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Education

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

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Abstract

Background: There is no national screening programme for prostate cancer in Sweden. Instead, population-based organised prostate cancer testing (OPT) projects are introduced to make information and testing more equal and effective.

Objective: To evaluate men's perception of being invited to OPT and of the information in the invitation letter, and whether their perception is influenced by educational level.

Design, setting, and participants: A questionnaire was sent out to men invited to OPT in 2020: 600 50-yr-old men in Region Västra Götaland and 1000 50-, 56-, and 62-yr-old men in Region Skåne.

Outcome measurements and statistical analysis: Responses were evaluated on a Likert scale. The chi-square test was used to compare proportions.

Results and limitations: A total of 534 men (34%) responded. Almost all considered the OPT concept as very good (84%) or good (13%). Among men not previously undergone a prostate-specific antigen (PSA) test, a larger proportion with nonacademic (53%) than with academic education (41%) responded that the text about disadvantages was very clear ($p = 0.03$). A similar difference was observed for the text about advantages (68% vs 58%, $p = 0.09$). There was no association between education and searching for more information elsewhere. The low response rate is the main limitation.

Conclusions: Almost all responding men evaluating the invitation letter for OPT were positive about making a personal decision regarding whether or not to have a PSA test. Most were content with the brief information. Men with academic education were somewhat less likely to find the information very clear. This shows a need for further research about how best to describe the advantages and disadvantages of prostate cancer testing.

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Patient summary: Almost all men who responded to a questionnaire to evaluate the invitation letter for organised prostate cancer testing were positive about the opportunity to make a personal decision regarding whether or not to have a prostate-specific antigen test.

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1. Introduction

Screening for prostate cancer has been debated and studied for many years. The main argument against population-based screening is overdiagnosis. In recent years, complementary diagnostic tests have, however, been shown to reduce overdiagnosis [1,2]. Some of these are currently being evaluated in randomised screening trials [3–5].

In 2018, the Swedish Ministry of Social Affairs commissioned the Confederation of Regional Cancer Centres to develop standardised and more efficient testing for prostate cancer that also contributes to new knowledge of relevance for a future national screening programme. This resulted in population-based regional projects with organised prostate cancer testing (OPT) [6]. The Swedish OPT programmes agree well with European Union's recent recommendation to evaluate the feasibility and effectiveness of organised screening programmes for prostate cancer [7].

The first OPT projects started in 2020 in two of Sweden's larger regions. By the end of 2023, most Swedish regions will have an on-going OPT project. The OPT projects are not research but developmental projects run by the public, tax-funded, health care system. A central part of OPT is offering brief, neutral, easy-to-understand information to all eligible men about the possible advantages and disadvantages of being tested for early detection of prostate cancer [6].

The aims of this study were to evaluate how the invited men consider being actively contacted and thereby compelled to decide whether to be tested for prostate cancer, their perception of the information in the invitation letter, and whether they searched for more information elsewhere. We also wanted to investigate how educational level, country of birth, and previous experience of prostate-specific antigen (PSA) testing affected the men's perception of the description of the advantages and disadvantages of testing.

2. Patients and methods

2.1. Study setting: regional OPT projects

The two first Swedish OPT projects started in 2020 in two of Sweden's 21 regions: Region Västra Götaland and Region Skåne [6]. Together these regions have 3 million inhabitants and include urban, semiurban, and rural areas. In Region Skåne, a pilot project included 1000 randomly selected men aged 50, 56, and 62 yr. The Region Västra Götaland project started with inviting all 12 000 men born in 1970 (ie, aged 50 yr). The information provided in the invitation letter included a short text with a neutral description of the advantages and disadvantages of testing for the early detection of prostate cancer (12 sentences; [Supplementary material](#)) and a description of the diagnostic investigations for men with raised PSA (magnetic resonance imaging and transrectal ultrasound with

a biopsy), in total 570 words. The text about the advantages and disadvantages was identical in the two regions. It was written by the National Working Group for Organised Prostate Cancer Testing, and had been reviewed and approved by several professional organisations and the national prostate cancer patients' organisation. The text was then tested on lay people of various backgrounds, which led to a few minor changes before it was finalised. The invitation letter also included a link to a public health care website with more detailed information about OPT and prostate cancer.

In both regions, the men could have a PSA test free of charge within 4 wk after receiving the invitation letter, either at a primary health care centre or at any of the public hospitals in the region. Of the invited men, 39% in Region Västra Götaland and 42% in Region Skåne chose to have a PSA test within the OPT project [6].

