Prostate Cancer Screening – Attendance and Psychological Consequences

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‘Difficult roads often lead to beautiful destinations.’

Anonymous

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ABSTRACT

Participation in prostate cancer screening may confer both benefits and harms, which can be perceived and weighted differently by individual men. The blood test PSA (prostate-specific antigen) may provide reassurance when the value is below the threshold, whereas an elevated value triggers a diagnostic process. For a screening programme to be successful, both adequate participation and a high level of acceptance of the diagnostic process within the population are necessary.

Paper I report a questionnaire survey of men's perceptions of being invited to organised prostate cancer testing (OPT) and the information about benefits and harms, and whether these perceptions varied by educational level. Almost all men expressed positive attitudes toward the OPT concept and most considered the information clear, although a somewhat smaller proportion of men with academic education perceived the information about the potential disadvantages as clear. **Paper II** is an interview study describing which aspects men valued in their personal decision to undergo or to decline an invitation to PSA testing, and how the information presented in the invitation letter was helpful in their understanding of potential benefits and harms. Men reported that this information was not central to their decision-making process. Instead, their decision was shaped by fear (both as a driving force and a barrier), intuitive reasoning, and perceived risk—highlighting the challenge of achieving truly informed decision-making. Many men requested guidance from authorities. **Paper III** reports an investigation of the psychological consequences of participating in the diagnostic process within the Gothenburg-2 prostate cancer screening trial. Self-reported symptoms of anxiety, depression and intrusive thoughts were assessed through questionnaires. Although many men reported some distress, few reported moderate to severe symptoms of anxiety. Symptoms of anxiety and event-specific stress were reported across different stages of the diagnostic process.

Cancer-related worry was present both before MRI and before receiving biopsy results. **Paper IV** reports how the diagnostic investigation in the first screening round and individual factors affect re-attendance in the Gothenburg-2 trial. The overall re-attendance was high. It was somewhat higher attendance among men with an elevated PSA in the previous screening round than among those with a PSA value below the cut-off for further investigation. Re-attendance rates in the targeted and systematic biopsy groups were estimated, and the rates were similar between the groups. Low income, short education, non-Swedish mother tongue, unhealthy lifestyle and erectile dysfunction were all associated with not re-attending, but all factors together only explained a fraction of why men attended or not attended repeat participation in the study.

Keywords: Prostate Cancer Screening; Prostate-Specific Antigen; Magnetic Resonance Imaging; Patient Participation; Decision Making; Anxiety; Health Communication; Population-Based Study

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SAMMANFATTNING PÅ SVENSKA

Prostatacancer är den vanligaste cancersjukdomen bland män i Sverige och många andra länder. Eftersom prostatacancer har en lång, symtomfri fas då den oftast går att bota, har screening (allmän testning) diskuterats och utforskats sedan 1980-talet. Studier har visat minskad risk för allvarlig sjukdom och dödlighet efter screening för prostatacancer, men att den samtidigt leder till en hög grad av överdiagnostik och överbehandling, det vill säga upptäckt och behandling av prostatacancer som aldrig skulle ha orsakat symtom eller påverkat mäns livslängd. Blodprovet prostataspecifikt antigen (PSA) används bland annat för att upptäcka prostatacancer redan innan män får symtom. Förhöjda PSA-värden kan bero på prostatacancer, men också på godartade tillstånd som prostataförstoring och inflammation. Detta är en av många anledningar varför testning och diagnostik av prostatacancer länge varit föremål för forskning. De senaste åren har kompletterande diagnostiska tester utvecklats, vilka visat sig kunna minska risken för överdiagnostik. Flera av dessa tester utvärderas nu i randomiserade screeningstudier. Detta har lett till att EU rekommenderar sina medlemsländer att utvärdera organiserade program.

I Sverige har Socialstyrelsen inte rekommenderat allmän screening för prostatacancer, då de bedömt att fördelarna inte tydligt överväger nackdelarna utifrån det aktuella forskningsläget. Samtidigt är individbaserad, oorganiserad PSA-testning vanligt förekommande i Sverige. För att skapa en mer jämlik och strukturerad testning har sedan 2020 flera regioner infört organiserad prostatacancertestning (OPT), vilket är världsunikt. Inom OPT erbjuds män PSA-testning från det år de fyller 50, efter neutral information om för- och nackdelar. Ett förhöjt PSA-värde leder till en diagnostisk utredning med magnetkameraundersökning (MR) av prostatan. Om MR visar något tumörmisstänkt område tas vävnadsprover. Dessa undersökningar behövs för att bekräfta eller utesluta prostatacancer, men kan medföra fysiska och psykologiska konsekvenser.

Syftet med denna avhandling är att undersöka mäns uppfattningar om att erbjudas PSA-testning inom ramen för OPT, att kartlägga psykiska konsekvenser hos män som deltar i den diagnostiska processen vid prostatacancerscreening, samt att identifiera faktorer som påverkar deltagandet vid återinbjudan till ett screeningprogram.

Delstudie 1 var en enkätstudie. Nästan alla män som besvarade enkäten var positiva till att bli erbjudna OPT och uppgav att de kunde fatta ett personligt beslut utifrån de för- och nackdelar som presenterades i brevet. Män med akademisk utbildning upplevde oftare att informationen om nackdelar var mindre tydlig. I delstudie 2 intervjuades arton män, som beskrev att det var svårt att värdera hur informationen i brevet berörde dem själva och hur stor deras personliga risk att drabbas var. De hade svårt att förstå risken för överdiagnostik, särskilt med tanke på den allmänna uppfattningen att det alltid är bra att upptäcka cancersjukdom i ett tidigt skede. Många tyckte att myndigheterna skulle ta ansvar och ge vägledning i beslutet. Beslutet om att testa sitt PSA eller att avstå avgjordes inte främst av informationen i brevet, utan av personliga aspekter såsom rädsla för att missa en cancerdiagnos, rädsla för fysisk undersökning och förlorad maskulinitet, socialt stöd, tidigare erfarenheter av vården och den egna magkänslan.

Delstudie 3 undersökte med enkäter de psykologiska konsekvenserna av att delta i utredningsprocessen efter ett förhöjt PSA-värde i screeningstudien Göteborg-2. Även om männen upplevde viss oro och psykologiska påfrestningar under utredningen, var det få som rapporterade måttliga till svåra ångestsymtom.

Vi undersökte också hur olika faktorer påverkade deltagandet vid återinbjudan till Göteborg-2 (Delstudie 4). Deltagandet var över lag högt. Män med PSA-nivå över tröskelvärdet deltog i något högre utsträckning än de med lägre PSA-värde. Deltagandet var liknande bland män som genomgått riktad respektive systematisk biopsi. Kort utbildning, låg inkomst, annat modersmål än svenska, ohälsosam livsstil och erektil dysfunktion var associerade med uteblivet deltagande vid återinbjudan, men tillsammans förklarade de endast en mycket liten del av icke-deltagandet.

LIST OF PAPERS

This thesis is based on the following papers:

I. Svensson L, Stinesen Bratt K, Jiborn T, Börjedahl A-C, Bratt O.

Men's Perception of Being Invited for Prostate Cancer Testing and the Information About Its Pros and Cons – A Survey from Two Population-based Testing Programmes.

European Urology Open Science. 2023; 52: 66–71.

II. Svensson L, Bratt O, Stinesen K, Hugosson J.

Prostate Cancer Screening Decisions: Which Aspects Do Men Value Most? An Interview Study with Men Invited to a Population-Based Program.

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III. Svensson L, Hugosson J, Månsson M, Stinesen K, Wallström J, Arnsrud Godtman R, Bratt O.

Psychological Consequences with the Diagnostic Process in the Göteborg-2 Prostate Cancer Screening Trial in Men with Raised PSA.

(In manuscript.)

IV. Svensson L, Månsson M, Bratt O, Wallström J, Arnsrud Godtman R, Hugosson Jonas.

Re-Attendance in Prostate Cancer Screening: Associations with Investigations in the First Screening Round and Individual-Level Factors.

(In manuscript.)

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1 INTRODUCTION

Prostate cancer—the most common malignancy among men in Sweden—continues to be of broad societal interest. Patient organisations and the debate surrounding a potential national screening programme actively shape the public discourse. In recent decades, extensive research has sought to determine how prostate cancer screening programmes should best be structured. At present, however, the Swedish National Board of Health and Welfare has chosen not to recommend national screening, as current evidence does not demonstrate that the benefits outweigh the harms. Because of the widespread, resource demanding, unorganised prostate-specific antigen (PSA) testing, several Swedish regions have since 2020 instead implemented active information about the potential benefits and harms of PSA testing and an offer for organised prostate cancer testing OPT(1). Recently, the European Union included prostate cancer in its recommendations for organised cancer screening, emphasising PSA testing combined with magnetic resonance imaging (MRI) and advocating risk-stratified approaches to balance early detection with reduced risk of overdiagnosis (2).

If PSA-based screening carried only advantages, the decision would be simple: all men should be tested. Such a scenario would presuppose full participation, risk-free diagnostic procedures, and no diagnoses of cancers that would never have caused symptoms or impaired quality of life. Reality is more complex. Evidence highlights a delicate balance between the potential to detect clinically significant prostate cancer at an early stage and the risks of overdiagnosis, overtreatment (3, 4) and associated physical and psychological consequences (5, 6). Many men undergo extensive diagnostic investigations without ultimately being diagnosed with prostate cancer, while others are found to have low-risk disease where active surveillance is recommended rather than immediate treatment. This dynamic illustrates both the potential for reduced mortality through early detection and the risks of overdiagnosis, overtreatment, and psychological distress associated with false positives, repeated investigations, and uncertainty about living with an untreated cancer. Medical advances—particularly the use of MRI and more selective biopsy techniques—have improved diagnostics, yet many questions remain unanswered.

This thesis addresses some of these issues: how men experience invitation to organised PSA testing, how they perceive and value the information

provided, how they weigh benefits against possible disadvantages, psychological consequences of participating in the diagnostic process, factors associated with attendance at re-invitation, and acceptance of the screening algorithm.

1.1 THE PROSTATE

Despite its small size, the prostate has a central function in the male reproductive system. The prostate produces a slightly alkaline fluid rich in enzymes such as PSA, zinc, and citric acid (7). This prostatic secretion has several functions: to protect sperm in the acidic vaginal environment, provide energy and mobility, and contribute bioactive and immunological components that facilitate fertilisation. In addition, nerves running alongside the prostate play an important role in controlling erections and supporting normal sexual function (8). Its anatomical position, just below the bladder and surrounding the proximal part of the urethra with the rectum behind, enables clinical examinations such as digital rectal palpation and transrectal ultrasound.

With increasing age, hormonally driven changes occur in the gland. Benign prostatic hyperplasia usually develops in the transition zone and can cause urinary tract obstruction with symptoms from the lower urinary tract. The peripheral zone, on the other hand, is the most common origin of prostate cancer and is also susceptible to inflammatory conditions such as prostatitis. (9).

1.2 PROSTATE CANCER

Prostate cancer is a heterogeneous malignancy that originates in the epithelial cells of the prostate gland, were disruptions in normal cell growth and differentiation lead to uncontrolled cell division. In the early stages, prostate cancer is often asymptomatic and may have a slow progression over many years, sometimes without ever developing into a clinically significant condition. Such tumours are often identified after PSA testing of asymptomatic men.

In more advanced stages, the disease may spread beyond the prostatic capsule and involve adjacent tissues, regional lymph nodes, or distant organs such as the skeleton (10). The symptoms vary greatly, from urinary difficulties to

skeletal pain and other signs of disease spread in the body. The natural course of prostate cancer is therefore highly variable: while some tumours progress slowly and may not require immediate treatment, others exhibit aggressive behaviour with rapid progression and significant morbidity. This biological diversity underscores the central challenge in the treatment of prostate cancer—to distinguish slow-growing prostate cancer that can be monitored and may never require curative treatment from clinically significant tumours that require curative or palliative treatment. Prostate cancer often has a prolonged asymptomatic course, allowing for curative treatment if detected early, whereas the disease is typically incurable once clinical symptoms appear. Understanding this spectrum is crucial for evaluating the benefits and harms of screening, diagnostics, and therapeutic strategies. For advanced disease, therapy is directed at managing symptoms and limiting disease progression, thereby enhancing quality of life, including mental health (11).

1.2.1 EPIDEMIOLOGY

Prostate cancer is the second most common cancer among men worldwide, with nearly 1.5 million new cases diagnosed annually (12). Incidence rates vary considerably across geographic regions, with Europe alone accounting for almost half a million new cases each year (13). In Sweden, approximately 11,000 men were diagnosed with prostate cancer in 2024, the majority between 60 and 85 years of age, while cases under 50 years of age are rare (14).

In recent decades, the incidence of prostate cancer has increased in Sweden, as a consequence of the widespread use of PSA testing and the increased elderly male population. Today, prostate cancer is the most common cancer type among men, and a substantial proportion of cases are detected at an early stage, often in asymptomatic individuals who have undergone voluntary testing. An increasing number of cases are being diagnosed in men aged 50–69 years, indicating a gradual age shift. A compilation from the Swedish National Board of Health and Welfare (14) indicates that prostate cancer is more frequently diagnosed in socioeconomically advantaged areas, likely reflecting greater access to healthcare services and a higher propensity to undergo PSA testing. In contrast, socioeconomically disadvantaged groups exhibit higher cancer-related mortality, which may partly be explained by the fact that prostate cancer in these populations is often detected at a more advanced stage. Men with lower income have been shown to have a lower

incidence of low-risk prostate cancer but a higher prevalence of advanced disease, suggesting that diagnosis occurs later in the disease trajectory (15).

1.3 PSA IN THE CONTEXT OF SCREENING

Under normal conditions, small amounts of PSA leak into the bloodstream PSA levels may increase in cases of benign prostatic hyperplasia, infections such as urinary tract infections, inflammation such as prostatitis, and in prostate cancer. PSA is not a perfect cancer test as it has a low specificity meaning that PSA-based screening does not simply categorise men as either ‘cancer-free’ or ‘requiring treatment’. PSA is an enzyme excreted by both benign and malignant prostate cancer cell. In cancer, damage to the basal membrane and glandular structure leads to increased PSA release, resulting in elevated blood levels (16).Thus, PSA can serve as an indicator of disease burden.

PSA became a tool for prostate cancer screening through a series of important scientific discoveries and clinical studies during the 1980s and 1990s. Its development was gradual: early studies were crucial for establishing its clinical role. Initially, PSA was used primarily as a tumour marker to monitor disease progression, but by the early 1990s, its potential as a screening tool became clear (17). Since then, evidence-based adjustments to PSA threshold values, along with the introduction of complementary diagnostic methods, have enhanced the clinical utility of the test. A reduction of the threshold from 4 to 3 ng/mL led to a 30 % increase in the detection of clinically significant prostate cancer (18).

