

HHS Public Access

Patient Educ Couns. Author manuscript; available in PMC 2020 August 01.

Published in final edited form as:

Author manuscript

Patient Educ Couns. 2019 August ; 102(8): 1483-1489. doi:10.1016/j.pec.2019.03.009.

Informed decision-making based on a leaflet in the context of prostate cancer screening

Tessa Dierks, MSc¹ [junior researcher], Eveline A.M. Heijnsdijk, PhD¹ [assistant professor], Ida J. Korfage, PhD¹ [assistant professor], Monique J. Roobol, PhD² [professor of decision making in urology], Harry J. de Koning, PhD¹ [professor of public health, and screening evaluation]

¹Dept. of Public Health, P.O. Box 2040, 3000 CA Rotterdam, Erasmus MC, University Medical Center Rotterdam, the Netherlands. ²Dept. of Urology, P.O. Box 2040, 3000 CA Rotterdam, Erasmus MC, University Medical Center Rotterdam, the Netherlands.

Abstract

Objective: We aimed to assess to what extent men make informed choices in the context of prostate cancer screening and how written material contributes to that process.

Methods: We developed a leaflet describing prostate cancer screening, and a questionnaire consisting of knowledge, attitude, and intended screening uptake components to assess informed decision-making. The leaflet and questionnaire were pilot-tested among men of the target population, adapted accordingly, and sent to 761 members of an online research panel. We operationalized whether the leaflet was read as spending one minute on the leaflet page and by a self-reported answer of respondents.

Results: The response rate was 66% (501/761). The group who read the leaflet (n=342) correctly answered a knowledge item significantly more often (10.9 versus 8.8; p<0.001) than those who did not read the leaflet (n=159), and made more informed choices (73% versus 56%; p=0.001). There were no significant differences in attitude and intended screening uptake between both groups.

Conclusion: Having read the leaflet could be one of the factors associated with increased levels of knowledge and informed decision-making.

Practical implications: The results of this study showed that increasing knowledge and supporting informed decision-making with written material are feasible in prostate cancer screening.

COMPETING INTEREST

All authors declare that there are no competing interests.

CORRESPONDING AUTHOR: Tessa Dierks, MSc, junior researcher, Kortekade 30-1, 3062 GS Rotterdam, The Netherlands, Tel: +31 6 83 05 71 50, tessa_dierks@hotmail.com.

Publisher's Disclaimer: This is a pre-publication version of the article Dierks T, Heijnsdijk EAM, Korfage IJ, Roobol MJ, de Koning HJ. Informed decision-making based on a leaflet in the context of prostate cancer screening. Patient Education and Counseling 2019;102(8):1483–1489. The final version is available at https://doi.org/10.1016/j.pec.2019.03.009

Informed choice; informed decision-making; prostate cancer screening; mass screening; leaflet

1. INTRODUCTION

Prostate cancer is the most common cancer and the third cause of cancer mortality among men in Europe (1, 2). Population-based screening might reduce the mortality rate of prostate cancer; however, the harm-benefit ratio of such a screening program is being debated (3, 4, 5). The European Randomized Study of Screening for Prostate Cancer (ERSPC) has shown that screening based on Prostate-Specific Antigen (PSA) can reduce the mortality rate of prostate cancer by 20% to 30%; nonetheless, concerns about overdiagnosis and overtreatment were expressed as well (6). Elaborating on the results of the ERSPC study, a simulation study showed that implementing prostate cancer screening may be effective and cost-efficient – with minimal overdiagnosis and overtreatment – when it is limited to two or three screenings among men between the ages of 55 and 59 (7).