2.2. Study participants and ethical approval

In October and November 2020, a questionnaire and a copy of the OPT invitation letter were sent by mail 6 wk after the OPT invitation to 600 men in Region Västra Götaland, randomly selected from the 12 000 invited 50-yr-old men, and to all 1000 men (aged 50, 56, or 62 yr) in Region Skåne' OPT project (Fig. 1). All 1000 men in Region Skåne's pilot project were included. The study was approved by the Ethics Review Authority (2020-00699).

2.3. Questionnaires

The questionnaire consisted of six background questions (Table 1), six questions about the information on the advantages and disadvantages of testing (Table 2), one about whether they decided to participate in OPT or not, and seven evaluating organisational aspects (not included in the present analysis). The response options were value statements on a Likert scale (response options are shown in Table 2). The process of developing the questionnaire included face-to-face validation by a study nurse (L.S.) with 22 participants in the Goteborg Prostate Cancer Screening Trial 2 [3]. The men responded anonymously. The questionnaire was returned in a prestamped, addressed envelope.

2.4. Statistical analysis

The responses to the questions are reported with descriptive statistics. To avoid issues with multiple testing, a strict hypothesis testing hierarchy was followed when analysing associations with possible explanatory variables such as educational level. As the disadvantages of PSA testing may be more difficult to understand than the advantages ("A simple blood test may reduce your risk of dying from cancer"), we decided first to test the hypothesis that education level was associated with the perception of the information about disadvantages. We chose to primarily analyse the responses of men who had not previously had a PSA test, because they had probably not earlier taken a personal stand on prostate cancer testing. Men who did not know whether they had previously been PSA tested were grouped with those who responded that they had not been tested previously.

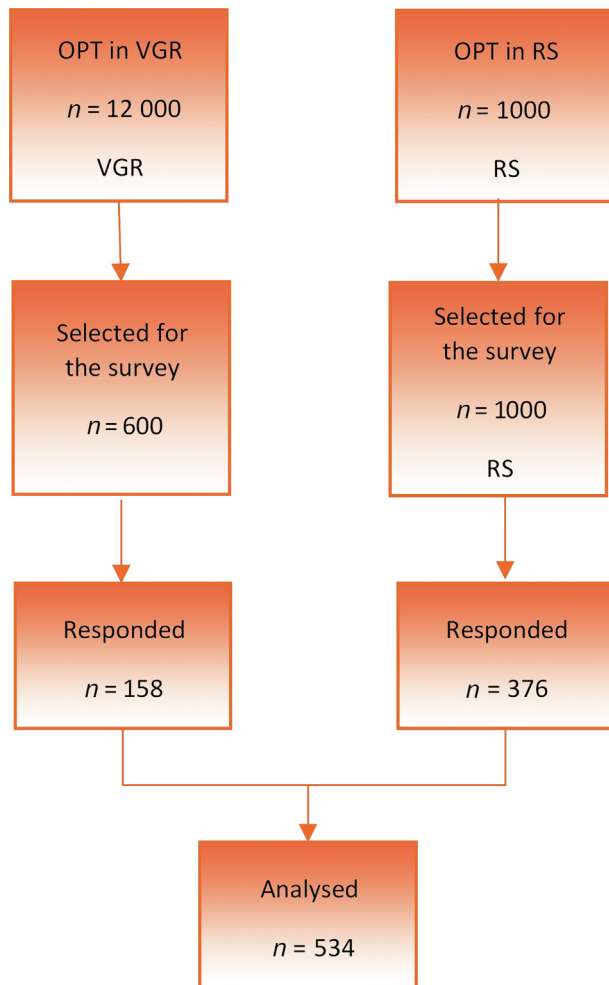


Fig. 1 – Flow chart of participants and data collection. OPT = organised prostate cancer testing; RS = Region Skåne; VGR = Västra Götaland region.

Table 1 – Sociodemographic baseline characteristics of the 534 survey responders

	Number	%
Born in Sweden		
Yes	444	83
No	90	17
Education		
Primary school (9 yr)	76	14
Secondary school (3 yr)	252	47
High school/university	206	39
Age (yr)		
50	270	51
56	124	23
62	140	26
Family history of prostate cancer		
Yes	75	14
No	402	75
Unknown	57	11
Close friend with PC		
Yes	259	49
No	199	37
Unknown	76	14
Previous PSA testing		
Yes	213	40
No or don't know	321	60

PC = prostate cancer; PSA = prostate-specific antigen.