1.3.1 OTHER BIOMARKERS

The PSA test’s poor specificity has initiated research with the aim to develop tests that can complement or replace PSA and provide a more reliable assessment of the risk for clinically significant prostate cancer. Two examples are the Stockholm3 test and the 4Kscore, which combines multiple biomarkers, clinical variables, and genetic information. These tests have higher precision than PSA alone and may reduce the number of unnecessary biopsies (19, 20) Although these tests are not yet routinely used in screening, they represent important advances toward more targeted and less invasive diagnostics and are currently evaluated in randomised screening trials (20, 21).

1.3.2 DIAGNOSTIC PATHWAYS

Systematic biopsy using transrectal ultrasound was introduced in the 1980s and quickly became the standard method. The method improved diagnostics compared with the previous routine to direct the biopsy to palpable tumours or lesions visible on ultrasound but had low accuracy by both missing aggressive tumours and over diagnosing clinically insignificant cancer.

In recent years, Swedish research has played a pivotal role for establishing MRI as a key component of prostate cancer diagnostics. MRI is now clinical routine for men with elevated PSA levels. The primary purpose of MRI in this context is to identify men with clinically significant cancer, for whom a prostate biopsy is warranted, from men with clinically insignificant or no cancer, and thereby reduce overdiagnosis. The Göteborg-2 trial contributes to a deeper understanding of its role in screening (22).

Suspicion of a prostate tumour on MRI is assessed using the standardised classification system Prostate Imaging Reporting and Data System (PI-RADS) (23). This system was developed through an international consensus process with the aim of reducing inter-reader variability and facilitating the interpretation of images (24). PI-RADS does not provide direct information about the microscopic aggressiveness of the tumour but rather estimates the probability that a lesion represents clinically significant cancer. Lesions are graded on a five-point scale, where PI-RADS 1–2 indicates low likelihood of clinically significant cancer, PI-RADS 3 is equivocal, and PI-RADS 4–5 corresponds to high and very high likelihood. In clinical practice, biopsy is generally recommended for PI-RADS 4–5, whereas PI-RADS 3 findings are often considered in relation to PSA levels and prostate volume before a decision on biopsy is made.

In recent years, a paradigm shift has occurred with the introduction of MRI into the diagnostic pathway. Since MRI enables the identification of areas with suspicious changes, biopsies are targeted to those lesions. Targeted biopsies have been shown to increase the detection of clinically significant prostate cancer while reducing the number of unnecessary biopsies and overdiagnoses (25) but there is an ongoing discussion of the most optimal way to biopsy men with a suspicion of cancer.

Prostate cancer is histopathologically classified with the Gleason system and ISUP (International Society of Urological Pathology) Grade Groups. The Gleason system assesses the morphological characteristics of the tumour on a

scale from 3 to 5, where grade 3 having a strong resemblance to a healthy prostate gland and grade 5 represents undifferentiated cancer without glandular structures. The Gleason score is calculated by combining the most common and the most aggressive among other grades (26), resulting in a score between 6 and 10 that reflects the tumour's aggressiveness. To simplify clinical interpretation, ISUP has developed a simplified system with five grade groups, where ISUP Grade Group 1 corresponds to Gleason score 6 and Grade Group 5 corresponds to Gleason score 9–10 (27).

A high PSA value in an individual with a large prostate is more likely to be caused by BPH than a cancer, whereas even a relatively low PSA in a man with a small prostate is more suspicious for cancer. The use of prostate-specific antigen density (PSAD) therefore improves risk assessment in men with suspected prostate cancer. PSAD is calculated by dividing PSA by prostate volume, estimated using ultrasound or MRI (28). In current clinical practice, PSAD is mainly applied to guide the decision on whether a biopsy is warranted in men with an unsuspicious or equivocal prostate MRI.

1.4 SCREENING

Screening is a process in which a population or a specific group of individuals is tested to detect potential diseases or risk factors at an early stage (29-31). The effectiveness of a screening programme is determined by several key factors: the ability to identify treatable disease with high sensitivity, population acceptance of the diagnostic process, and a high participation rate (32-34). Screening in healthcare may include medical tests, blood samples, imaging examinations, or structured questionnaires. Participation in a screening programme is regarded not only as an individual health choice but may also be regarded as a moral responsibility, with an underlying norm that participation is the 'right' decision (35). This can create subtle pressure, where individual may feel obliged to participate even if they have doubts. It can also reinforce the perception that declining participation equates to taking a risk or being irresponsible.

Normative frameworks therefore influence decisions about what is considered appropriate and reasonable in the design of screening programmes, highlighting that screening should not only be medically effective, but also fair, ethically defensible, and socially acceptable within the context in which the individual lives (36). In Sweden, there are three

screening programs for cancer diseases: breast cancer, cervical cancer and colorectal cancer (37).

1.4.1 INDIVIDUAL SCREENING DECISIONS

Decisions to participate or forgo screening involve values about quality of life, risk appetite, and views on what constitutes health for the individual. However, these values are often given little attention in healthcare communication. Screening programmes are based on medical expertise and evidence, which can create an imbalance between healthcare providers and the individual faced with the decision (38). Individuals offered screening may have poor knowledge and understanding of complex concepts such as overdiagnosis, false positive results and test accuracy (39). As a result, their decision may not be fully informed, even though it is formally regarded as autonomous.

Cancer-related worry is well documented in the Western world, where cancer is one of the most feared and deadly diseases (40, 41). The decision to be screened is also influenced by the opinions of relatives, especially the partner, from whom emotional support can be crucial (42). Awareness that decisions may change over time and that long-term consequences can be overlooked at the outset are central prerequisites for individual decision-making.

Women who had declined mammography screening up to two times described in interviews that they understood the importance of detecting breast cancer at an early stage (43). The reasons for non-participation were described as concrete factors, such as work-related conditions, illness in a family member, and financial constraints. The absence of symptoms and a perceived sense of being healthy further contributed to down prioritisation of screening appointments when practical obstacles arose. The reliability of the screening programme was also considered in their decision-making, as several women emphasised that regular participation does not necessarily guarantee early detection of breast cancer. Previous negative experiences, such as false-positive results or investigations prompted by a suspected cancer, also influenced the decision-making process. The women expressed ambivalence regarding their choice: despite being aware that breast cancer is a potentially fatal disease, they did not perceive it as a serious personal threat. The opposite was also described: the fear of breast cancer being detected created anxiety, which contributed to non-participation.

In prostate cancer screening, PSA testing for some men represents an opportunity for reassurance and a sense of control, whereas others perceive it as a potential source of anxiety and risk of unnecessary medical interventions. The decision-making process tends to evolve gradually, with initial attention frequently directed toward the test itself rather than the potential consequences of an abnormal test result or value over cut off (44). The assumption of healthcare that men make rational and well-considered decisions about PSA screening is challenged by research showing that personal values and emotional drives often outweigh a systematic comparison of advantages and potential disadvantages (44).

Individual decision-making can be understood in the light of confirmation bias: individuals tend to selectively attend to information that supports an already made decision, while underestimating or ignoring conflicting information (45). This can lead to the decision being perceived as well-founded, even though in practice it is based on an incomplete assessment of risks and benefits. Similar results were described by colorectal cancer screening although autonomy and informed choices are valued, the current model of fully informed decision-making does not adequately capture the complex interplay of values, experiences and social norms that shape participation (46). In decisions about participation in colorectal cancer screening in Sweden, it was found that non-participants focused on the risk of discomfort and possible complications during further investigation, which was a central reason for abstaining. Participants emphasised the value of early detection and the concern that cancer would be diagnosed at a late stage. Questionnaires were completed to assess preferences, information and knowledge about colorectal cancer screening, which was found to be limited. Individual overestimated or underestimated their risk. Healthcare professionals were not consulted to any great extent for in-depth information. Both non-participants and participants responded that healthcare professionals were an important source of information and contributed to the decision to participate or to abstain (46).

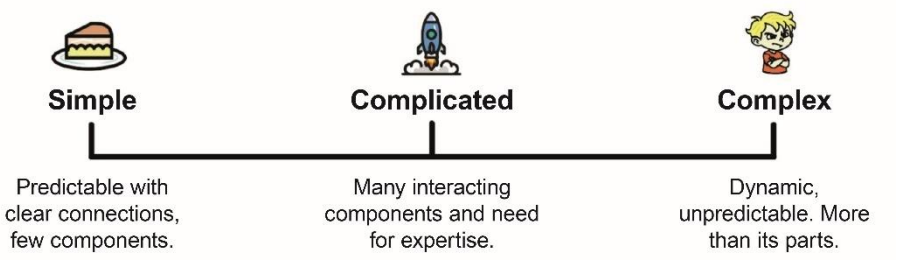


Figure 1. Illustrates the increasing complexity of decision-making, ranging from simple and predictable, to complicated, to complex and dynamic. Illustration: Ilja Karilampi

1.4.2 SHARED DECISION-MAKING AND DECISION AIDS

Historically, healthcare decisions were largely guided by medical experts. Over time, patients have been increasingly involved and shared decision-making has been established as a central concept (47). In this framework, clinicians provide comprehensive medical knowledge and evidence-based information, including clear explanations of potential benefits and harm, while individuals contribute their personal values, preferences, and risk perceptions (48, 49).

In parallel, decision aids have been developed as structured tools to support informed decision-making. Unlike in shared decision-making, which relies on interactive dialogue with healthcare providers, decision aids can be used both alongside clinical consultation and independently, often via digital platforms or applications. Decision aids present evidence-based information about benefits, risks and alternatives, and guide individuals in reflecting on their own values and preferences before or during the decision-making process. Some decision aids are interactive (50), meaning they actively engage users through questions or tailored feedback, further supporting value-based decisions. Meta-analyses show that decision aids can be integrated into prostate cancer screening practices and influence how individual men perceive PSA testing, highlighting that screening is no longer a ‘one-size-fits-all’ intervention but a decision that requires individual guidance (51).

According to the 2022 European Commission cancer screening recommendations, PSA-based screening should be complemented with risk

stratification and clear information (52). The PRAISE-U project aims to harmonise guidelines and information practices across EU member states, emphasising informed and value-based decision-making. A combination of sufficient knowledge and men's own values forms the basis for a 'good decision' (53). Defining the content of decision aids from a strictly scientific perspective is possible, but it does not always align with men's actual needs. For some men, the only relevant aspect is the test result itself, and they may not consider information about the test characteristics necessary. Nevertheless, it remains essential to clarify that different options exist—to undergo testing, to defer, or to decline—and that the choice should be guided by the individual man's own values and preferences (54, 55).

Studies from over a decade ago (56, 57) describe a low proportion of men reported participating in shared decision-making about testing for prostate cancer, and that the conversations are often inadequate and do not cover the benefits, risks, and uncertainties of PSA testing. In the United States (40) and Europe (52), current guidelines state that prostate cancer screening should not be undertaken without an informed decision-making process, where relevant and personalised information is provided based on the person's risk level. The risk level is determined by the presence of prostate cancer in close family members, which in turn affects the age at which PSA testing should begin. They also advocate that the information be provided by health care providers or culturally appropriate sources.

1.4.3 HEALTH LITERACY

Health literacy can be understood as the extent to which individuals are able to access, interpret, critically assess, and effectively apply health-related information. Its dynamic nature implies that healthcare cannot assume that all individuals have the same capacity to process information (58). Health literacy extends beyond reading skills or the comprehension of written materials; it also encompasses the ability to interpret information in context and translate knowledge into practical action. Research consistently identifies health literacy as a central determinant of health, influencing individuals' capacity to prevent disease, adhere to treatment recommendations, and manage chronic conditions (59).

In the field of cancer screening, research has primarily focused on cognitive aspects, emphasising that individuals must weigh potential benefits against possible harms to be able to make informed decisions about participation (60, 61).While health knowledge reflects what a person knows about health,

disease, and prevention, health literacy captures how this knowledge is accessed, interpreted, and applied in decision-making, and is shaped by social and contextual factors.

Importantly, health literacy is not static. It may change over time depending on life circumstances, age, educational background, language skills, and context. For instance, a person with high health literacy in everyday life may encounter difficulties when faced with complex health-related decisions involving new terminology and uncertainty. Stress, mental health problems, or high cognitive load can also temporarily reduce an individual's ability to comprehend and process information. The effectiveness of decision-making is further influenced by health knowledge, prior healthcare experiences, and personal values, while emotional factors—such as cancer-related worry or trust in the healthcare system—shape how information is interpreted and integrated into choices (62).

Health literacy also affects men's likelihood of undergoing PSA testing for prostate cancer (63). Evidence shows that men with higher levels of health literacy are more inclined to undergo PSA testing, particularly when they receive clear information and the opportunity for dialogue with healthcare professionals. These findings highlight the importance of considering patients' health literacy in the development of screening guidelines, especially to support men with lower levels of health literacy (64).

1.4.4 MEN IN SCREENING PROGRAMMES

Men often have lower participation than women in screening programmes (65, 66) for instance in colorectal cancer screening programmes in Sweden (67, 68). Men tend to postpone examinations, often related to fatalistic beliefs, feelings of vulnerability, and a more distant relationship with healthcare compared to women (69, 70). This has been linked to various barriers, such as low perceived risk, fear of receiving a diagnosis, and lack of time (71). A systematic review of qualitative studies from eight countries presents another perspective: men express a willingness to participate in screening, primarily to prevent cancer and to gain reassurance about their health. This willingness was further strengthened when they received support from healthcare professionals or their social networks. At the same time, men faced several obstacles, including fears associated with loss of masculinity, discomfort with the intrusive nature of screening, and uncertainty regarding its benefits (72).

Previous limited exposure to organised screening programmes may shape men's expectations, level of knowledge, and need for support. In Sweden, participation in organised prostate cancer testing programmes has so far been relatively low, 38 % (73).

Gender-related norms play a central role in these patterns. Masculinity ideals emphasising independence, strength, and resistance to seeking help may reduce men's likelihood of accepting screening (74). A review of prostate cancer patients further shows that masculinity norms and concerns related to sexuality influence how men engage in both diagnostics and treatment (75). In the context of cancer prevention, this means that uncertainty regarding the benefits and risks of screening is often reinforced by concerns that the screening process might conflict with masculinity norms.

1.5 FROM OPPORTUNISTIC PSA TESTING TO ORGANISED PROGRAMMES

In 2016–2018, the Swedish National Board of Health and Welfare investigated the conditions for a national screening programme for prostate cancer and concluded that the benefits do not clearly outweigh the disadvantages. Because of the widespread, resource demanding, unorganised prostate-specific antigen (PSA) testing, several Swedish regions have since 2020 instead started organised, population-based prostate cancer testing (OPT) programmes In October 2025 19 of Sweden's 21 regions have introduced OPT in some form.

One of the aims of OPT is to replace the unorganised, unequal and often poorly informed PSA testing on the man's own initiative. This so-called opportunistic testing has been shown to be less effective and associated with a higher ratio of overdiagnosis (76). In OPT, men from the age of 50 years receive brief, neutral information about the potential advantages and disadvantages of prostate cancer testing and an offer to participate in a long-term testing programme (77). In-depth information and a video with audio and visual adaptation are available online. The information to the men has been continuously developed, men who choose not to participate are not sent reminders; instead, they receive new invitations every other year.