Despite these promising results, population-based screening for prostate cancer has not been introduced yet (7). Also in the Netherlands, where over 10,000 men are diagnosed with prostate cancer and 2.500 men die of this disease annually, no prostate cancer screening program has been introduced (8). Dutch general practitioners have a guideline stating that they should not offer a PSA test to men when they do not ask for it. However, when men do ask, a PSA test can be offered on the basis of shared decision-making. If a pilot prostate cancer screening program is implemented at any point to investigate whether a nationwide screening program in the Netherlands would be effective and cost-efficient, all invited men need to be well informed and able to make an informed choice about their participation in this program (9, 10). An informed choice is defined in this paper as a choice which is based on relevant, high-quality knowledge and which represents the values of the decision-maker (11). In this paper, the term is synonymous with informed decision-making. We consider relevant, high-quality knowledge as knowledge which is based on guidelines of the Dutch National Institute for Public Health and the Environment (12). Unlike shared decisionmaking where clinicians and people make choices together (13), decision-making in the context of screening is mainly based on written information as a result of which the person him- or herself makes a decision about participation. Consequently, the aim of this study is to assess to what extent men make informed choices in the context of prostate cancer screening and how written information contributes to that process.

2. METHODS

2.1 Questionnaire study

2.1.1. Development of leaflet and questionnaire—We developed a leaflet about prostate cancer screening based on a study about the information quality of PSA screening programs, literature about the communication of medical information, and leaflets of already existing screening programs (8, 14–21). This leaflet was developed for a potential pilot of a population-based prostate cancer screening program in the Netherlands. The resulting draft

leaflet was extensively discussed and reviewed by the authors until consensus was reached. This leaflet contained general information on prostate cancer, the pilot research project, the PSA test and possible results, the procedures for biopsy and MRI, and possible treatment options. In addition, an overview of harms and benefits of prostate cancer screening was presented (see Appendix for an English version of the Dutch leaflet text). The topics are based on the guidelines of the Dutch National Institute for Public Health and the Environment (12). These guidelines state 15 topics of screening that have to be mentioned in the information provided for a population-based screening program.

Additionally, we developed a questionnaire to assess the level of informed choice based on similar studies about informed decision-making (11, 22–28). The questionnaire consisted of the following components: knowledge, attitude, intended screening uptake, and familiarity with the PSA test. To further optimize the leaflet and questionnaire, we pilot-tested them in structured face-to-face and phone interviews with six men in the age range of 53 to 57. Questions on the readability, completeness, clarity, and layout of the leaflet and the questionnaire were asked.

2.2. Data collection

The revised versions of the leaflet and the questionnaire were sent to members of the Flycatcher panel. This panel consists of people from the Dutch general public who volunteer to participate in online questionnaire surveys. Male members of this panel in the age range of 45 up to and including 65 years with sufficient understanding of the Dutch language and with no medical history of prostate cancer were asked to read the leaflet and fill out the questionnaire. The respondents had access to the leaflet and questionnaire via the website of Flycatcher. The time that respondents spent on the page of the leaflet was measured and demographic details of these respondents were additionally collected.

As population-based screening for prostate cancer has not currently been introduced in the Netherlands, we had to test in a hypothetical situation. To make this hypothetical situation as realistic as possible, the survey asked our respondents to pretend that this leaflet was attached to a real invitation for participation in the Dutch prostate cancer screening program.

2.3 Outcome measures of the questionnaire

2.3.1. Knowledge—Decision-relevant knowledge was measured using 13 multiplechoice items (Table 2). The 13 multiple-choice items covered decision-relevant knowledge of prostate cancer screening, and were determined on the basis of previously used screeningrelated knowledge items with regard to colorectal cancer screening, breast cancer screening, and cervical cancer screening. These items were extensively discussed by the authors and piloted in interviews with six men in the target age of prostate cancer screening (29, 30, 31). The items addressed the purpose of the prostate cancer screening program, the prevalence of prostate cancer, the symptoms and development of prostate cancer, the benefits and harms of the screening program, the uncertainty of a PSA test, the treatment options after diagnosis, and the voluntary nature of participation. Response options to these items were "True", "False" and "I don't know." Each correct answer added one point to the knowledge score. As a result, the range of the total knowledge score was 0 to 13. Because there is still no

psychometric evaluation of the knowledge element, following earlier research (23, 24, 26), the midpoint of the knowledge scale was used as the threshold for "sufficient knowledge"; a score of eight or higher was categorized as "sufficient knowledge" and a score of seven or lower was categorized as "insufficient knowledge."