Table 2 – Questions and answers of a survey of 534 men who were offered population-based organised prostate cancer testing (OPT) in two Swedish regions

	All respondents (n = 534)	No previous PSA test (n = 321)	Previously PSA tested (n = 213)
Did you read the invitation letter with information about OPT?			
Yes, all of it	437 (82)	258 (80)	179 (84)
Yes, parts of it	83 (16)	52 (16)	31 (15)
No	14 (3)	11 (3)	3 (1)
What do you think about making a decision in this way to test your PSA for PC detection?			
Very good	448 (84)	260 (80)	188 (88)
Good	71 (13)	49 (15)	22 (10)
Fairly good	14 (3)	11 (3)	3 (1)
Not good	1 (0.2)	1 (0.3)	0
Was the information about the advantages of testing yourself clear enough for you to make a decision?			
Very clear	361 (68)	205 (64)	156 (73)
Fairly clear	143 (27)	92 (29)	51 (24)
Neither clear nor unclear	23 (4)	17 (5)	6 (3)
Fairly unclear	6 (1)	6 (2)	0
Very unclear	1 (0.2)	1 (0.3)	0
Was the information about the disadvantages of testing yourself clear enough for you to make a decision?			
Very clear	280 (52)	156 (49)	124 (58)
Fairly clear	192 (36)	118 (37)	74 (35)
Neither clear nor unclear	48 (9)	35 (11)	13 (6)
Fairly unclear	10 (2)	9 (3)	1 (0.5)
Very unclear	4 (0.7)	3 (0.9)	1 (0.5)
The letter said that you could read more about testing for PC on health care website. Did you read on this website?			
Yes, I read most of it	65 (12)	48 (15)	17 (8)
Yes, I read a little	79 (15)	60 (19)	19 (9)
No	390 (73)	213 (66)	177 (83)
Did you search for information about PC anywhere else than at a health care website?			
Yes	58 (11)	43 (13)	15 (7)
No	476 (89)	278 (86)	198 (93)
Did you receive enough information to make a decision?			
Yes, completely	448 (84)	257 (79)	193 (90)
Yes, partly	74 (14)	55 (17)	18 (8)
No	12 (2)	9 (3)	2 (0.9)

PC = prostate cancer; PSA = prostate-specific antigen.
Percentages are provided in brackets.

Throughout, response options were dichotomised. We chose to dichotomise the responses as “very clear” versus all others, because we believe it to be essential that men really understand the disadvantages before they decide to have a PSA test. The highest level of education was dichotomised as nonacademic (primary or secondary school) or academic (high school or university) education in all analyses.

Secondary analyses included other associations between educational level and perception of the clarity of the advantages and disadvantages, whether the men thought that they had received sufficient information to make a decision (responses categorised as “yes, completely” vs all other answers), and whether the previously tested men had searched additional information elsewhere. Further secondary analyses were of the associations between the perception of the descriptions of the advantages and disadvantages versus previous PSA testing, and between the perception of the descriptions of the advantages and disadvantages versus country of birth (born in Sweden: yes/no).

The IBM SPSS Statistics for Windows (2020) software was used for all statistical analyses. The chi-square test was used to compare proportions. As the secondary analyses were not independent of each other, no correction was made for multiple testing.

3. Results

Of the 1600 men who received the questionnaire, 534 (34%) responded. Sociodemographic characteristics of the respondents are presented in [Table 1](#).

3.1. Descriptive results

Almost all (97%) thought that it was very good (84%) or good (13%) to be actively invited to OPT and offered an opportunity to decide whether or not to have a PSA test for prostate cancer detection; only one man answered that this was not good.

The responses to the questions about the information in the invitation letter are shown in detail in [Table 2](#). Most men (81%) responded that they had read the invitation letter in its entirety. Almost all thought that the information letter, in its entirety (78%) or parts (21%) of it, was easy to understand. A similar proportion (84%) responded that they had received sufficient information in the invitation letter ([Supplementary material](#)) to be able to make a decision. One-third (33%) of the men read further on the OPT website or sought information elsewhere.

Most men considered that the advantages were described very clearly (68%) or fairly clearly (27%); only seven (1%) thought that these were unclear. A slightly lower proportion considered the description of the disadvantages to be very (52%) or fairly clear (36%). Most of the responding men (82%) claimed that they would accept the offer to participate in OPT.

3.2. Associations with level of education, previous PSA testing, and country of birth

Among men who had not previously been PSA tested, a greater proportion of those with nonacademic (53%) than those with academic education (41%) considered the text about the disadvantages very clear ($p = 0.03$). A similar,

but not statistically significant, difference was observed for the text about the advantages (68% vs 58%, $p = 0.09$). Similar associations were observed among men who were PSA tested previously ([Table 3](#)).