Unorganised PSA testing is unequal: Swedish men with higher education are more likely to be tested and are more likely to be investigated for a high PSA

value than men with shorter education (78). The National Board of Health and Welfare emphasises that OPT should create conditions to reduce differences between men in different socioeconomic groups. A study of 50-year-old men offered PSA testing in Region Västra Götaland's OPT programme in 2020 did, however not suggest that OPT reduced socioeconomic inequality compared with unorganised PSA testing (73, 79).

1.5.1 RANDOMISED PROSTATE CANCER SCREENING TRIALS

Randomised trials have been conducted to evaluate the effect of PSA-based screening for prostate cancer, including ERSPC, PLCO, CAP, and the Göteborg Prostate Cancer Screening Trial 1(Göteborg-1) and The Göteborg Prostate Cancer Screening Trial 2 (Göteborg -2). Although these studies differed in design, they all shared the overarching aims of determining whether screening reduces prostate cancer mortality and assessing the extent of overdiagnosis.

The ERSPC (European Randomised Study of Screening for Prostate Cancer) trial is the largest prostate cancer screening trial, involving more than 160,000 men across eight countries (e.g., Sweden, the Netherlands, Finland, Belgium, Switzerland, Spain, France and Italy). Men aged 50–74 years were randomised to PSA screening, every two, four or seven years, or to a control group without invitation. After 13 years of follow-up, ERSPC demonstrated a 21 % relative reduction in prostate cancer mortality in the screening group (80). However, the study also revealed a substantial degree of overdiagnosis, raising questions about whether the benefits outweighed the harms.

The Göteborg-1 trial, which forms part of the ERSPC, was initiated in 1995 and enrolled 10,000 men aged 50–64 years who were invited to biennial PSA testing with as many uninvited men as the control group. The 18-year follow-up of The Göteborg-1 trial showed that the invited screening group had a 35 % lower prostate cancer mortality than the control group and that 231 men needed to be invited to be screened, and 9 extra men were diagnosed to prevent one prostate cancer death (76). At the 22-year follow-up, increased risks of prostate cancer death were observed in men who declined participation, men who joined the programme after the age of 60, and in those followed for more than ten years after screening cessation (81). Sociodemographic factors influenced participation in the screening

programme. Men with higher education and higher socioeconomic status participated more often (82).

The Göteborg-2 trial began in 2015 with almost 40,000 men in the screening group and 20,000 men in the control group, all aged 50–60 year at first invitation. The screening group participants are randomly allocated into three different trial arms with different PSA cut-off for MRI and different use of targeted and systematic biopsies (83). The main aim of the trial is to investigate whether the use of MRI and targeted biopsy can reduce overdiagnosis with maintained detection of clinically relevant tumours (22). An early report showed that excluding biopsy in men with a negative MR result reduced detection of clinically insignificant prostate cancer by half, with only a very low, reduced detection of clinically significant incurable cancer (29).

The PLCO (Prostate, Lung, Colorectal and Ovarian Cancer Screening Trial) (84) was conducted in the United States from 1993 to 2001 and 38,350 men were randomly assigned to the PSA screening arm and a group of similar size acted as a non-invited control arm. Although men in the intervention arm were offered annual PSA testing for six years, the trial showed no significant difference in prostate cancer mortality between the study arms. However, these findings do not allow for any conclusions about the effectiveness of screening because a great proportion of men were PSA tested before the study start, a low proportion of men with a high PSA had a prostate biopsy and most men in the control arm underwent opportunistic PSA testing (85).

The CAP (Cluster Randomised Trial of PSA Testing for Prostate Cancer) trial in the United Kingdom randomised over 400 general practitioners to either offer men single PSA test or no PSA testing. The study included approximately 400,000 men but only 67,313 (36 %) participated and underwent PSA testing (86). After 15 years of follow-up, a small (8 %) but statistically significant reduction of prostate cancer mortality was observed, suggesting that a one-time PSA test is insufficient as a screening strategy (87).

Taken together, the Göteborg-1 trial and ERSPC trials demonstrated a clear mortality reduction and the CAP trial a small prostate cancer mortality reduction, whereas PLCO did not show any such reduction—largely due to differences in study design, screening frequency, compliance with diagnostic investigations and contamination in the control group. Despite the evidence

of mortality reduction, overdiagnosis and treatment-related harms remain major concerns. For this reason, national healthcare authorities across the European Union and the United Kingdom, including Sweden, advise against routine prostate cancer screening (88).

1.5.2 BENEFITS AND HARMS OF PROSTATE CANCER SCREENING

Evidence highlights a delicate balance between the potential to detect clinically significant prostate cancer at an early stage and the risks of overdiagnosis and overtreatment (3, 4). PSA testing and further investigations to detect prostate cancer at an early, potentially curable stage have been shown to reduce disease-specific morbidity and mortality (22, 76, 83). While many men perceive PSA testing as a means to affirm their health, gain a sense of control, and experience peace of mind (5), the screening process is not without disadvantages. False-positive results during the diagnostic process pose a significant challenge, which may lead to unnecessary biopsies. Overdiagnosis can lead to overtreatment, which in turn can cause complications and significant permanent side effects such as urinary incontinence and erectile dysfunction (89).

Deciding about PSA testing involves weighing potential benefits against possible harms—balancing the reassurance of early cancer detection with the risks of overdiagnosis, overtreatment, and treatment-related side effects. The decision-making process is therefore not solely medical but also value-based, requiring an understanding of both medical facts and personal priorities (54, 55). For a decision to be truly informed, individuals must not only understand the purpose of the test but also the potential consequences of a positive test, such as the need for biopsy, treatment, and the risk of side effects such as urinary incontinence or erectile dysfunction. Experiences described by women in personalised breast cancer screening programmes illustrate that risk communication is often complex. In a study involving both women and healthcare professionals, the credibility and comprehensibility of risk assessments were frequently questioned, particularly when based on genetic factors and lifestyle (90). Limited understanding of individually tailored screening strategies contributed to uncertainty, and some participants expressed mistrust in the healthcare system’s ability to manage genetic information.

1.5.3 PHYSICAL CONSEQUENCES

The testing and diagnostic process may lead to physical consequences, particularly when it extends beyond PSA testing and imaging to include transrectal ultrasound-guided prostate biopsy. The most common physical side effects of a prostate biopsy are hematuria, hematospermia, rectal bleeding, pain, and temporary urinary retention (91). Transient post-biopsy-related erectile dysfunction has been described (92). More serious but rare complications include infections requiring hospitalisation (93). These adverse events constitute an important component of the spectrum of screening-related harms and patient discomfort.

In the Göteborg-2 trial, men who underwent targeted biopsy reported less discomfort and demonstrated a greater willingness to repeat the procedure compared with men who underwent a systematic or combined biopsy. Despite that many men found the prostate biopsy uncomfortable, willingness to repeat the examination remained high provided it would be deemed clinically necessary for diagnostic purposes (94).

Local treatment for prostate cancer is associated with a range of potential complications that can significantly affect quality of life (95, 96). Short- and long-term adverse effects include urinary incontinence, which may result from damage to the sphincter mechanism (97). Although the incontinence is usually transient, it may persist despite pelvic floor muscle training and rehabilitation efforts (98). Erectile dysfunction is another common sequela, primarily caused by injury to the neurovascular bundles involved in erectile function. Even with nerve-sparing surgical techniques, the risk of impaired erectile function remains high (99). In addition, deterioration in bowel function—including faecal incontinence and rectal irritation—has been reported following radiation treatment, and such symptoms may persist long after completion of therapy(100).

1.5.4 PSYCHOSOCIAL CONSEQUENCES

Research has clearly shown that a prostate cancer diagnosis may have a profound impact on psychological well-being (96, 101, 102). Despite this, we still know relatively little about how men psychosocially adapt to being a cancer patient, especially when the diagnosis comes unexpectedly—as when detected through screening (76).

The psychological consequences of cancer screening depend on which stage in the process the individual experiences: prior to screening (anticipatory anxiety), immediately after the screening test and subsequent procedures (reaction to the test or procedure as such and concerns about what it may reveal), and following the disclosure of results (much depending on the type of result).

Screening is aimed at a population that typically perceives itself as healthy, so the announcement of a need for further investigation can be experienced as an abrupt intrusion into everyday life, which in turn can trigger psychological stress and existential anxiety (103). Men who have access to emotional support from a partner, family, or friends generally report lower levels of anxiety and distress following a cancer diagnosis. Strong interpersonal relationships actively promote psychosocial adjustment, whereas a low-level support increases the risk of psychological strain (104, 105). Men with an elevated PSA level in The Göteborg-1 trial who were informed of a 15 % risk of being diagnosed with prostate cancer reported low levels of anxiety (106). Their anxiety was assessed using two questions administered immediately prior to the clinical examination, including prostate biopsy. Only a small proportion reported high anxiety levels.

A review indicates that anxiety levels may temporarily increase around the time of receiving screening results, particularly when findings are elevated or uncertain, compared with baseline levels before testing. However, these reactions are typically short-lived and tend to return to baseline after a period of time (107). A systematic review on harms related to cancer diagnostics shows that the psychological impact differs between asymptomatic individuals participating in screening and patients undergoing diagnostic investigation by symptoms. Screening is typically conducted among asymptomatic individuals, meaning that a positive test result may elicit a psychological response disproportionate to the medical risk—the emotional burden may exceed what is warranted by the actual likelihood of disease. The experience of screening is influenced by several individual factors, such as age, educational level, socioeconomic status, and previous experiences. Younger individuals, those who are unemployed, and those with lower levels of education are particularly vulnerable to psychological distress in connection with screening and should therefore be offered individually tailored support (108).

Active, problem-focused coping strategies have consistently been shown to facilitate both psychosocial and health-related adaptation among cancer survivors, while avoidant strategies are more frequently associated with maladaptive outcomes following diagnosis (109, 110). However, little is known about how such adaptation unfolds during the diagnostic process itself, especially within modern screening programmes where uncertainty and vulnerability may be particularly pronounced. Emerging research suggests that individuals with prior negative healthcare experiences, low socioeconomic status, or limited social support are more likely to experience psychological distress in connection with screening (111). Although psychosocial factors have long been recognised as important predictors of successful adjustment to a cancer diagnosis—particularly in breast cancer populations (112) these associations have yet to be systematically studied in larger groups of men diagnosed with prostate cancer through screening.

In a survey from the US, published in 2004, many men who had experienced a false-positive PSA test continued to feel anxious about future illness and carried a lingering sense of uncertainty, despite receiving confirmation that they did not have prostate cancer (113). This may reflect a dichotomy between perceiving oneself as either healthy or ill, so when individual men internalised the threat of a potential future prostate cancer diagnosis linked to an elevated PSA value, they had to leave the self-image of healthy and accept one of potential illness (114). At the same time, PSA testing has also been described as a means for men to affirm their health, regain a sense of bodily control, and achieve peace of mind (5). These contradictory experiences highlight the complexity of screening and underscore the importance of considering psychological and social dimensions when assessing its value, in addition to strictly medical aspects.

1.5.5 ASSESSING PSYCHOLOCICAL CONSEQUENCES

In the absence of an objective ‘anxiety-measure’—that is, a test that can reliably quantify anxiety—alternative instruments have been developed. Self-reported psychological symptoms may be assessed with a variety of validated questionnaires (115). Alternatively, a clinician may assess anxiety through conversation and observation. Although anxiety leads to measurable changes in various chemical substances in the body fluids, associations between such biomarkers and anxiety have been weak and inconsistent, and there is

currently no established, objective biomarker that can reliably measure anxiety (116).

Psychological consequences of and emotional reactions to various life events encompass several different aspects—worry, anxiety, fear, stress, depression, etc—that vary over time and between individuals (117). A systematic review that focused on the psychological impact on cancer screening in an asymptomatic population, assessed before and up to one year after general screening, showed that anxiety was the most commonly measured symptom. (107). The authors concluded that various instruments are used that are not specifically developed for the cancer screening context. Commonly used rating scales for anxiety or psychological distress include the State-Trait Anxiety Inventory, the Hospital Anxiety and Depression Scale, and the Impact of Event Scale), none of which were originally designed to capture the unique psychological reactions of screening.

Different psychological instruments capture different dimensions of anxiety. Some measure temporary anxiety (a state), while others assess more stable personality traits. Some focus on physical reactions associated with anxiety such as heart palpitations and sweating, while others focus on cognitive concerns, such as catastrophic thoughts and rumination (118). The reliability and validity of these measurements depend on several factors (119): the choice of instrument, whether the assessment is done immediately after a stressful event or later, and whether numerical scores are combined with the individual's own narrative.

Given its widespread use in both clinical and research contexts, the Hospital Anxiety and Depression Scale facilitates cross-study comparisons of psychological outcomes is one of the most commonly used questionnaires for assessing psychological issues in clinical settings (120). Nonetheless, the Hospital Anxiety and Depression Scale may not adequately capture the type of anxiety that screening can evoke in healthy individuals. Triangulation of methods—using several different approaches simultaneously, such as various rating scales and interviews—may provide a more nuanced and accurate picture of the individuals anxiety and reduce the risk of misinterpretation (107).

2 AIMS

The overall aim of this thesis was to deepen the understanding of men's decision-making process in and psychological consequences of prostate cancer screening.

Specific aims

I. To understand men's perception of receiving an invitation to organised prostate cancer testing (OPT), including how clearly the advantages and disadvantages of the PSA test are communicated, and whether educational level is associates with perception and decision-making.

II. To explore the aspects that guide men’s decision to accept or decline PSA testing following an invitation to OPT, particularly the role of the information given in the invitation letter.

III. To evaluate potential psychological harm of participating in the diagnostic process for men with a raised PSA in the Göteborg-2 screening trial.

IV. To study whether attendance at re-invitation to prostate cancer screening was related to MRI findings and biopsy type at the initial screening round as well as individual factors.

3 PATIENTS AND METHODS

All four papers included in this thesis are based on large, population-based samples of subjects. **Study 1** and **Study 2** report studies conducted within the framework of organised prostate cancer testing (OPT) in routine healthcare. **Study 3** and **Study 4** report research in the Göteborg-2 screening trial.

3.1 THE GÖTEBORG-2 PROSTATE CANCER SCREENING TRIAL

The Göteborg-2 trial is a prospective, population-based, randomised trial with the aim of evaluating new strategies for prostate cancer screening. Recruitment began in September 2015 and ended in January 2020. A total of approximately 60,000 men aged 50–60 years were identified from the city of Gothenburg and nearby municipalities, covering urban, semi-urban and rural areas. Men without previously diagnosed prostate cancer, verified via the cancer registry, were initially randomised 1:1, later changed to 2:1, between a screening group (SG) and a control group (CG). Recruitment and management were carried out according to an opt-out procedure, and all men received written information about the purpose and design of the study (83). Men who accepted participation in the SG were randomly assigned to one of three investigation arms:

- Arm 1. Men with PSA ≥ 3.0 ng/mL are referred for a prostate MRI and a systematic biopsy (10–12 tissue cores). In case of a suspicious lesion (PI-RADS 3–5) on MRI, targeted biopsy cores are also taken.