2.3.2. Attitudes—Respondents' attitudes toward participation in the screening program were assessed using five items based on similar studies (11, 22, 24, 28). Each item started with the following sentence: "In my opinion, participation in the prostate cancer screening program within 3 months for myself is..." Items were anchored by unimportant/important, frightening/reassuring, not self-evident/self-evident, uncomfortable/not uncomfortable, or harmful/not harmful, each scored on a 7-point Likert scale. The Cronbach's alpha of the attitude scale of 0.81 indicated good internal consistency.

All answers were summed up and subtracted by 5 (the lowest score that the participant could have). This figure was divided by 30 (the highest score possible minus the lowest score possible) and multiplied by 100, which resulted in a score ranging from 0 to 100. Following the reasoning that the midpoint of the scale represents a neutral attitude (28), a score between 44 and 56 was categorized as "neutral." A score of 44 or lower was categorized as a "negative attitude toward participation in the prostate cancer screening program" and a score of 56 or higher was categorized as a "positive attitude toward participation in the prostate cancer screening program."

2.3.3. Intended screening uptake—Intended screening uptake was assessed by the question: "Imagine that you will receive an invitation within three months to participate in a prostate cancer screening program. Will you participate?" The answer was given on a 7-point Likert scale, anchored by 1 "definitely not" and 7 "definitely." An answer of 1, 2, or 3 was categorized as "unlikely to participate"; 4 was categorized as "undecided"; and 5, 6, or 7 were categorized as "likely to participate."

2.3.4. Informed choice—To assess the level of informed choice, we combined the scores of the knowledge, attitude, and intended screening uptake components (11). A respondent was considered to have made an informed choice when they: 1) had sufficient knowledge, had a positive attitude, and were likely to participate in the screening program; 2) had sufficient knowledge, had a negative attitude, and were unlikely to participate; 3) had sufficient knowledge, had a neutral attitude, and were undecided about participation. All other combinations were categorized as uninformed choices. Because there is no population-based prostate cancer screening program in place yet, we could not follow men over time to see whether they did or did not participate in such a screening program.

2.4. Statistical analyses

We operationalized whether the leaflet was read as follows: we measured with a timetracking device how long respondents spent on the leaflet page and we asked the question "did you read the leaflet?" If respondents answered "yes" to the question "did you read the leaflet?" and spent one minute or more on reading the leaflet, they were categorized as having read the leaflet. If respondents answered "no" to the question "did you read the

leaflet?" or spent less than one minute on reading the leaflet, they were categorized as not having read the leaflet.

Chi-square tests were used to compare the respondents who read the leaflet and the respondents who did not read the leaflet on categorical variables; t-tests were used for continuous variables. All reported p-values are corrected for educational level and are two-sided, with p<0.05 considered as significant. Analyses were carried out using SPSS version 24 for Windows.

The Medical Research Ethics Committee of Erasmus University Medical Center approved the study protocol of MEC-2017–1074.

3. RESULTS

3.1. Response and descriptive characteristics

In total, 761 men were sent a questionnaire; 557 of them filled in the questionnaire. However, data from 56 of these 557 respondents were excluded from our analyses because their answers were quite incomplete. As a result, the response rate is 66% (501/761). The mean age of our respondents was 56, while 96% of the respondents were born in the Netherlands (Table 1). Most of the respondents lived together with a partner and children; 16% had a low educational level, 36% an intermediate educational level, and 47% a high educational level. The group who read the leaflet had a significant higher level of education than the group who did not read the leaflet (p<0.001). Overall, the mean time that respondents used to read the leaflet was four minutes and 86% of all respondents reported that the leaflet was clear. Thirty-four percent of the respondents had considered having a PSA test before they filled in the questionnaire and 20% of all respondents had already had a PSA test.

