across cancer care there seems to be limited evidence to understand to which degree patients want to take a more active role in their decision making. In addition, it is not clear how to best guide patients on how to improve their comprehension of risks and benefits of treatments like for example AS. Nevertheless, across cancer care they show that outcomes are poorer for patients which experience difficulties with health literacy. Hence, they advise to improve efforts to facilitate understanding to support current and future patients to be more involved in their care (36).

One limitation of this review is that we only included studies which directly looked at health literacy, which for example made us exclude the ENACT trial (35). This decision was taken to focus the research on studies which outcome was directly linked to health literacy. In addition, we only looked at studies which assessed health literacy and not purely literacy as the concepts differ and standardised outcomes should be assessed.



## Conclusions

Across the PCa patient journey, there is evidence on the importance of health literacy to guide men in their decision making. Health literacy plays an important role in enabling men to take an active part in their treatment journey. However, looking at AS in particular, there is currently limited evidence available whereas across PCa there are examples of interventions targeting health literacy available. To improve adherence to AS, we need to better support men in their treatment decision process and improve their disease understanding. This may in turn also improve AS adherence. Therefore, it is utterly important to further develop interventions targeting health literacy in the context of AS choice/adherence for men with localised PCa.

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## Footnote

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## References

1. International World Cancer Research Fund. Prostate Cancer statistics. Available online: <https://www.wcrf.org/cancer-trends/prostate-cancer-statistics/>
2. Parr H, Hall E, Porta N. Joint models for dynamic prediction in localised prostate cancer: a literature review. *BMC Med Res Methodol* 2022;22:245.
3. Donovan JL, Hamdy FC, Lane JA, et al. Patient-Reported Outcomes after Monitoring, Surgery, or Radiotherapy for Prostate Cancer. *N Engl J Med* 2016;375:1425-37.
4. Mottet N, Bellmunt J, Briers E, et al. EAU – ESTRO – ESUR – SIOG Guidelines on Prostate Cancer. EAU Annual Congress; Milan. Arnhem, The Netherlands.: EAU Guidelines Office; 2021.
5. Bokhorst LP, Valdagni R, Rannikko A, et al. A Decade of Active Surveillance in the PRIAS Study: An Update and Evaluation of the Criteria Used to Recommend a Switch to Active Treatment. *Eur Urol* 2016;70:954-60.
6. Klotz L, Vesprini D, Sethukavalan P, et al. Long-term follow-up of a large active surveillance cohort of patients with prostate cancer. *J Clin Oncol* 2015;33:272-7.
7. Cooperberg MR, Carroll PR. Trends in Management for Patients With Localized Prostate Cancer, 1990-2013. *JAMA* 2015;314:80-2.
8. Kinsella N, Stattin P, Cahill D, et al. Factors Influencing Men's Choice of and Adherence to Active Surveillance for Low-risk Prostate Cancer: A Mixed-method Systematic Review. *Eur Urol* 2018;74:261-80.
9. Davison BJ, Breckon E. Factors influencing treatment decision making and information preferences of prostate cancer patients on active surveillance. *Patient Educ Couns* 2012;87:369-74.
10. Volk RJ, McFall SL, Cantor SB, et al. 'It's not like you just had a heart attack': decision-making about active surveillance by men with localized prostate cancer. *Psychooncology* 2014;23:467-72.
11. Mader EM, Li HH, Lyons KD, et al. Qualitative insights into how men with low-risk prostate cancer choosing active surveillance negotiate stress and uncertainty. *BMC Urol* 2017;17:35.
12. O'Callaghan C, Dryden T, Hyatt A, et al. 'What is this active surveillance thing?' Men's and partners' reactions