- Arm 2. Men with PSA ≥ 3.0 ng/mL are referred for MRI. Only men with findings on MRI proceed to biopsy and then only with targeted cores. Men with PSA ≥ 10 ng/mL and PSA density ≥0.1 ng/ml^2 are recommended additional systematic biopsies irrespective of the MRI result.

- Arm 3 follows the same protocol as arm 2, but with a lower PSA cut-off for MRI (≥ 1.8 ng/mL). Also in this group, exceptions for men with PSA ≥ 10 ng/mL and PSA density ≥0.1 ng/ml^2 who are invited for systematic biopsies.

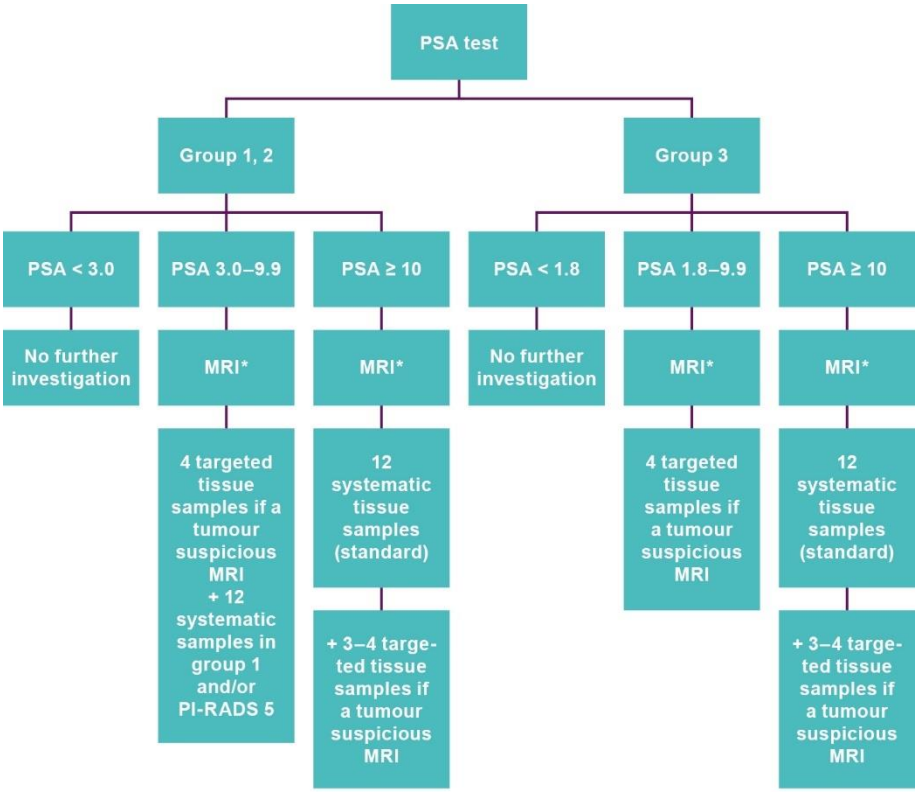


*Figure 2. Design of the GÖTEBORG Prostate Cancer Screening 2 Trial. * If a previous MRI scan was normal, not all men with an elevated PSA value will be referred for a new MRI and new tissue sample.*

In all three arms of the Göteborg-2 trial, men with PSA levels below the cutoff receive a letter stating that their PSA is normal, and that they will be re-invited after a specified number of years (Table 1).

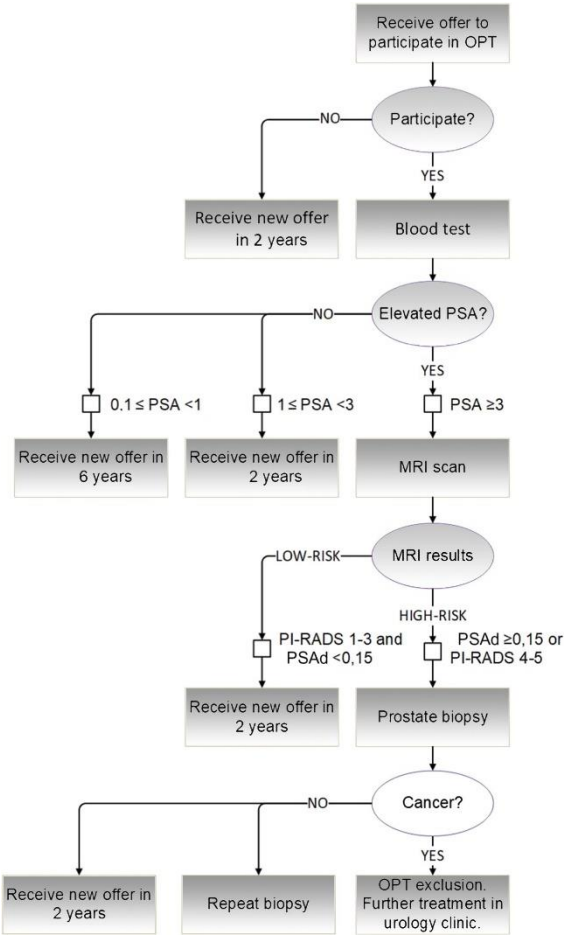
PSA level (ng/mL)	**Screening interval**
< 0.6	8 years
0.6–1.19	4 years
1.2–2.99	2 years
≥ 3 and no cancer detected	2 years
Not participating at latest invitation	2 years

Table 1. Re-invitation intervals are based on PSA at previous invitation.

3.2 ORGANISED PROSTATE CANCER TESTING

The organised prostate cancer testing (OPT) initiative was launched as regional development programmes following a 2018 mandate from the Swedish Ministry of Health and Social Affairs. Its objective is to establish more standardised and efficient strategies for the early detection of prostate cancer. The assignment was given to the Regional Cancer Centres in Collaboration, with the purpose of creating a structure that ensures equitable access to testing while simultaneously generating knowledge to inform a potential future national screening programme. Unlike randomised clinical trials, OPT does not constitute a research project but is a public healthcare initiative integrated within the regional healthcare system (1).

Figure 3. Design of organised prostate cancer testing.



The first pilot projects were initiated in 2020 in Region Västra Götaland and Region Skåne. The invitation letter contained a brief text providing a balanced overview of the potential benefits and harms of prostate cancer testing for early detection, along with information about subsequent diagnostic procedures for men with elevated PSA levels, including magnetic resonance imaging and transrectal ultrasound-guided biopsy. Together, these two regions encompass approximately 3 million inhabitants, representing urban, semi-urban, and rural areas. In Skåne, 1,000 randomly selected men aged 50, 56, and 62 years were included, while in Västra Götaland, all 12,000 men born in 1970 (50 years old at the start of the project) were initially invited. PSA testing was offered free of charge within four weeks of the invitation being sent, with blood samples drawn either at primary care centres or at public hospitals in the region. Men with a PSA level ≥ 3 ng/ml were referred for further evaluation, including MRI and possibly a biopsy at a urology department at a public hospital.

3.3 SPECIFIC METHODOLOGY IN THE THESIS FOUR STUDIES

This section provides a brief overview of the methods used in each study. A more detailed discussion and interpretation of the findings follow in the methodological considerations in Section 3.4.

3.3.1 METHODOLOGY IN STUDY 1

Data collection was carried out during October and November 2020, after approval from the Swedish Ethics Review Authority (ref. 2020-00699). A questionnaire, accompanied by a copy of the information and invitation to OPT, was distributed by mail six weeks after the initial OPT invitation. The sample included 600 randomly selected men from the 12,000 invited 50-year-old men in Västra Götaland and 1,000 men aged 50, 56 or 62 years invited to Region Skåne's OPT pilot project.

The questionnaire, consisting of 20 items, was developed by the research team specifically for the purpose of this study. It comprised six background questions, six items assessing the clarity of information regarding the advantages and disadvantages of prostate cancer testing, one item on participation in OPT, and seven items evaluating organisational aspects (which were not analysed). Response options were presented on a Likert scale. The development of the questionnaire included face-to-face validation

with 22 participants from The Göteborg-2 trial, conducted by PhD student L.S.

Participants completed the questionnaire anonymously by returning it in prepaid, addressed envelopes. The analysis was divided into primary hypothesis analysis and secondary hypotheses, proportions were compared between potential explanatory variables such as educational level, using the chi-squared test.

Given that the disadvantages of PSA testing may be more difficult to comprehend than the advantages (e.g. 'A simple blood test can reduce the risk of dying from cancer'), the primary hypothesis tested was whether educational level was associated with the perception of information regarding disadvantages. The analysis focused primarily on responses from men who had not previously undergone PSA testing, as they were less likely to have formed prior opinions about prostate cancer screening. Respondents who indicated uncertainty about prior PSA testing were grouped with those who reported no previous testing. All response options were dichotomised, with 'very clear' contrasted against all other responses, based on the rationale that a clear understanding of the disadvantages is essential before making an informed decision about PSA testing. Educational level was dichotomised in all analyses as non-academic (primary or secondary education) versus academic (upper secondary or university education).

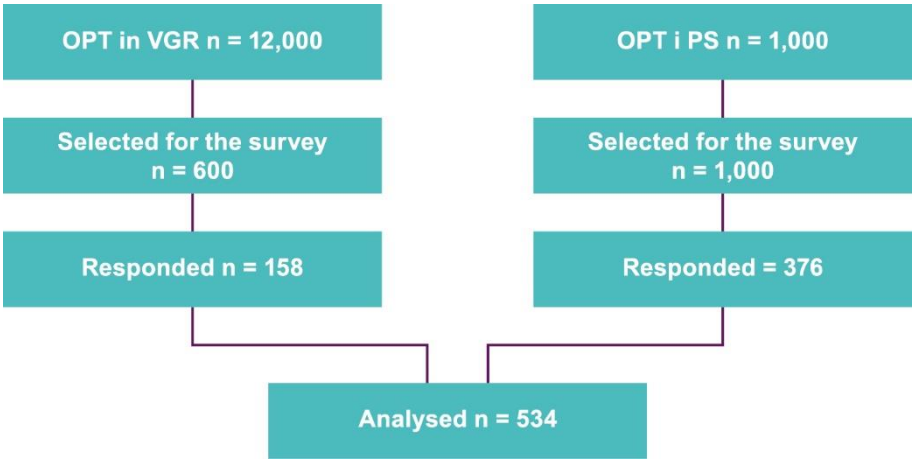


Figure 4. Flow chart study 1.

3.3.2 METHODOLOGY IN STUDY 2

Following ethical approval from the Swedish Ethics Review Authority (2020-00699), recruitment for the interview study commenced in November 2020. The OPT office distributed invitations to participate in interviews to 400 randomly selected men who had received the initial OPT information letter regarding PSA testing six weeks earlier. To ensure adequate representation of individuals who had declined PSA testing, an additional targeted sample of 200 men who had opted not to participate in OPT was identified and invited.

Men who were interested in participating contacted us by email. Between March and May 2021, a total of 18 interviews were conducted by the PhD student (L.S.), following verbal informed consent and using a semi-structured interview guide. All interviews were carried out by telephone. One pilot interview was conducted and subsequently included in the final analysis, as no revisions to the interview guide were deemed necessary. The interviews lasted between 12 and 25 minutes, were audio-recorded, and transcribed verbatim by a professional transcriptionist. The interview questions explored how participants perceived the clarity and relevance of the information about the benefits and risks of PSA testing, and how this influenced their decision-making.

Data were analysed using qualitative content analysis with an inductive approach, aiming to capture experiences and perspectives grounded in the participants' own realities. The transcripts were read repeatedly to ensure familiarity with the material. Meaning units—defined as sentences or phrases relevant to the research question—were identified, resulting in 201 units. These were condensed to retain core meaning while minimising unnecessary wording, with low levels of abstraction to preserve participants' expressions. The condensed units were then coded into short phrases or single words, which were grouped into 16 subcategories. Subcategories were colour-coded to facilitate pattern recognition and subsequently organised into four overarching categories.

The initial coding and condensation were performed by the PhD student (L.S.), in close collaboration with the last author and supervisor (K.S.), who provided ongoing feedback and contributed to the interpretation throughout the analytical process. Through conversation and reflection between all authors, main categories were developed, focusing on how these structures emerged from the material.

3.3.3 METHODOLOGY IN STUDY 3

Study 3 included men in The Göteborg-2 trial with a first elevated PSA who were eligible for MRI and had completed at least one follow-up questionnaire. Data collection began in October 2019, after approval by the Swedish Ethical Review Authority (2019-00725), and was conducted using self-administered questionnaires distributed at different stages of the diagnostic work-up.

Two questionnaires were part of the core protocol: one at baseline before PSA testing and one prior to the communication of biopsy results. For the purpose of this study, these questionnaires were supplemented between 2019 and 2024 with validated instruments and study-specific questions to assess psychological consequences. The Hospital Anxiety and Depression Scale (121) and the Impact of Event Scale–Revised (122) were used, together with questions on intrusive thoughts, worry related to PSA/MRI/biopsy, and the impact of investigations on daily life. The questionnaires were administered at four time points: at baseline, before MRI, before biopsy, and before the communication of biopsy results. Data collection was coordinated at the Urology Department, Sahlgrenska University Hospital. The primary outcome was HADS Anxiety, and the sign test (one-tailed) was used to assess changes from baseline. The other outcomes are reported descriptively using bar graphs.