3.2 Knowledge

Of all respondents, 86% had sufficient knowledge and 10 knowledge items were answered correctly on average (Table 2). The three items answered correctly the most often concerned the chance of mortality when prostate cancer is found at an early stage, the aim of the screening program, and the presence of prostate cancer while symptoms are absent. These items were answered correctly by 97%, 96%, and 96% of the respondents who read the leaflet, and by 95%, 95%, and 85% of the respondents who did not read the leaflet respectively. The three items answered the least correctly regarded the need for treatment when prostate cancer is found, a false-negative test result, and complaints when urinating. These items were answered correctly by 63%, 66%, and 67% of the respondents who read the leaflet respectively. There was a significant difference in the level of sufficient knowledge between the groups who did and did not read the leaflet. Ninety-six percent of the group who did read the leaflet had sufficient knowledge, whereas 67% of the group who did not read the leaflet had sufficient knowledge (p<0.001).

3.3 Attitude

Overall, 67% of the respondents had a positive attitude about participation in the prostate cancer screening program, 15% had a neutral attitude, and 18% had a negative attitude about participation in the prostate cancer screening program (Table 3). There was no significant difference between the group who read the leaflet and the group who did not read the leaflet.

3.4 Intended screening uptake

The majority of the respondents (77%) indicated that they were likely to participate in the prostate cancer screening program, 13% indicated that they were unlikely to participate, and 10% indicated that they were undecided about their participation (Table 3). Of the group who read the leaflet, 79% were likely to participate in the screening program. This figure was 74% in the group who had not read the leaflet. There was no significant difference between the groups who did and did not read the leaflet.

3.5 Informed choice

In this hypothetical situation, 68% of all respondents made an informed choice (Table 4). This percentage was significantly higher in the group who read the leaflet (p=0.001). Seventy-three percent of the respondents who read the leaflet made an informed choice; furthermore, 62% of all respondents who read the leaflet had a positive attitude and indicated that they were likely to participate in the screening program. By contrast, 56% of the respondents who did not read the leaflet made an informed choice, while 44% of all respondents who did not read the leaflet had a positive attitude and indicated that they were likely to participate in the screening program. By contrast, 56% of the respondents who did not read the leaflet had a positive attitude and indicated that they were likely to participate in the prostate cancer screening program. In total, 24% of the respondents who read the leaflet made an uninformed choice due to conflicting attitudes and intentions. This figure was 21% among respondents who did not read the leaflet. Three percent of the respondents who did read the leaflet made an uninformed choice due to insufficient knowledge, in contrast to 23% of the respondents who did not read the leaflet. Of all men who reported to have had a PSA test before, 83% made an informed choice.

4. DISCUSSION AND CONCLUSION

4.1. Discussion

The group who read the leaflet reported significantly better knowledge levels than the group who did not read the leaflet, and hence made more informed choices. Seventy-three percent of the respondents who read the leaflet about prostate cancer screening made an informed decision. In a similar study about informed decision-making in the context of breast cancer screening, 88% of the respondents made an informed decision (24). However, breast cancer screening was introduced in the Netherlands in 1990 and we expect the breast cancer screening program to be better known. Based on our study results, we have now adapted the leaflet about prostate cancer screening with regard to the explanation of false-negative test results, urinary tract problems, and treatment options. We consequently expect it to result in informed decision rates of above 73%.