Men who were PSA tested previously were more likely to consider the description of the advantages (73% vs 64%, $p = 0.02$) and disadvantages (58% vs 49%, $p = 0.03$) very clear, compared with men who were not tested previously.

Among men who had not been PSA tested previously, a similar proportion with (43%) and without (38%) academic education answered that they read further on the OPT website or sought information elsewhere ($p = 0.4$).

There was no significant association between education and considering the information in the letter sufficient to make a decision, between education and opting for OPT among men not PSA tested previously, or between country of birth and the perception of the clarity of information ([Table 3](#)).

4. Discussion

This population-based study shows that almost all responding men appreciated being offered the possibility to make an informed, personal decision regarding whether or not to participate in organised testing for early detection of prostate cancer. Despite the brevity of the text about the advantages and disadvantages of testing (12 sentences; see the [Supplementary material](#)), most men thought that they had received sufficient information to make a decision. As expected, the information about the advantages was easier to understand than the information about the disadvantages. Interestingly, men with academic education were less likely to consider the information about the disadvantages very clear; this has as far as we know not been reported before.

Men born in another country were not more likely to perceive the information unclear than those who were born

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

Question	Sample	Category 1	Proportion 1	Category 2	Proportion 2	<i>p</i> value
The disadvantages were described clearly enough to allow for making a decision	No previous PSA (<i>n</i> = 321)	Academic education	51/124 (41%)	Nonacademic education	105/197 (53%)	0.03
	Previous PSA (<i>n</i> = 213)	Academic education	42/82 (51%)	Nonacademic education	82/131 (63%)	0.10
The response “very well” was compared with all others	All men (<i>n</i> = 534)	No previous PSA	156/321 (49%)	Previous PSA	124/213 (58%)	0.03
	All men (<i>n</i> = 534)	Born in Sweden	228/444 (54%)	Not born in Sweden	42/90 (47%)	0.23
The advantages were clear enough to make a decision	No previous PSA (<i>n</i> = 321)	Academic education	72/124 (58%)	Nonacademic education	133/197 (68%)	0.09
	Previous PSA (<i>n</i> = 213)	Academic education	58/82 (71%)	Nonacademic education	98/131 (75%)	0.51
The response “very well” was compared with all others	All men (<i>n</i> = 534)	No previous PSA	205/321 (64%)	Previous PSA	156/213 (73%)	0.02
	All men (<i>n</i> = 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: yes	All men (<i>n</i> = 534)	Academic education	168/206 (82%)	Nonacademic education	280/328 (86%)	0.21
Sought further information	No previous PSA (<i>n</i> = 321)	Academic education	53/124 (43%)	Nonacademic education	74/197 (38%)	0.41
Opted for OPT	No previous PSA (<i>n</i> = 321)	Academic education	98/124 (79%)	Nonacademic education	164/197 (83%)	0.34

OPT = organised prostate cancer testing; PSA = prostate-specific antigen.

in Sweden. A possible explanation is that few men with poor Swedish reading skills responded to the survey. It was expected that previously PSA tested men were more likely to consider the text about advantages and disadvantages easy to understand.

The OPT information may be regarded as more complex than information about a formal cancer screening programme as it does not include a recommendation to participate. Most women who are invited to screening for breast cancer know that the health care authorities recommend screening and probably believe that there are good reasons for this. They are thus probably less likely to weigh the advantages and disadvantages on their own. In contrast, the invitation to OPT states the following: “When it comes to prostate cancer the benefits don’t necessarily outweigh the drawbacks. As a result, the National Board of Health and Welfare does not recommend any national screening programme for early detection of prostate cancer”. This may make some men scrutinise the possible disadvantages of OPT more thoroughly than if they had been invited to a national screening programme.

In our study, a somewhat smaller proportion of men with academic education than those with nonacademic education thought that the description of the disadvantages of PSA testing was very clear. This suggests that men with academic education are more likely to understand the complexity of the decision for or against PSA testing. The complexity of weighing possible consequences of testing prostate cancer may require a better than average communicative and critical health literacy. On the contrary, if men with academic education were more likely to see the complexity, one would expect that they would also be more likely to seek more information elsewhere before making their decision, which they were not. We are currently analysing semistructured interviews with men offered OPT and hope that these will help us better understand the association between education and perception of the information text.