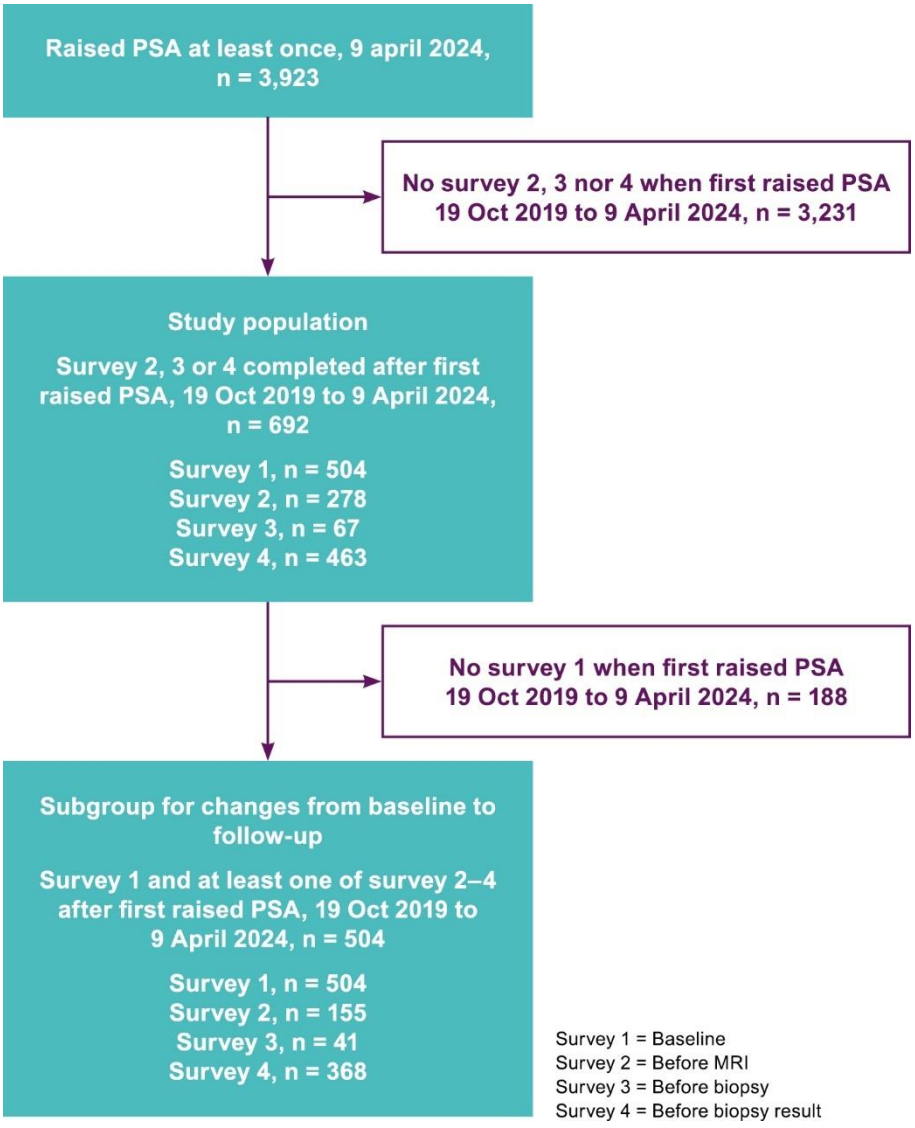


Figure 5.Flow chart study 3.

3.3.4 METHODOLOGY IN STUDY 4

This study is based on The Göteborg-2 trial. The trial was approved by the Swedish Ethical Review Authority (2015-00725/1094-18), and an opt-out procedure was accepted both in the group of men randomised to screening and men randomised to the non-invited control group.

The primary objective of this study was to find out whether re-attendance at the second screening invitation was associated with differences in diagnostic algorithms at the first screening visit—particularly whether men who underwent only a few targeted biopsies differed from those who had more extensive systematic biopsies. We also examined whether individual factors were associated with re-attendance.

At baseline, men who attended their first invitation to the study were asked to complete a questionnaire. The questionnaire covered background variables, socioeconomic status, lifestyle, comorbidity, Lower Urinary Tract Symptoms (LUTS), and Erectile Dysfunction (ED). In the present study, re-attendance rates after the first screening round were analysed in relation to biopsy method (targeted vs. systematic). Risk factors such as individual background for non-attendance were assessed using modified Poisson regression, with results presented as relative risks (RR) and 95 % confidence intervals. Sensitivity analyses accounted for the COVID-19 pandemic, PSA range, and missing data.

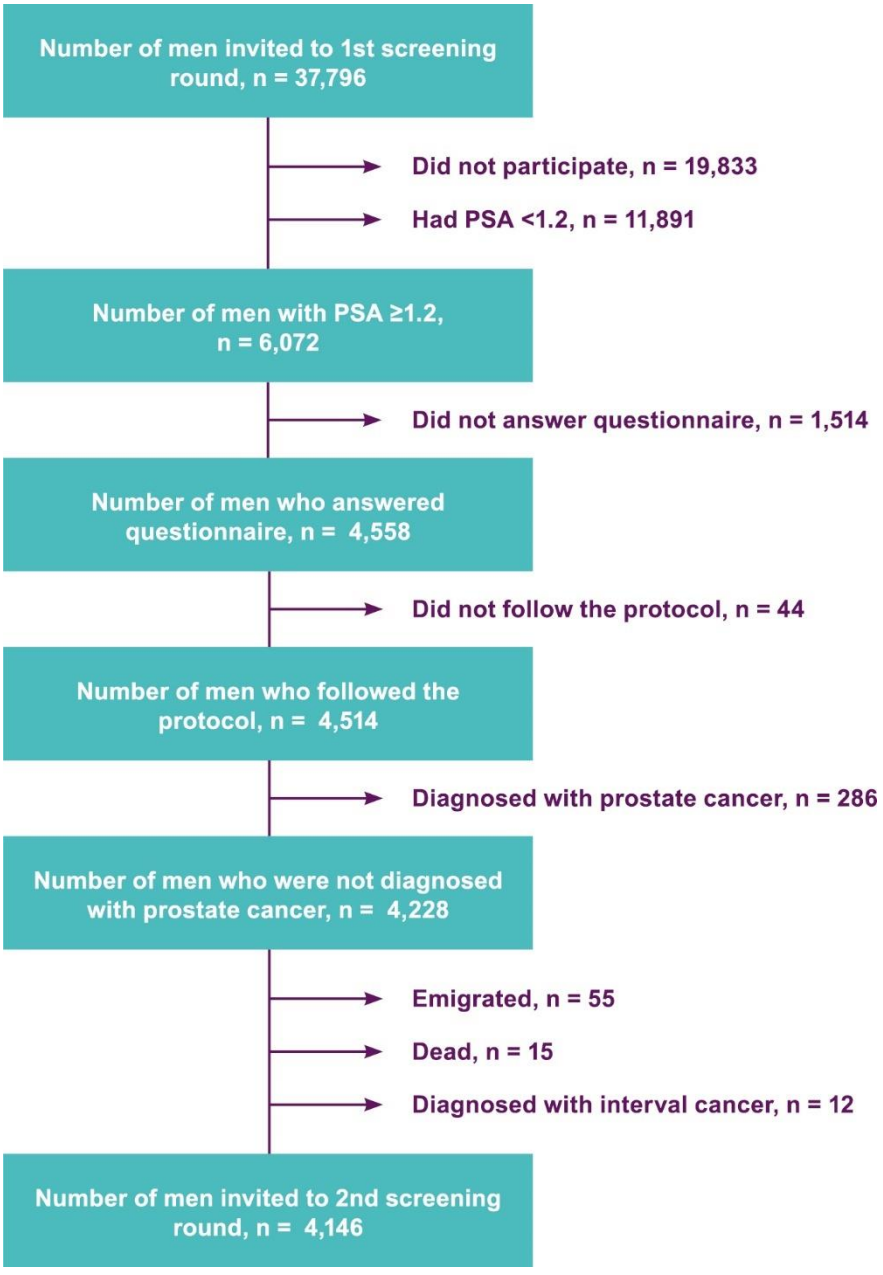


Figure 6. Flow chart study 4

3.4 METHODOLOGICAL CONSIDERATIONS

Clinical research requires careful methodological rigor to ensure valid, reliable, and interpretable results. Regardless of methodological approach, the research process demands a conscious and critical attitude toward interpretation. In qualitative research, interpretation is more directly linked to the researcher's active role in the analysis. This requires continuous reflexivity, meaning that the researcher throughout the research process actively reflects on their own role, assumptions, and influence on the interpretation of data. It involves examining how the researcher's preunderstanding affects coding, categorisation, and thematisation. Moving from meaning-bearing units to overarching categories involves several levels of interpretation, which places demands on transparency and grounding in the empirical material.

In quantitative research, this involves understanding the limitations of statistical models, handling missing data in a transparent manner, and interpreting results with consideration of confidence intervals, effect size, and context. A p-value alone does not provide a complete picture but must be interpreted in relation to study design, sample, and research question.

Beyond study design and data collection, aspects such as hypothesis testing, statistical inference—methods used to draw conclusions about a population based on sample data—handling of missing data, and validation of measurement instruments are central to the credibility of results.

Common to both methodological approaches is the need to constantly question and test the interpretations made. Whether it involves identifying a pattern in a statistical model or discerning a manifest meaning in an interview text, a critical and conscious analysis is required to ensure the credibility and relevance of the results. Combining qualitative and quantitative methods within a dissertation enables a more nuanced and comprehensive exploration of the research question. The quantitative approach contributes with the potential for generalisation, statistical precision, and the identification of patterns in larger datasets. Meanwhile, the qualitative method offers in-depth insights into individual experiences, contextual factors, and the process of meaning-making. By integrating these two perspectives, the research captures both the breadth and depth of the empirical material, thereby strengthening the study's validity and relevance.

In this section, these methodological considerations are discussed in relation to the present thesis.

This section presents the methodological choices made to answer the research questions of the thesis. To achieve both breadth and depth in our understanding of the empirical material, we combined qualitative and quantitative methods and research designs (123). A research design functions as a blueprint for how a Study is to be conducted, ensuring that the research questions are systematically addressed while minimising potential sources of bias that could distort the results. The design specifies which questionnaires or interview techniques are employed, the frequency of data collection, and the types of comparisons and measurements to be performed.

To investigate perceptions of organised prostate cancer testing—at the time in 2020 a new and unexplored healthcare initiative—the research group jointly developed a questionnaire instrument. As no specific measurement tools were available in this area, the questionnaire was constructed and validated within the framework of **Study 1**. It was pilot tested with 22 men from The Göteborg-2 trial, who were in a situation similar to the intended study population, which was essential for establishing content validity (124). In **Study 1,** a quantitative approach was applied, using a questionnaire for data collection. The study employed a cross-sectional design, with data collected at a single time point, and primary and secondary hypotheses were evaluated. For the analysis, descriptive statistics and chi-square tests were applied to examine group differences.

In the primary analysis, we chose men who had not previously undergone PSA testing, as their perceptions of the described advantages and disadvantages were less likely to be influenced by prior diagnostic experiences. This approach allowed us to more clearly capture the ‘level of clarity’, particularly regarding the disadvantages of PSA testing, which is critical for making an informed decision.

A central methodological decision was to dichotomise the response options, categorising the perception of information clarity as ‘very clear’ versus all other responses. While dichotomisation inevitably entails some loss of nuance—since intermediate response options are not distinguished— we considered ‘very clear’ as the desirable level for making the important decision whether to participate or not. Since education may influence the way

written information is understood and interpreted, this remains a relevant aspect to consider in relation to the aim of the study.

An important methodological weakness concerns selection bias. Only about 10 % of the men who responded to the questionnaire had chosen not to test their PSA in the OPT. As a result, the findings largely reflect the perceptions of men who were already positively inclined toward PSA testing, which may have influenced the outcomes. Taken together, these factors mean that the results cannot be fully generalised to the broader screening population.

In **Study 1**, we employed a method that enabled standardised data collection from a large sample, whereas in **Study 2**, we sought a deeper understanding of individuals' reasoning and experiences. By combining these research approaches, we achieved both breadth and depth in understanding men's perceptions of information regarding PSA testing. The questionnaire provided comparable data from a large number of participants, while the semi-structured interviews captured nuances and spontaneity in the participants' own words and values. This approach was particularly valuable in a context where organised PSA testing had not previously been offered in Sweden, and where it was necessary to explore how men personally interpret and evaluate information on the benefits and harms of testing.

In **Study 2,** we conducted semi-structured interviews and applied qualitative content analysis. The 18 men who participated contributed richness, variation, and depth to the data, providing the information power needed to address the aim of the study. In designing the study, it was important to ensure balanced representation of both men who had chosen to undergo PSA testing in OPT and men who had declined testing. To achieve this, active recruitment measures were implemented: after the initial randomised mailing, an additional 200 invitations were sent specifically to men who had not undergone testing. This supplemented the original sample of 400 participants and enabled a more nuanced data collection. The interviews were conducted via telephone at a scheduled time. This approach proved beneficial as it enabled anonymity while simultaneously fostering an intimate conversational climate. By following a structured interview guide, the research question was maintained throughout the interviews, while allowing space for individual narratives and experiences.

Our choice of inductive qualitative content analysis aimed to allow patterns and categories to emerge from the empirical material. The analysis focused

on manifest content, meaning that emphasis was placed on participants' own expressions, with limited interpretation by the researchers. To clarify the relationship between description, interpretation, and abstraction during the analysis, we were guided by the model presented by Lindgren, Lundman, and Graneheim, in which these analytical levels are illustrated through an 'interpretation cross' (125). This approach contributed to transparency and reduced the risk of researcher (LS) influence, while preserving the participants' voices.

After each interview, reflective memos were written in a research diary, serving as a complementary data source. These memos contributed to making the analytical development visible and acted as a guide for the authors during the analysis phase in cases where consensus was not initially reached (126).

The analytical process involved systematic coding and categorisation of meaning-bearing units, followed by collaborative discussions to reach consensus between two of the authors, during which we compared our respective analyses. Subcategories and main categories were developed through dialogue among all three authors, involving joint discussions and reflections on how these structures emerged from the material. The concept of 'saturation' is widely discussed in modern qualitative methodology, and its interpretation has evolved over the past 10–15 years. Saturation has traditionally been described as the point in data collection where no new themes or codes emerge and has often been used as a criterion for determining when 'enough' data has been collected (127).

Contemporary qualitative research increasingly views saturation as a problematic and sometimes misleading concept. Instead, the focus has shifted toward the information power, richness, variation and depth of the data. Information power suggests that sample size in qualitative interview studies should be guided by the strength and relevance of the data rather than statistical representativeness (128).

In qualitative research, the researcher's preunderstanding constitutes both a potential strength and a methodological challenge. Prior clinical experience and familiarity with the study context can introduce bias in data collection and interpretation, as the researcher may risk overlooking alternative perspectives or unconsciously confirming preconceived assumptions (129). At the same time, such expertise can enhance the depth of analysis by facilitating nuanced interpretation and a more authentic understanding of

participants' experiences. Acknowledging and critically reflecting on the dual role of preunderstanding is therefore essential, ensuring that its advantages can be leveraged while minimising its potential influence on the credibility of the findings.

Study 3 was a quantitative, prospective study with sequential measurement points using questionnaires during the diagnostic process within The Göteborg-2 trial. An important lesson was that, despite careful planning, the research procedure did not fully account for the practical conditions of everyday clinical work. Two of the measurement points were from start of Study 1 integrated into existing routines and carried out via digital tablets, which worked well. However, for the later measurement points, no established routine for data collection was in place, and time or structure for administering the questionnaires had not been allocated within the clinical workflow. This negatively affected data collection.

To measure symptoms of anxiety, stress, and event-related impact during participation in the diagnostic process, established and validated instruments were selected. The Hospital Anxiety and Depression Scale (121) was used to assess symptoms of anxiety and depression, with the anxiety subscale Hospital Anxiety Scale serving as the primary outcome measure. Impact of Event Scale-Revised (122) was applied to capture event-related stress. Both instruments enabled systematic and comparable assessments and allowed for tracking changes over time.

To identify individuals with clinically relevant anxiety symptoms, we applied a threshold of Hospital Anxiety and Depression Scale ≥ 11, which corresponds to moderate anxiety and provides higher specificity. Lower cut-off scores, such as 8, have been used in other screening studies where the aim was to capture milder reactions and assess procedural acceptability. However, we adopted a different approach: some level of worry following a positive screening result is considered a normal psychological response and does not necessarily indicate clinical relevance. In somatic care, such results should therefore be viewed as indicators of a potential need for further conversation or support, rather than as a basis for clinical decisions regarding mental health.