These knowledge gaps are related to knowledge of complaints when urinating or treatment of prostate cancer. Only 58% of all respondents knew that more frequent urination or a weak

stream are often not being caused by prostate cancer and 53% of all respondents knew that treatment is not always needed when prostate cancer is found (see Table 2). So far, population-based prostate cancer screening programs have not been introduced in the Netherlands, nor elsewhere. As a result, we cannot assume our respondents to know all about this topic, even more so since screening is a complicated topic. Interestingly, 82% of the respondents who read the leaflet knew that a high PSA value does not mean that a person certainly has prostate cancer. Conversely, only 66% of this same group knew that a low PSA value in the blood does not mean that a person certainly has no prostate cancer. The fact that false-positive results are easier to understand than false-negative results was also found in other studies (24, 32). It is of importance that not only a false-positive result is understood but also a false-negative result. Insufficient knowledge of a false-negative result may cause a delay in seeking treatment if symptoms appear, for example (33). This delay may subsequently affect survival. To improve the understanding of a false-negative result, a short statement can be added to the written information in order to explain that a normal test result means a low risk of developing cancer (34). For this reason, we recommend reviewing and improving the information provided in the leaflet about false-negative results, so that the concept of false-negative results and false-positive results are both understood.

A literature review determining the contribution of written material to informed decisionmaking in the context of screening has shown that no differences in attitude or intended screening uptake between the group who read and the group who did not read the leaflet were found in the majority of the studies in this literature review (35). Also in our study, we found no significant difference in intended screening uptake and attitude between the group who read and the group who did not read the leaflet. This fact may have two explanations. Firstly, the time at which the questionnaire about intended screening uptake and attitude has been filled out may influence the results. We asked the respondents directly after reading the leaflet what their attitude and intended screening uptake were. The time between reading the leaflet and filling out the questionnaire may have given the respondents no opportunity to think about all information provided on the screening program. If the leaflet induced a shift in attitude and intended screening uptake, this shift may consequently have been less likely to be detected. Secondly, a respondent may have a positive or negative attitude toward all screening programs, as a result of which the disease being screened for presumably has limited impact on the attitude and intended screening uptake. In a sample of 500 adults in the United States, 87% believed that routine cancer screening is almost always a good idea, while between 32% and 41% believed that an 80-year-old was irresponsible when they chose not to be tested (36). Also, a study among 2,368 individuals in Switzerland showed that most respondents had a positive attitude in general toward cancer screening and that these attitudes were strongly related to their screening practice (37). Reading the leaflet may therefore have minimal impact on attitude or intended screening uptake.

One strength of this study is that we carefully prepared the leaflet with the input of the target group. We observed that the leaflet presumably contributed to the knowledge levels of respondents, also on sensitive topics such as false-positive PSA test results, without influencing attitude and intended screening uptake. As a result, a possibly useful information source for prostate cancer screening is now available.

Another strength is the large sample size (n=501) of respondents in a comparable age category of the target population of a potential future screening program for prostate cancer. Consequently, the level of informed choices among respondents in this study is presumably comparable to the level of informed choices among possible participants of a potential future screening program for prostate cancer.

Some limitations of this study need to be addressed. First of all, respondents only filled out the questionnaire once. As a result, we do not know what the knowledge, attitude, and intended screening uptake of the respondents were before they read the leaflet or what the influence of the leaflet was on these components. However, as the results of this study showed, some significant differences were found in knowledge and informed choice levels between the respondents who read the leaflet and the respondents who did not read the leaflet. Previous studies about the influence of written information on informed decision-making showed these results as well (35). Consequently, our leaflet presumably induced these differences.