The wording of the text about the advantages and disadvantages of testing is of course crucial for the decision men make. It must include the most important aspects but also be reasonably short; a long text may not be read in its entirety or even at all. Despite that the here evaluated information about the advantages and disadvantages of testing was brief and neutral, most considered it sufficient to make a decision. Only one-third of the men read more information elsewhere. This is somewhat surprising as the information sent with the invitation to the Swedish OPT projects is short, 570 words, but agrees well with an evaluation of a brief decision aid about lung cancer screening [8]. For comparison, the corresponding text in the brochure about PSA testing published by the European Association of Urology is 1153 words long, including a description of the anatomy and more information about prostate cancer [9]. The UK National Health Service’s information about the advantages and disadvantages of breast cancer screening is also longer: 1881 words. It includes why women are invited to screening, statistical results, the screening process, and that more investigative tests may be necessary [10]. Although our results suggest that a short information text may be pre-

ferred over a longer one, further research is needed to establish not only the optimal contents, but also the optimal length of prostate cancer testing decision aids; a too short text may not include enough information, but a long text is more likely not to be read in its entirety. Both participants and nonparticipants in a Swedish colorectal cancer screening study expressed that it was important that the invitation letter highlighted a clear message that attracted attention, that it did not contain too much text, and that different sources of information were offered [11]. A systematic review concluded that the motivation and ability to use information to promote good health varies throughout life and can be influenced by external circumstances, as well as by how information is presented in writing, using moving image, and through conversation [12].

We investigated a screening-like situation, where a population-based sample of men received information and an invitation by post. We have not been able to identify any other studies on how people perceive the posted written information about the advantages and disadvantages of cancer screening that is supposed to lead to a personal decision without contact with the health care system. A systematic review of the effects of decision aids on breast cancer screening showed that their use increased the proportion of women with adequate knowledge to inform their screening decision by only 12% [13]. Interestingly, it suggested that decision aids may reduce confidence in the screening decision and reduce participation in screening. Fewer women had a positive attitude towards screening after being informed about overdiagnosis in the decision aid [13]. This may also be the case for men invited for prostate cancer screening. A more recent systematic review, focusing on breast cancer screening in women under 50 yr of age, showed similar results [14]. In contrast, a systematic review suggested that decision aids for colorectal cancer screening may increase the participation rate [15].

In Western countries, there is a move away from decisions about individuals’ care and treatment being made by the health care to increased autonomy and thus responsibility for the individuals to make their own decisions [16]. An example is the Swedish OPT projects, in which men receive an invitation letter with neutral information and must decide for themselves whether to participate—a very different context from the shared decision-making for PSA testing that is recommended by many health care authorities and professional organisations [17].

Strengths of our study include the population-based design and that the context is similar to a formal screening programme. An important weakness is the low response rate.

As many as 82% of the responders stated that they chose to have a PSA test in the OPT programme, but only 39% and 42% of all men invited to OPT in the two regions actually chose to participate [6]. This means that the responders constituted a selected group of men who were more positive towards PSA testing than the nonresponders, which may have affected our results. Nevertheless, although only 34% responded, one may argue that the nonresponders were given the opportunity to voice their concerns if they strongly disagreed with the OPT concept and that only

one of 1600 men chose to communicate this. Similarly, low response rates were found in a German breast cancer screening study [18] and in a Swedish prostate cancer screening study [19]. We chose to prioritise a short questionnaire as a longer one might have resulted in an even lower response rate. The number of background questions was therefore limited. Another consequence of the poor response rate is that the number of responders reduced the statistical strength of the analyses of factors associated with the men's perception of the text. Moreover, our results may be applicable only to countries with a culture and a health care system similar to that of Sweden; the optimal type and amount of information may vary across countries and cultural contexts. Finally, we did not assess the participating men's health literacy, which may affect the understanding of the invitation letter.

5. Conclusions

Almost all responding men were positive about being offered a possibility to make an informed, personal decision about whether or not to be tested for prostate cancer in an organised testing programme. The study also shows that most men considered the brief information about advantages and disadvantages sufficient for making a decision. Men with academic education were somewhat less likely to find the information very clear; this shows a need for further research about how best to describe the advantages and disadvantages of testing for prostate cancer.

Author contributions: Linda Svensson had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Study concept and design: All authors.

Acquisition of data: Svensson, Börjedahl.

Analysis and interpretation of data: Svensson, K.S. Bratt, O. Bratt.

Drafting of the manuscript: Svensson.

Critical revision of the manuscript for important intellectual content: All authors.

Statistical analysis: Svensson, K.S. Bratt.

Obtaining funding: Svensson, O. Bratt.

Administrative, technical, or material support: Börjedahl.

Supervision: O. Bratt, K.S. Bratt.

Other: None.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.euro.2023.03.012>.

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