The Hospital Depression Scale was used as a measure of psychological depressive symptoms rather than to establish a clinical diagnosis of depression, making it suitable for identifying patients in somatic care who

may need support. The Hospital Depression Scale measures symptoms of anxiety and depression experienced during the past week and is thus appropriate for capturing short-term psychological responses during the diagnostic process.

To assess event-related stress during the diagnostic process, we used the Impact of Event Scale-Revised, a validated instrument commonly employed to measure psychological impact following potentially traumatic events. In our study, we did not report the subscales, as the aim was not to distinguish types of stress reactions but to identify whether participants experienced event-related stress to a degree that might indicate a need for support. This approach aligns with the study's focus on psychological impact rather than diagnostic classification.

The Impact of Event Scale-Revised allows for systematic and quantitative assessment of stress levels related to a specific event, in this case the notification of further investigation following screening. A commonly used threshold for clinically significant stress reactions is ≥ 33, but no international consensus exists on a fixed cut-off. In our study, the Impact of Event Scale-Revised was therefore used as a symptom-scale-based measure of event-related stress, not to identify Post-Traumatic Stress Disorder.

A methodological characteristic of the Impact of Event Scale-Revised is its sensitivity to context: the questions must be tied to a clearly defined event for the results to be meaningful. In this study, the event was specified as 'proceeding to further investigation', and participants were asked to respond with this situation in mind within seven days of receiving the notification. This procedure aimed to enhance the validity of the measurement and ensure that responses reflected the actual stress experienced in relation to the event.

Study-specific questions were developed as a complement to established instruments to capture cancer-related worry, intrusive thoughts, and the impact on daily life. By linking the questions to specific diagnostic moments (before MRI following elevated PSA, before biopsy, and before pathological results), we were able to describe variations in emotional impact at each diagnostic occasion. The use of non-validated questions posed methodological challenges, as their psychometric properties have not been tested, limiting comparability with other studies. We included these questions to fulfil the study's exploratory purpose and to capture nuances not addressed by standardised instruments. The questions were carefully designed and

tested in collaboration with clinical staff, ensuring both content relevance and clarity.

We chose non-parametric sign tests to analysed changes in Hospital Anxiety Scale scores across the defined diagnostic time points (baseline, before MRI, before biopsy, and before pathology results) because the data was neither normally distributed nor did meet the assumptions for the Wilcoxon signed rank test. We applied one-sided tests, based on the directional hypothesis that anxiety symptoms would increase compared to baseline. This approach increased the statistical power to detect changes in the expected direction, especially with limited sample sizes. Other outcomes, including Impact of Event Scale-Revised scores and study-specific measures of cancer-related worry, were reported descriptively due to smaller subgroup sizes and potential variability. By selecting these methods, we prioritised validity and interpretability over complex modelling that might have introduced assumptions unsupported by the data, ensuring that our analyses accurately reflect patterns of psychological responses during the diagnostic process.

Study 4 investigated how diagnostic procedures in the first screening round and individual factors influence participation at re-invitation. We conducted a retrospective cohort study based on data in Göteborg-2 trial starting from a defined group of men who had completed the initial screening round. The cohort was followed over time to study attendance rate at the first re-invitation to screening, and groups were compared based on biopsy type (targeted or systematic) as the exposure.We estimated the difference in re-attendance rates between men who had 1–4 biopsy cores and those with ≥ 5 cores at the initial screening, and calculated 95 % confidence intervals to assess the precision of the estimate. In the second part of the study, we analysed individual factors potentially influencing re-attendance and applied modified Poisson regression, both univariable and multivariable. We chose this model because it allows estimation of relative risks (RR), which are easier to interpret than odds ratios and thus provide more clinically meaningful information. An RR greater than 1 indicates a higher likelihood of non-attendance compared to one level of a factor compared to a reference level, whereas an RR less than 1 suggests a lower likelihood. The confidence interval (CI) provides an estimate of the uncertainty surrounding the relative risk (RR). If the CI includes the value 1, the estimate is compatible with both an increased, decreased, or no difference in risk. By reporting both the RR and its 95 % CI, we provide a more informative and transparent presentation of the results

To systematically assess the contribution of different variables, we grouped them into thematic blocks (medical, socioeconomic, lifestyle, and organisational factors) and evaluated each block's impact on re-attendance sequentially. This block-wise approach enabled us to control for correlations within blocks and identify which factors contributed most to non-attendance. We assessed the model's explanatory power using Nagelkerke's R^2, which showed that all variables together explained only 7.5 % of the variation in re-attendance. This finding underscores that other, more difficult-to-capture factors likely influence participation, highlighting the need for cautious interpretation of the results.

3.5 SOME STATISTICAL CONSIDERATIONS

Measurement errors and statistical errors

Random measurement errors arise from unpredictable variations in measurements or observations and are a natural part of any data collection process. These errors affect precision but do not systematically influence the direction of the results. They can be reduced by increasing the sample size or addressed through statistical methods that estimate uncertainty. Systematic measurement errors on the other hand cannot be reduced by larger sample sizes and can give biased results. Statistical errors, such as Type I errors (false positives) and Type II errors (false negatives), occur during hypothesis testing and influence the conclusions drawn about the presence or absence of an effect. A Type I error occurs when a true null hypothesis is incorrectly rejected, leading to the incorrect conclusion that an association or effect exists. In contrast, a Type II error involves failing to reject a false null hypothesis, thus overlooking a real effect. Systematic errors (bias), on the other hand, originate from flaws in the study design, measurement, or sampling and lead to consistent distortion of results in a specific direction, thereby threatening the validity of the findings.

Management of missing data

Missing data is a recurrent methodological challenge in clinical survey research and may arise for several reasons, including question sensitivity, lack of perceived relevance, or respondent fatigue when faced with extensive questionnaires. In our studies, a substantial part of the missing information was likely attributable to questionnaire fatigue rather than systematic refusal, making it reasonable to assume that the data were missing at random, although this assumption cannot be fully verified. Such missingness can

reduce measurement precision and statistical power and may also introduce bias (systematic error) if the missing data are not random.

The management of missing data varied across the sub-studies. In **Study 4**, multiple imputation by chained equations with 50 imputed datasets was applied, thereby reducing the risk of biased estimates (130). The response option 'don't know/prefer not to answer' was coded as NA, not available and analysed separately in regression models. In **Study 1**, no missing data occurred since only fully completed questionnaires were included. In **Study 3**, missing responses on the Hospital Anxiety and Depression Scale and Impact of Event Scale-Revised scales were imputed if at least half of the items (131) within a scale had been answered, by replacing missing values with the mean of the completed items; if more than half of the items were missing, the score was considered missing and excluded from the analyses. The response option 'don't know/prefer not to answer' was coded as NA (not available) and analysed separately in regression models. In **Study 1**, no missing data occurred since only fully completed questionnaires were included. Through this consistent and transparent handling of missing data, the interpretability of the results was strengthened, even though limitations remain due to the unverifiable assumption of randomness in the missingness.

Interpretation of p-values and effect sizes

The p-value quantifies the probability of observing the result, or more extreme results, if the null hypothesis is true. Conventionally, a threshold of 0.05 is applied to denote statistical significance and was used in studies 1,3 and 4. However, statistical significance does not necessarily imply clinical relevance. For example, a small p-value may result from a negligible effect size in a large study, while a clinically meaningful effect may not reach significance in a smaller study due to limited statistical power. The p-value does not convey the magnitude or practical relevance of an effect. Therefore, p-values were considered alongside effect estimates and confidence intervals when interpreting our results **Study 1, 3, 4**, to provide a more robust evaluation of their potential clinical implications.

Confidence level

For all estimates in Study **1, 3**, and **4**, we used 95 % confidence intervals to clarify statistical uncertainty and provide an opportunity to assess the strength of the observed associations. A 95 % confidence interval reflects the uncertainty in the estimate, and there is a 95 % probability that the interval includes the true value. By reporting confidence intervals for both

proportions and regression results, the findings gain greater transparency and allow for comparisons with previous research. Including confidence intervals improves the interpretation by quantifying uncertainty and variation in the estimates.

3.6 ETHICAL CONSIDERATIONS AND SAFETY OF PARTICIPANTS

The four studies included in this thesis were approved by the Swedish Ethical Review Authority. Informed consent was obtained from all participants in **Study 1, 2, 3**. The Göteborg-2 trial uses an opt-out procedure that is provided with clear information regarding the purpose and data collection procedures. Details are described under each section of 'Specific Methodology' for **Study 1–4**.

The Declaration of Helsinki is a central document in medical ethics, developed by the World Medical Association (132). The Declaration of Helsinki emphasises that medical research must respect the rights and well-being of individuals, that participation should be based on informed consent, and that research may only be conducted if the potential benefits outweigh the risks. Vulnerable groups must be given special protection, studies must maintain high scientific quality and be approved by an independent ethics committee, and results should be reported transparently to ensure accountability. Reporting research findings in a fair and transparent manner, while ensuring data security and personal protection, is essential. In a Swedish context, this type of information is considered particularly sensitive under current legislation and is therefore subject to both legal and ethical guidelines to safeguard the individual's right to privacy.

Data from The Göteborg-2 trial are stored on password-protected servers managed by the University of Gothenburg. To prevent unauthorised access or misuse, all data were handled by designated research personnel following established data protection procedures. Access to the data was granted only after a formal request specifying the purpose and type of information required. Data from the organised prostate cancer testing programme were managed by its administrative office, where personal information was encrypted, and only registered residential addresses were used for contact purposes.

Personal identification numbers were never available to the research team. Questionnaire data were collected anonymously, assigned a unique code number, and registered in an Access database. Interview recordings were transcribed verbatim and subsequently deleted. Transcribed materials, labeled only with code numbers, were securely stored in a locked cabinet at the research unit of the Department of Urology, Sahlgrenska University Hospital.

All study participants in the four included studies were men who had been offered cancer screening. Particular attention was given to the ethical principle of protecting potentially vulnerable groups, as participation in cancer screening may evoke anxiety and psychological distress.

In undertaking this research, careful attention was given to fundamental ethical principles, including the obligation to do good, to avoid harm, to respect participants' autonomy, and to uphold justice. All individuals taking part were made aware of the study's aims, that participation was voluntary, and that they could discontinue their involvement at any time without facing any consequences. Special care was taken to ensure that the diagnostic and screening procedures did not cause unnecessary physical or psychological discomfort, and participants who expressed a need for support were offered access to a counsellor.

The Göteborg-2 trial involves multiple points of contact between the research team and study participants, which entails a considerable ethical responsibility. These interactions include in-person meetings during the diagnostic process, where screening results are discussed with participants and, when relevant, their relatives, as well as regular access to a study phone and email communication. Maintaining a factually neutral stance—informing without influencing—can be ethically challenging, particularly when discussing closely related urological issues. While such accessibility promotes trust and transparency, it also requires a deliberate effort to maintain clear boundaries between research and clinical care.

	Research aim	**Study population**	**Study design & metods**
1	To understand men's perception of being invited to OPT including how clearly the advantages and disadvantages of the PSA test are communicated, and whether educational level affects perception and decision-making	In Oct and Nov 2020, 600 men 50-year-old men in the Västra Götaland region and Region Skåne 1,000 men (aged 50, 56, or 62 years) invited to Region Skåne **(n = 534)**	Population-based Cross-sectional study Questionnaire
2	To explore the aspects that guide men's decision to accept or decline PSA testing following an invitation to OPT, particularly the role of the information given in the invitation letter	In Nov 2020, the OPT office sent out a request to participate in an interview to men in the Västra Götaland region and the Region Skåne study to 600 men **(n = 18)**	Semi-structured Interviews
3	To evaluate potential psychological harm of participating in the diagnostic process for men with a raised PSA in the Göteborg 2 screening trial	Data collection: Oct 2019-Apr 2024.Included men with a first cot off PSA value in the G2- trial who were eligible for MRI and completed at least one follow-up questionnaire **(n = 692)**	Population-based randomises screening prospective o study with sequential measurement points in the diagnostic process (baseline, before MRI, before biopsy, and before pathological results) Questionnaires
4	To study whether attendance at re-invitation to prostate cancer screening was related to MRI findings and biopsy type at the initial screening round as well as individual factors.	Data collection: Oct 2015–Jan 2015: Participated in the first screening round completed the baseline questionnaire, had a PSA value level ≥ 1.2 ng/ml, and were re-invited for a second screening round in G2- trail **(n = 4146)**	Population-based, randomised screening Retrospective cohort study Questionnaires

Table 2. Methodological aspects of the four studies.

Data analysis	**Strengths & weaknesses**
Quantitative method. Descriptive statistics Chi-square test for comparing groups	Strengths: Population-based design and a context similar to a formal screening programme Weaknesses: Low response rate and limited generalisability to other cultural or healthcare settings
Qualitative content analysis with an inductive approach at the manifest level	Strengths: Population-based recruitment ensuring representativeness. Similar response rates in participants and non-participants Weaknesses: Email-based recruitment may have limited participation; sample may not represent all cultural or educational groups; OPT was not nationally implemented; findings may only generalise to countries with similar healthcare systems and cultural contexts
Quantitative method. The Sign test (one-tailed) was used to assess changes from baseline; other outcomes are reported descriptively Proportions of participants reporting symptoms on the scale were calculated with 95 % confidence intervals	Strengths: Use of multiple instruments (HADS, IES, and study-specific questions) capturing various psychological aspects within a population-based screening study Weaknesses: Uneven response rates, small number of respondents before biopsy, non-responders not recorded
Univariable and multivariable regression—estimate relative risks (RR) with 95 % confidence intervals (CI) for factors potentially associated with non-attendance. To evaluate the contribution of domains of related factors, block-wise modelling with likelihood ratio tests and Nagelkerke´s R2 were used	Strengths: Conducted within a population-based, randomised screening trial Weaknesses: Limited age range (52–64 years); baseline questionnaire data may not reflect circumstances at the second screening round, potentially affecting associations with re-attendance

4 RESULTS

This section summarises the main findings of the four papers included in the thesis. The complete results are presented in detail in each respective paper, which are provided in full at the end of the thesis.

4.1 STUDY 1

Of the 1,600 men who received the questionnaire, 534 responded, corresponding to a response rate of 34 %. The vast majority (97 %) expressed a positive view of being actively invited to participate in organised prostate cancer testing (OPT) and appreciated having the opportunity to decide for themselves whether to undergo PSA testing or not. Furthermore, 84 % reported that the information provided in the invitation letter was sufficient to make an informed decision regarding participation.