- to treatment decision making for prostate cancer when active surveillance is the recommended treatment option. *Psychooncology* 2014;23:1391-8.
13. Best AL, Vamos C, Choi SK, et al. Increasing Routine Cancer Screening Among Underserved Populations Through Effective Communication Strategies: Application of a Health Literacy Framework. *J Cancer Educ* 2017;32:213-7.
  14. Visscher BB, Steunenberg B, Heijmans M, et al. Evidence on the effectiveness of health literacy interventions in the EU: a systematic review. *BMC Public Health* 2018;18:1414.
  15. Stormacq C, Wosinski J, Boillat E, et al. Effects of health literacy interventions on health-related outcomes in socioeconomically disadvantaged adults living in the community: a systematic review. *JBIM Evid Synth* 2020;18:1389-469.
  16. Page MJ, McKenzie JE, Bossuyt PM, et al. The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *PLoS Med* 2021;18:e1003583.
  17. Jamieson SC, Mallory CW, Jivanji DR, et al. The Role of Health Literacy in Prostate Cancer Screening. *Urology* 2022;163:112-8.
  18. Nguyen DD, Trinh QD, Cole AP, et al. Impact of health literacy on shared decision making for prostate-specific antigen screening in the United States. *Cancer* 2021;127:249-56.
  19. Joyce DD, Heslop DL, Umoh JI, et al. Examining the association of health literacy and numeracy with prostate-related knowledge and prostate cancer treatment regret. *Urol Oncol* 2020;38:682.e11-9.
  20. Haack M, Kramer S, Seidel G, et al. Quality of life and fear of disease progression are associated with aspects of health literacy in men with prostate cancer from Germany. *Support Care Cancer* 2020;28:2283-92.
  21. Seaton CL, Oliffe JL, Rice SM, et al. Health Literacy Among Canadian Men Experiencing Prostate Cancer. *Health Promot Pract* 2020;21:1004-11.
  22. Kayser L, Hansen-Nord NS, Osborne RH, et al. Responses and relationship dynamics of men and their spouses during active surveillance for prostate cancer: health literacy as an inquiry framework. *BMC Public Health* 2015;15:741.
  23. Mazor KM, Rubin DL, Roblin DW, et al. Health literacy-listening skill and patient questions following cancer prevention and screening discussions. *Health Expect* 2016;19:920-34.
  24. Wang DS, Jani AB, Tai CG, et al. Severe lack of comprehension of common prostate health terms among low-income inner-city men. *Cancer* 2013;119:3204-11.
  25. Song L, Mishel M, Bensen JT, et al. How does health literacy affect quality of life among men with newly diagnosed clinically localized prostate cancer? Findings from the North Carolina-Louisiana Prostate Cancer Project (PCaP). *Cancer* 2012;118:3842-51.
  26. Bennett CL, Ferreira MR, Davis TC, et al. Relation between literacy, race, and stage of presentation among low-income patients with prostate cancer. *J Clin Oncol* 1998;16:3101-4.
  27. Friedman DB, Corwin SJ, Dominick GM, et al. African American men's understanding and perceptions about prostate cancer: why multiple dimensions of health literacy are important in cancer communication. *J Community Health* 2009;34:449-60.
  28. Sundberg K, Lindström V, Petersson LM, et al. Supporting health literacy using an interactive app for symptom management during radiotherapy for prostate cancer. *Patient Educ Couns* 2021;104:381-6.
  29. Kim SP, Knight SJ, Tomori C, et al. Health literacy and shared decision making for prostate cancer patients with low socioeconomic status. *Cancer Invest* 2001;19:684-91.
  30. Kripalani S, Sharma J, Justice E, et al. Low-literacy interventions to promote discussion of prostate cancer: a randomized controlled trial. *Am J Prev Med* 2007;33:83-90.
  31. Khanchandani AT, Larkins MC, Tooley AM, et al. The impact of curated educational videos on pathology health literacy for patients with a pancreatic, colorectal, or prostate cancer diagnosis. *Acad Pathol* 2022;9:100038.
  32. Wang DS, Jani AB, Sesay M, et al. Video-based educational tool improves patient comprehension of common prostate health terminology. *Cancer* 2015;121:733-40.
  33. Oliffe JL, Bottorff JL, McKenzie MM, et al. Prostate cancer support groups, health literacy and consumerism: are community-based volunteers re-defining older men's health? *Health (London)* 2011;15:555-70.
  34. Marziliano A, Diefenbach MA, Hudson SV, et al. Demographic and Psychosocial Characteristics Associated With Use of a Prostate Cancer Survivorship Website: Implications From a Multisite Randomized Controlled Trial. *J Med Internet Res* 2022;24:e27890.
  35. Murphy AB, Abern MR, Liu L, et al. Impact of a Genomic Test on Treatment Decision in a

Predominantly African American Population With Favorable-Risk Prostate Cancer: A Randomized Trial. *J Clin Oncol* 2021;39:1660-70.

36. Holden CE, Wheelwright S, Harle A, et al. The role of health literacy in cancer care: A mixed studies systematic review. *PLoS One* 2021;16:e0259815.

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