Furthermore, misclassification of respondents having or not having read the leaflet could have occurred. To minimize misclassification, we used a time-tracking device and added a question to the questionnaire asking whether respondents read the leaflet. A cut-off time of one minute was chosen, because some respondents whose reading time was just above one minute answered "yes" to the question "did you read the leaflet" and provided detailed information in some open questions. However, respondents might have incorrectly answered this question, opened the leaflet without reading it, or saved the leaflet on their computer and read it without being registered by the time-tracking device. As a result, there is a possibility that respondents were included in the wrong group. Nonetheless, when only looking at the classification based on "did you read the leaflet" without taking the reading time of one minute into consideration, 90% of the respondents who self-reported to have read the leaflet had sufficient knowledge and 70% of them made an informed choice. Fifty-one percent of the respondents who self-reported to not have read the leaflet had sufficient knowledge and 45% of them made an informed choice. Consequently, it is unlikely that men who spent very little time on reading the leaflet did so because they were already well informed. However, since about 30% of the men did not read the leaflet, other ways of informing high-risk and other categories of men might be thought of in the future. A limitation of the leaflet is that participants were potentially unable to understand it. Although special attention was paid to the readability by using short sentences and clear headings, for example, 33% of the respondents who did not read the leaflet for longer than one minute indicated that they considered the leaflet unclear.

Additionally, it is known that people with higher educational levels are more likely to participate in surveys (38). The percentage of men between 45 and 65 years old who are highly educated is about 30% in the Netherlands (39). In our study, the percentage of highly educated men was 47% and in the group of men who read the leaflet even 53%. Because men with a high educational level are overrepresented in our study, the results of our study may not apply to the general Dutch population.

4.2. Conclusion

To conclude, reading the leaflet might be one of the factors for increased knowledge levels and informed choices. We recommend paying specific attention to false-negative test results, the need for treatment, and specific complaints when providing information, because these aspects were not yet well understood by respondents.

4.3. Practical implications

The results of this study showed that the leaflet might be one of the factors to support informed decision-making without influencing intended screening uptake and attitude toward the program. It may be feasible to increase decision-relevant knowledge and decrease knowledge gaps with written material.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

FUNDING

We would like to thank the Cancer Intervention and Surveillance Modeling Network (CISNET consortium; http:// cisnet.cancer.gov) for important background discussions on information about prostate cancer screening.

LITERATURE

- Arnold M, Karim-Kos HE, Coebergh JW, Byrnes G, Antilla A, Ferlay J, et al. Recent trends in incidence of five common cancers in 26 European countries since 1988: analysis of the European Cancer Observatory. European journal of cancer. 2015;51(9):1164–87. [PubMed: 24120180]
- 2. Bolla M, Van Poppel H. Management of prostate cancer: Springer; 2017.
- 3. Dunn MW, editor Prostate Cancer Screening. Seminars in oncology nursing; 2017: Elsevier.
- Sanghera S, Coast J, Martin RM, Donovan JL, Mohiuddin S. Cost-effectiveness of prostate cancer screening: a systematic review of decision-analytical models. BMC Cancer. 2018;18(1):84. [PubMed: 29347916]
- 5. US Preventive Services Task Force, Grossman DC, Curry SJ, Owens DK, Bibbins-Domingo K, Caughey AB, Davidson KW, Doubeni CA, Ebell M, Epling JW Jr,Kemper AR, Krist AH, Kubik M, Landefeld CS, Mangione CM, Silverstein M, Simon MA, Siu AL, Tseng CW. Screening for Prostate Cancer: US Preventive Services Task Force Recommendation Statement. JAMA. 2018 5 8;319(18):1901–1913. [PubMed: 29801017]
- Schroder FH, Hugosson J, Roobol MJ, Tammela TL, Ciatto S, Nelen V, et al. Screening and prostate-cancer mortality in a randomized European study. N Engl J Med. 2009;360(13):1320–8. [PubMed: 19297566]
- Heijnsdijk EA, de Carvalho TM, Auvinen A, Zappa M, Nelen V, Kwiatkowski M, et al. Costeffectiveness of prostate cancer screening: a simulation study based on ERSPC data. J Natl Cancer Inst. 2015;107(1):366. [PubMed: 25505238]
- KWF. Prostaatkanker: KWF Kanker Bestrijding; 2017 [Available from: https://www.kwf.nl/kanker/ prostaatkanker/pages/default.aspx.
- Andermann A, Blancquaert I, Beauchamp S, Déry V. Revisiting Wilson and Jungner in the genomic age: a review of screening criteria over the past 40 years. Bulletin of the World Health Organization. 2008;86(4):317–9. [PubMed: 18438522]
- 10. Final Recommendation Statement: Prostate Cancer: Screening: U.S. Preventive Task Force; 2018 [updated May 2018. Available from: https://www.uspreventiveservicestaskforce.org/Page/ Document/RecommendationStatementFinal/prostate-cancer-screening1.