The majority of respondents perceived the information about the potential benefits of participating in organised prostate cancer testing as clearly presented; 68 % found the description to be very clear and 27 % fairly clear, while only a few considered it unclear. In contrast, the perceived clarity of the information about possible disadvantages was slightly lower, with 52 % rating it as very clear and 36 % as fairly clear. Overall, most men (82 %) indicated that they would accept the invitation to participate in organised testing if offered again. Among men who had not previously undergone PSA testing, a higher proportion of those with a non-academic educational background (53 %) compared with those with an academic education (41 %) perceived the description of potential disadvantages as very clear ($p = 0.03$). A similar, though not statistically significant, pattern was observed regarding the clarity of the information on potential benefits (68 % vs. 58 %, $p = 0.09$).

The questionnaire consisted of fixed-response items, several men provided additional handwritten comments in the margins or on the back of the form. These spontaneous remarks offered valuable insights into participants' experiences and perceptions of the screening process that were not captured by the predefined questions. Some of the spontaneous comments are listed below.

'The staff at the health centre didn't know I could take the test there, and they couldn't answer my questions'

‘I wanted to do the test, but I’m sick—it’s hard to get to the hospital’

‘Can I donate blood if my level (PSA) is high?’

‘I’m on strong medication, so maybe that affects the result’

Question	Sample	Category 1	Proportion 1	Category 2	Proportion 2	p-value
The disadvantages were described clearly enough to allow for making a decision	No previous PSA (n = 321)	Academic education	51/124 (41 %)	Non-academic education	105/197 (53 %)	0,03
	Previous PSA (n = 213)	Academic education	42/82 (51 %)	Non-academic education	82/131 (63 %)	0,10
The proportion responding 'Very well' was compared to all other responses	All men (n = 534)	No previous PSA	156/321 (49 %)	Previous PSA	124/213 (58 %)	0,03
	All men (n = 534)	Born in Sweden	228/444 (54 %)	Not born in Sweden	42/90 (47 %)	0,23
Advantages clear enough to make a decision	No previous PSA (n = 321)	Academic education	72/124 (58 %)	Non-academic education	133/197 (68 %)	0,09
The proportion responding 'Very well' was compared to all other responses	Previous PSA (n = 213)	Academic education	58/82 (71 %)	Intermediate or short education	98/131 (75 %)	0,51
	All men (n = 534)	No previous PSA	205/321 (64 %)	Previous PSA	156/213 (73 %)	0,02
	All men (n = 534)	Born in Sweden	303/444 (68 %)	Not born in Sweden	58/90 (64 %)	0.48
The invitation letter contained sufficient information for making a decision	All men (n = 534)	Academic education	168/206 (82 %)	Non-academic education	280/328 (86 %)	0,21
Sought further information	No previous PSA (n = 321)	Academic education	53/124 (43 %)	Non-academic education	74/197 (38 %)	0,41
Opted for OPT	No previous PSA (n = 321)	Academic education	98/124 (79 %)	Intermediate or short education	164/197 (83 %)	0,34

Table 3. Factors affecting the perception of the clarity of the information in invitation letter.

4.2 STUDY 2

Figure 7 illustrates how the four categories identified through qualitative content analysis interact in men's decision-making about PSA screening. These categories emerged from interviews with 18 men who participated in the study.

1. Expectations That Authorities Should Take Responsibility
Many men expressed a strong trust in the healthcare system and believed that authorities should provide clear recommendations rather than leaving the decision entirely to the individual. The organised nature of the screening programme was perceived as a sign that testing was medically justified and socially endorsed. Previous experiences from healthcare and the feeling of being 'personally invited' strengthened men's willingness to participate and created a sense of security and legitimacy in the decision-making process.

2. Fear: Both a Driving Force and a Barrier
Fear played a dual role in men's reasoning. For some, anxiety about developing undetected cancer and missing a potential cure motivated participation. For others, fear of diagnostic procedures, adverse treatment effects, or potential loss of sexual function acted as deterrents. The emotional balance between fear of illness and fear of unnecessary medicalisation was central to how men evaluated their choices.

3. Intuition and Social Support
Men described how personal intuition, and social context influenced their decisions. Those with partners often discussed the decision together and valued emotional support, while others relied on peers or colleagues. Some men followed their 'gut feeling', deciding quickly without extensive reflection. Som men described a pragmatic stepwise reasoning—focusing first on taking the test and postponing worries about potential consequences.

4. Accessing Information and Evaluating Personal Risk
Participants highlighted the challenge of interpreting complex information about screening benefits and harms. While most found it natural to assume that early detection is beneficial, many struggled to grasp concepts such as overdiagnosis or to translate population-level statistics into personal relevance. Some desired more quantitative, individualised risk information, while others expressed confusion over conflicting messages from health

authorities. Men who felt confident in their understanding tended to be more decisive in their choices, regardless of whether they opted for testing or not.

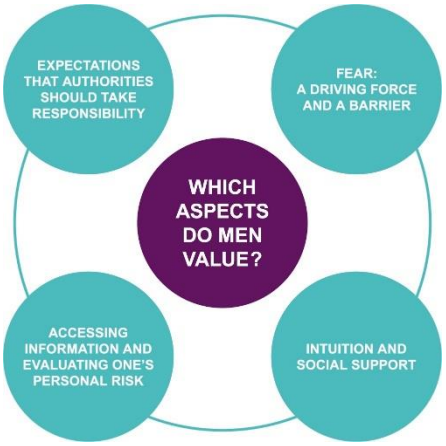


Figure 7. The four categories identified in the analysis of men's decision-making process.

4.3 STUDY 3

A total of 692 men completed at least one follow-up questionnaire during the study period, of whom 504 also responded to the baseline survey. The proportion of men reporting moderate to severe anxiety symptoms The Hospital Anxiety (HADS-A ≥ 11) was 3.8 % at baseline (19/495; 95 % CI: 2.3–5.9), 4.7 % before MRI (13/277; 95 % CI: 2.5–7.9), 12 % before prostate biopsy (8/67; 95 % CI: 5.3–22), and 4.8 % prior to receiving biopsy results (22/463; 95 % CI: 3.0–7.1).

Paired analyses demonstrated a significant increase in anxiety levels from baseline to both the pre-MRI phase ($p < 0.001$, $n = 151$) and the waiting period before receiving biopsy results ($p = 0.031$, $n = 362$), while no statistically significant change was observed prior to biopsy ($p = 0.092$, $n = 39$).

In the study-specific questions, 17 % (46/277; 95 % CI: 12.4–21.6) of men reported considerable worry about their elevated PSA level before the MRI examination. Corresponding levels of worry were 9.2 % before biopsy (6/65; 95 % CI: 3.5–19) and increased to 26.1 % prior to receiving biopsy results (120/460; 95 % CI: 22.1–30.4). Up to 4.2 % (19/458; 95 % CI: 2.5–6.4) indicated that their daily life was substantially affected during the waiting period for biopsy results.

Intrusive thoughts were also most prevalent before MRI, when 14.1 % (39/277; 95 % CI: 10.2–18.7) experienced daytime intrusive thoughts nearly every day, and 2.5 % (7/277; 95 % CI: 0.1–5.1) reported similar nighttime disturbances.

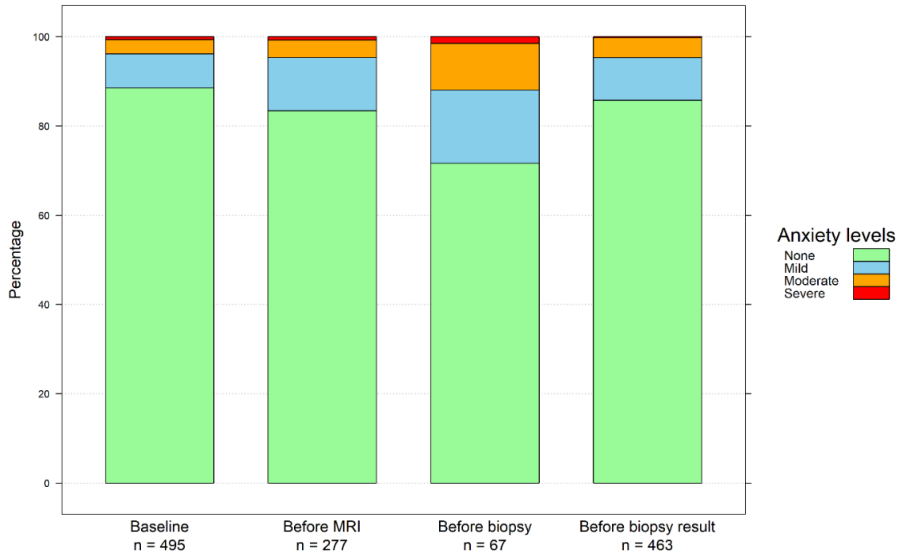


Figure 8. Distribution of anxiety levels (HADS-A) throughout the diagnostic process, based on all evaluable questionnaires.

4.4 STUDY 4

The study population comprised 4,146 men who had completed the initial screening round and were subsequently invited to participate in the second round. Of these, 3,079 men (74.3 %; 95 % CI: 72.5–75.3) attended again. Among participants whose PSA levels were below the cut-off at the first screening, 72.2 % (2,243/3,104; 95 % CI: 70.7–73.8) returned for the second round. The corresponding proportion among men with PSA levels above the cut-off was 80.2 % (836/1,042; 95 % CI: 77.8–82.7).

Among men with elevated PSA and a prostate biopsy during the first screening, re-attendance was 82.9 % in those who had 1–4 biopsy cores compared with 77.1 % among those with ≥ 5 cores—a difference of 5.8 percentage points (95 % CI: –3.6 to 14.7).

Univariable analyses identified characteristics associated with lower likelihood of re-attendance. These included younger age, having a PSA below the cut-off in the first round, absence of a partner, lower income, non-Swedish first language, erectile dysfunction, lack of sexual activity, low physical activity, and infrequent consumption of a healthy diet. Re-invitations issued during February to March and during the COVID-19 pandemic were also linked to reduced participation. In contrast, family history of prostate cancer, lower urinary tract symptoms (LUTS), and comorbidity were not statistically associated with re-attendance. The overall explanatory power of the model was low (Nagelkerke's $R^2 = 0.075$), indicating that the included variables explained only a small proportion of the variation in re-attendance.

Outcome of 1st screening round	**No biopsy**	**1–4 cores (median = 4)**	**5–12 cores (median = 12)**	**> 12 cores (median = 15)**	**Total**
PSA above cut-off, no MRI Ψ	9/16 = 56% (95% CI 32–81)		9/13 = 69% (95% CI 42–87)		18/29 = 63% (95% CI 44–80)
PSA above cut-off, MRI negative	585/722 = 81% (95% CI 78–84)		93/119 = 78% (95% CI 71–86)	2/3 = 67% (95% CI 13–100)	680/843 = 81% (95% CI 78–84)
PSA above cut-off, MRI positive	2/2 = 100% (95% CI 16–100)	102/123 = 83% (95% CI 76–90)	6/9 = 67% (95% CI 34–90)	28/35 = 80% (95% CI 64–90)	138/169 = 82% (95% CI 76–87)
Total (1st/2nd round)	2,839/3,844 = 74% (95% CI 72–75)	102/123 = 83% (95% CI 76–90)	108/141 = 77% (95% CI 69–83)	30/38 = 79% (95% CI 63–90)	836/1,042 = 80,2% (95% CI 77,8–82,7)

Ψ Include men who had a contraindication for MRI such as pacemaker and claustrophobia (men who refused MRI despite no medical contraindication were excluded from the analysis).

Table 4. Re-attendance rates depending on the diagnostic investigations in the first screening round. The rates are presented as number of attendees per subgroup, and as percentages with 95 % confidence intervals (CI).

5 DISCUSSIONS

This thesis aimed to deepen the understanding of men's decision-making processes and psychological consequences in relation to prostate cancer screening. By combining quantitative and qualitative methods, as described above in methodological considerations for studies 1–4, the results highlighted how individual and contextual factors—that is, the circumstances and conditions that surround the individual and influence decisions, experiences and behaviours—interact in the decision-making process.

The four sub-studies in this thesis addressed research questions that have not previously been investigated in a contemporary screening context. We evaluated the information in the invitation letter within the Swedish OPT programme, the psychological consequences of undergoing the diagnostic process in modern prostate cancer screening, as well as factors associated with refraining from participation after re-invitation in a screening programme in which MRI is part of the screening investigations.

Communicating medical information is a central yet complex aspect of clinical care, particularly in contexts where individuals are expected to make informed decisions regarding prevention, diagnosis, or treatment. Communication involves not only the transmission of facts, but also the process in which the recipient’s understanding, experiences, and values actively influence how the information is interpreted and translated into action.

In the context of prostate cancer screening, where decisions concern risks rather than existing disease, the communication of uncertainties and probabilities regarding the likelihood of developing illness and experiencing adverse outcomes is challenging. In the Swedish OPT programmes and The Göteborg-2 trial, the invited individuals must evaluate neutral information about both benefits and potential harms.

Findings from **Study 1** show that men who were invited to OPT perceived the testing programme positively and felt they had received sufficient information to make a personal decision. As expected, the benefits were easier to understand than the harms. Among men who had not previously undergone a PSA test—and perhaps had not previously considered the issue—differences emerged in how clearly the disadvantages were perceived. Surprisingly, men with academic education were less likely to perceive this

information as clear, compared with men without academic education. Men's level of education has also been associated with how they estimate their lifetime risk of developing prostate cancer (133). Men with lower levels of education rated their perceived risk as higher—both those who participated in screening and those who declined.

Weighing information about benefits and potential harms toward an informed decision relies on the individual not only understanding the purpose of the test, but also the possible consequences, such as having a prostate biopsy, receiving a cancer diagnosis and treatment, as well as potential side effects, including urinary incontinence and erectile dysfunction. Experiences from personalised breast cancer screening show that risk communication is complex. In a systematic review of studies involving both women and healthcare professionals, the credibility and comprehensibility of risk assessment were frequently questioned, especially when based on hereditary factors and personal lifestyle habits (90). Limited knowledge about individualised screening strategies created uncertainty, and some expressed distrust in the healthcare system´s ability to manage genetic information.

Screening programmes are based on evidence-based guidelines and medical expertise, which in themselves may create an imbalance between healthcare providers and the invited individuals faced with the decision whether to participate (38). Lay people's understanding of medical concepts such as overdiagnosis, test reliability, and the risk of false-positive results may be limited. Consequently, decisions are often shaped by personal experiences, values, and perceived relevance rather than by formal information (48, 49) (39, 134)

Findings from **Study 2** show that men's decisions were not dominantly based on the written information provided in the invitation letter but that this information was interpreted through individual frames of reference and personal experience. This unravels a challenge for the OPT programmes—to bridge the gap between formal autonomy and actual understanding: even when a decision is formally considered informed, it may not be grounded in a full comprehension of the medical information and therefore cannot be regarded as fully autonomous. Bridging this gap is crucial for improving the degree of truly informed decision-making in current and future screening programmes; clear communication and tailored decision support may contribute to well-informed decisions (39)(38).

The current decision support in the OPT programmes is neutral and evidence-based information along with a link to web-based resources. To improve the decision-making process, interactive decision aids could be developed. Unlike static information letters, interactive tools enable two-way communication, allowing individuals to actively engage through questions, reflections, and personalised feedback (50). Implementing such tools could be seen as part of the ongoing quality improvement efforts in many ongoing screening programmes.

Men in **Study 2** described how the content of the invitation letter influenced how they perceived the advantages and disadvantages of screening. Many perceived the information as difficult to interpret, especially concerning the risk of over diagnosing prostate cancer that is clinically indolent or does not require intervention.Uncertainties surrounding overdiagnosis led some to refrain from testing, while others referred to the widely accepted belief that early detection of cancer is always a good thing (40). Men who were comfortable with interpreting numerical data expressed a desire for quantitative information to better assess their own risk.

Men's decisions about PSA testing were also shaped by how they interpreted the organised invitation as such. The invitation was often perceived as a signal of recommendation from healthcare providers. Trust in medical expertise led men to preferring guidance over independent decision-making based solely on weighing benefits and harm; men tended to interpret the invitation as a recommendation, which in turn increased their likelihood of testing (44, 135).

Fear of clinical examinations and concern that undetected prostate cancer could progress to an incurable stage also influenced men's decisions. Physical discomfort—particularly related to rectal examination—and reluctance to expose the body led some to abstain. At the same time, fear of developing cancer served as a motivator for participation, as testing was perceived as a way to regain a sense of security. Similar patterns have been observed in colorectal cancer screening, where both cancer-related anxiety and anticipated discomfort affect participation (136).

Study 2 also showed that men who were uncertain about PSA testing actively sought support from trusted individuals, most commonly their partners. Previous research has shown that emotional support within relationships can be decisive for health-related decision-making (42). Our findings indicate

that partnerships provide a natural setting for discussion, while single men turned to friends or colleagues. Men expressed a preference for experience-based dialogue and described a stepwise decision-making process in which different aspects were weighed gradually. Men who felt they understood the information about PSA testing expressed confidence in their decisions. This may reflect a confirmation bias, where individuals tend to disregard information that contradicts their pre-existing views. Some men relied on intuition and held firm beliefs about what felt right for them. Similar patterns have been observed in colorectal cancer screening, where previous decisions and emotional factors have been shown to influence participation (46).

The occurrence of worry in connection with screening, even in the absence of abnormal findings, suggests that the psychological impact is not solely related to medical outcomes. Instead, anxiety may be associated with the screening process itself—for instance, the waiting period for results, thoughts about cancer as a disease, or the perception of being 'at risk' (107). Such reactions can be understood as a form of anticipatory anxiety, in which the individual responds to the possibility of an adverse outcome rather than to an actual diagnosis (108). This response may also reflect previous illness experiences or a general vulnerability to health-related stress, meaning that screening can act as a psychological stressor in itself.

In **Study 3,** only a small proportion of men with a raised PSA value reported moderate to severe levels of anxiety, event-related stress, or intrusive thoughts during the diagnostic process. Most participants described symptoms consistent with low to mild anxiety, which may be interpreted as an adaptive psychological response to a potentially stressful situation. These results indicate that worry in most cases represents a normal emotional adjustment rather than clinically significant psychological distress. This is consistent with previous systematic reviews and empirical studies showing that the psychological strain associated with screening is usually transient, with anxiety levels decreasing after a non-alarming result or over time (107).The fact that most men in **Study 3** reported only mild levels of anxiety suggests that they did not perceive their worry as overwhelming or disruptive to daily life, which is important from a clinical perspective. In breast cancer screening, for example, anxiety tends to peak while waiting for results but declines within a few months after a benign outcome (137). Nevertheless, even short-term emotional distress can have longer-term consequences, such as reduced participation in future screening rounds (138). One approach to mitigating such negative psychological effects is the provision of

personalised counselling—either face-to-face or by telephone—which has been shown to reduce anxiety following false-positive results (139).

An unexpected finding in **Study 3** was that anxiety symptoms increased early in the diagnostic process, before any invasive procedures were performed. This may reflect a redefinition of self-perception—from a perceived binary distinction between being healthy or ill—where the threat of a possible cancer diagnosis becomes internalised. Previous research has shown that men often view PSA testing as a means of confirming their health status, regaining control over their bodies, and achieving peace of mind (5). However, receiving a notice of elevated PSA levels can trigger uncertainty, primarily due to confusion about what the result implies for one's current health and future cancer risk (140). Experiences of anxiety and stress in this context thus appear to be linked more closely to individual interpretation of the situation than to objective medical findings (141, 142).

From a clinical perspective, it is essential to identify the few men who experience severe psychological distress during the diagnostic process. Such reactions may emerge early—before definitive test results are known—and may not correspond to the severity of the diagnostic findings but rather to the individual's perception of risk, uncertainty, and threat of illness. These observations underscore the importance of evaluating screening programmes not only in terms of their medical benefit (36) but also regarding their psychological implications and the need for tailored communication and support strategies.

The effectiveness of a cancer screening programme depends on a combination of medical and behavioural factors. First, the diagnostic methods' sensitivity is crucial—that is, their ability to correctly identify individuals with treatable conditions (29-31). Second, participants' acceptance of the screening algorithm plays a key role. If the method is perceived as too uncomfortable or physically or psychologically demanding, the willingness to participate may decrease, regardless of its medical value. The participation rate therefore serves as a direct indicator of the programme's reach and public health impact (34). A screening programme with low participation rates, both initially and upon re-invitation, risks missing large segments of the target population, thereby undermining its preventive potential.

A key finding from **Study 4** was that a systematic prostate biopsy, although often perceived as unpleasant and sometimes painful, did not appear to discourage men from future participation. This is particularly relevant in light of previous research from The Göteborg-2 trial showed that many men found the biopsy procedure bothersome, and that systematic biopsies were generally perceived as more uncomfortable than targeted ones. Despite these experiences, the same study reported that men were willing to undergo additional biopsies if needed, regardless of which type they had previously undergone (94).

It is also reassuring that men with PSA levels above the threshold, who subsequently underwent further diagnostic examinations, had a re-attendance rate as high as 80 %. Men with elevated PSA in the first screening round showed slightly higher re-attendance rates in the second round than those with values below the threshold. This pattern suggests that the experience of an elevated result may enhance motivation for continued health monitoring, likely due to increased awareness of perceived cancer risk. The higher re-attendance among risk groups strengthens the overall effectiveness of the screening programme and may, over time, contribute to improved population-level outcomes. Similar tendencies have been observed in breast cancer screening, where previous studies have shown both reduced (143) and increased (144) likelihood of re-attendance following false-positive findings. The discrepancy may stem from methodological differences, as one study examined actual re-attendance while the other assessed intention, which does not necessarily translate into behaviour.

Previous studies indicate that younger men tend to refrain from prostate cancer screening, which may be linked to a low perceived risk and the belief that screening is less relevant at a younger age (5, 72, 145). That prostate cancer has traditionally been associated with ‘an older man’s disease’ and younger men often lack personal or social references to the disease—such as peers affected by the condition—may contribute to lower engagement. This is problematic, as initiating screening earlier, particularly before the age of 60 years, is associated with the greatest potential benefit (146).

Furthermore**, Study 4** identified several individual-level factors associated with non-re-attendance. Socioeconomic variables such as education level, income, language proficiency, and social support were found to significantly influence the likelihood of non-re-attending. The absence of a partner was associated with lower participation, consistent with a study showing that

emotional support from a partner can reduce uncertainty and increase motivation to undergo screening (42). Despite a higher objective risk (147-149), men with a family history of prostate cancer did not exhibit higher re-attendance rates, possibly because these individuals more often undergo testing outside of organised screening programmes. Men without Swedish as their first language were less likely to re-attend, consistent with previous findings from breast and cervical cancer screening (150, 151). Since these men participated in the initial screening round, the results suggest that factors beyond language barriers influence re-attendance. A Nordic study found that translated invitations did not improve participation in breast cancer screening (152), indicating that cultural aspects, trust in healthcare, and health literacy may play a more substantial role than language. A systematic review supports this interpretation, emphasising understanding of the screening purpose and recommendations from healthcare professionals as decisive factors for participation (153). However, language barriers may amplify other obstacles, such as fear of diagnosis and difficulties navigating the healthcare system.

Low income and lack of physical activity were associated with lower re-attendance, consistent with findings from cervical cancer screening, where behaviours such as smoking have been linked to lower participation (153). Social risk factors, including economic vulnerability and mental health problems, have also been strongly associated with reduced screening participation (154). Moreover, erectile dysfunction was linked to lower re-attendance, which may reflect underlying health-related vulnerabilities or reluctance to engage in further medical examinations.

Achieving equal participation rates in PSA testing across different socioeconomic groups is a challenge. That men actually ‘take the ticket’—that is, evaluate the information provided and actively decide whether to test their PSA level or abstain—is central. However, an active offer of testing is not sufficient to ensure equal participation. This was demonstrated in previous studies within the OPT programme, where men with higher education and income participated to a greater extent (73).

6 CONCLUSIONS

This thesis provides a comprehensive examination of organised prostate cancer screening in Sweden, exploring men's decision-making, psychological experiences, and participation patterns across four interrelated studies.

Overall, men expressed positive attitudes toward being offered the opportunity to make an informed, personal choice regarding PSA testing. While brief information on potential benefits and harms was generally considered sufficient, some men with higher educational levels perceived it as less clear, highlighting the importance of improving the contents and forms of information about the potential advantages and disadvantages of screening for prostate cancer at least to a subset of men at request.

Decision-making was influenced not only by the provided information but also by, personal factors such as social support, and individual experiences. This emphasises that men do not rely solely on invitation letters when evaluating screening participation, and that future research should further investigate how cultural, social, and personal factors shape decision-making and how it could be improved.

The psychological consequences of the diagnostic process in prostate cancer screening were generally mild. Only a small proportion of participants reported moderate to severe anxiety, suggesting that modern screening programmes, including PSA testing, MRI, and biopsy, are associated with a low risk of significant psychological harm. These findings support the acceptability of organised screening while identifying opportunities to provide targeted support to men who may be at higher risk of adverse psychological effects.

Re-attendance in subsequent screening rounds was high, particularly among men who had false positive screening outcome in the first round. Men with elevated PSA were more likely to return, indicating that the screening procedures were acceptable to the target population. Socioeconomic factors, language, lifestyle, and urological symptoms were associated with re-attendance, but only partially explained the variation, suggesting that other individual or contextual factors also influence continued participation.

Taken together, the four studies show that organised prostate cancer screening is widely acceptable, psychologically safe for most men, and has

high re-attendance rates. The findings highlight the need for clearer, tailored information and recommendations from health authorities but also considerations of personal and social factors in screening programmes. They may provide valuable insights for those who design and implement population-based screening and help reducing barriers and optimising informed decision-making.

7 FUTURE PERSPECTIVES

The research presented in this thesis shows a need for better information to men about the potential advantages and, in particular, disadvantages of screening for prostate cancer. A research project at Lund University, planned for start in 2026 in collaboration with our research group, has the aim to improve this information. A person-centred decision aid will be developed, validated, and tested in the relevant target group of men through a randomised design.

The project will employ a multiphase methodology, combining qualitative and quantitative approaches, which is essential for developing, validating, and ultimately implementing a decision aid for prostate cancer screening in the Swedish context. It builds on men's own experiences and perspectives, aiming to create a person-cantered and culturally adapted decision aid that can enhance understanding, reduce uncertainty, and strengthen shared decision-making. Through a randomised controlled trial, we will evaluate the impact of the decision aid on men's knowledge, attitudes, and the extent to which decisions are autonomous and informed. The project will involve dedicated contributions from postdoctoral researchers and provides an opportunity to further advance research expertise in the field of screening.

The findings in Study 1V showed that men largely accept the diagnostic pathway. Although only small variations were observed between groups based on socioeconomic and language-related factors, the findings suggest that other, yet unidentified factors may influence men's decisions to return for screening. These should be explored in future research.

A planned doctoral project at the University of Gothenburg will specifically address re-attendance in OPT, with the aim of generating new knowledge to strengthen both the implementation and the overall effectiveness of OPT and a future national screening programme.

From clinical experience to research perspective

The results presented in **Study 3** show that only a small proportion of men who undergo diagnostic examinations in a modern screening programme experience moderate to severe anxiety. A national screening programme would, however, encompass a huge number of men, so identifying those individuals who are at greatest risk of clinically significant psychological adverse effects remains important. Future research therefore needs to

examine how support functions can be designed and integrated into the screening process in order to reach the men most in need.

In parallel with the PhD studies, clinical encounters with men in The Göteborg-2 trial have deepened my understanding of the psychological dimensions of screening. In the initial screening round, 521 men completed the entire diagnostic process with a benign biopsy result (29). Conversations with them made it clear to me that the men's knowledge about what a PSA test actually measures and how its results should be interpreted was often poor. Trust in radiological findings was high, and an abnormal MRI result could be perceived as contradictory when subsequent biopsies did not confirm cancer. This experience illustrates how uncertainty may persist even after a negative work-up, and how an elevated PSA value can lead to a lingering perception of 'not being completely healthy.' For future implementation of a screening programme, it is therefore essential to investigate how men's understanding and interpretation of diagnostic findings—such as elevated PSA levels, abnormal MRI results, and negative biopsies—affect their sense of security, worry, and trust in the prostate cancer screening process.

The Need for Research Grounded in Men's Perspectives

Historically, established screening programmes have primarily targeted female populations: mammography for breast cancer and cytology for cervical cancer. These programmes have been in place in Sweden for several decades and have shaped both the medical infrastructure and the psychosocial understanding of screening. As a result, much of the previous research on the psychological aspects of screening, communication, and support interventions is based on women's experiences (155). The possibility of a future national prostate cancer screening programme highlights the need for research that considers sex- and gender-specific differences in how screening is perceived, understood, and managed.

Men's historically limited exposure to organised screening programmes may influence their expectations, level of knowledge, and need for support. Participation in Swedish OPT has so far been moderate (77, 81, 83). One reason may be that there is no recommendation for screening from the healthcare system. It's unclear how men will respond to a national prostate cancer screening programme. In the recently introduced Swedish screening programme for colorectal cancer, men are less likely to participate than women (156). A key area for future research is therefore to deepen the

understanding of behaviours and barriers that specifically influence men's decisions to participate in screening.

Masculinity norms—such as ideals of independence, strength, and resistance to seeking help—may significantly impact the willingness to accept screening. At the same time, research must identify which strategies and interventions can effectively increase acceptance among men who are traditionally more reluctant to engage in preventive care (74). It is therefore essential that future research not simply transfers models from screening programmes for women but instead develop a sex-sensitive framework tailored to men's specific experiences and needs. This knowledge is crucial to ensure that future prostate cancer screening programmes not only achieve high participation rates but also promote health equity.

8 USE OF GENERATIVE AI

This section describes how generative artificial intelligence (AI) was used as a support tool during the work on this thesis.

In the final stages of the writing process, the language model ChatGPT was employed to improve grammar, spelling, and language flow. The AI tool was also used to a limited extent for translation between Swedish and English. All text was subsequently reviewed, edited, and approved manually by the author to ensure scientific accuracy and linguistic appropriateness.

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