- 11. Marteau TM, Dormandy E, Michie S. A measure of informed choice. Health Expect. 2001;4(2): 99–108. [PubMed: 11359540]
- 12. Ge
 ünformeerde keuze: Rijksinstituut voor Volksgezondheid en Milieu, Ministerie van Volksgezondheid Welzijn en Sport; 2018 [updated November 2018. Available from: https://www.rivm.nl/bevolkingsonderzoeken-en-screeningen/screening-theorie/ge-nformeerde-keuze]
- Elwyn G, Laitner S, Coulter A, Walker E, Watson P, Thomson R. Implementing shared decision making in the NHS. Bmj. 2010;341:c5146. [PubMed: 20947577]
- Korfage IJ, van den Bergh RC, Essink-Bot ML. Deciding on PSA-screening Quality of current consumer information on the Internet. Eur J Cancer. 2010;46(17):3073–81. [PubMed: 21047589]
- Politi MC, Han PK, Col NF. Communicating the uncertainty of harms and benefits of medical interventions. Med Decis Making. 2007;27(5):681–95. [PubMed: 17873256]
- Fagerlin A, Zikmund-Fisher BJ, Ubel PA. Helping patients decide: ten steps to better risk communication. J Natl Cancer Inst. 2011;103(19):1436–43. [PubMed: 21931068]
- Wald N Information leaflets in medical screening. J Med Screen. 2006;13(3):109. [PubMed: 17007649]
- Hoffman RM. Improving the communication of benefits and harms of treatment strategies: decision AIDS for localized prostate cancer treatment decisions. J Natl Cancer Inst Monogr. 2012;2012(45):197–201. [PubMed: 23271773]
- Bernardini C, Ambrogi V, Fardella G, Perioli L, Grandolini G. How to improve the readability of the patient package leaflet: a survey on the use of colour, print size and layout. Pharmacol Res. 2001;43(5):437–44. [PubMed: 11394935]
- 20. IKNL. Movember: prostaatkankermaand 2016: Integraal Kankercentrum Nederland; 2016 [Available from: www.iknl.nl.
- 21. Timmermans D Wat beweegt de kiezer ? Over de betekenis van weloverwogen en geïnformeerde keuzes voor gezondheid en preventie2013.
- Kellar I, Sutton S, Griffin S, Prevost AT, Kinmonth AL, Marteau TM. Evaluation of an informed choice invitation for type 2 diabetes screening. Patient Educ Couns. 2008;72(2):232–8. [PubMed: 18513916]
- 23. Michie S, Dormandy E, Marteau TM. The multi-dimensional measure of informed choice: a validation study. Patient Educ Couns. 2002;48(1):87–91. [PubMed: 12220754]
- 24. van Agt H, Fracheboud J, van der Steen A, de Koning H. Do women make an informed choice about participating in breast cancer screening? A survey among women invited for a first mammography screening examination. Patient Educ Couns. 2012;89(2):353–9. [PubMed: 22963769]
- Mathieu E, Barratt A, Davey HM, McGeechan K, Howard K, Houssami N. Informed choice in mammography screening: a randomized trial of a decision aid for 70-year-old women. Arch Intern Med. 2007;167(19):2039–46. [PubMed: 17954796]
- 26. Smith SK, Trevena L, Simpson JM, Barratt A, Nutbeam D, McCaffery KJ. A decision aid to support informed choices about bowel cancer screening among adults with low education: randomised controlled trial. BMJ. 2010;341:c5370. [PubMed: 20978060]
- Ghanouni A, Renzi C, Meisel SF, Waller J. Common methods of measuring 'informed choice' in screening participation: Challenges and future directions. Prev Med Rep. 2016;4:601–7. [PubMed: 27843761]
- van den Berg M, Timmermans DR, Ten Kate LP, van Vugt JM, van der Wal G. Are pregnant women making informed choices about prenatal screening? Genet Med. 2005;7(5):332–8. [PubMed: 15915085]
- Korfage IJ, Fuhrel-Forbis A, Ubel PA, Zikmund-Fisher BJ., Greene SM, McClure JB et al. Informed choice about breast cancer prevention: randomized controlled trial of an online decision aid intervention. Breast Cancer Research. 2013; 15(5), R74 [PubMed: 24004815]
- 30. Korfage IJ, van Ballegooijen M, Wauben B, Habbema JDF, Essink-Bot ML. Informed choice on Pap smear still limited by lack of knowledge on the meaning of false-positive or false-negative test results. Patient Education and Counseling. 2011; 85(2), 214–218. [PubMed: 21269793]

- 31. Van Dam L, Korfage IJ, Kuipers EJ, Hol L, van Roon AHC, Reijerink JCIY et al. What influences the decision to participate in colorectal cancer screening with faecal occult blood testing and sigmoidoscopy? European Journal of Cancer. 2013; 49(10), 2321–2330. [PubMed: 23571149]
- 32. Korfage IJ, van Ballegooijen M, Wauben B, Habbema JD, Essink-Bot ML. Informed choice on Pap smear still limited by lack of knowledge on the meaning of false-positive or false-negative test results. Patient Educ Couns. 2011;85(2):214–8. [PubMed: 21269793]
- Petticrew MP, Sowden AJ, Lister-Sharp D, Wright K. False-negative results in screening programmes: systematic review of impact and implications. Health Technol Assess. 2000;4(5):1– 120.
- 34. Marteau TM, Senior V, Sasieni P. Women's understanding of a "normal smear test result": experimental questionnaire based study. Bmj. 2001;322(7285):526–8. [PubMed: 11230068]
- 35. Fox R Informed choice in screening programmes: do leaflets help? A critical literature review. Journal of Public Health. 2006;28(4):309–17. [PubMed: 17060352]
- Schwartz LM, Woloshin S, Fowler FJ Jr, Welch HG. Enthusiasm for cancer screening in the United States. Jama. 2004;291(1):71–8. [PubMed: 14709578]
- Cullati S, Charvet-Berard AI, Perneger TV. Cancer screening in a middle-aged general population: factors associated with practices and attitudes. BMC Public Health. 2009;9:118. [PubMed: 19402895]
- 38. Van Gelder M, Pijpe A. E-epidemiology: a comprehensive update. Cancer. 2013;15(0.007).
- 39. CBS. Onderwijsniveau bevolking gestegen: CBS; 2013 [Available from: https://www.cbs.nl/nl-nl/ nieuws/2013/40/onderwijsniveau-bevolking-gestegen.

Table 1,

Descriptive characteristics of the study sample and outcome measures

Characteristic	All respondents n=501		Respondents who read the leaflet n=342*		Respondents who did not read the leaflet n=159**		p-value
Age, mean (SD)	56	(5.6)	56	(5.5)	57	(5.8)	0.30
Educational level, Number (%)							< 0.001
Low	82	(16)	36	(11)	46	(29)	
Intermediate	181	(36)	126	(37)	55	(35)	
High	238	(47)	180	(53)	58	(37)	
Country of birth, Number (%)							0.53
Netherlands	482	(96)	331	(97)	151	(95)	
Other	29	(4)	11	(3)	8	(5)	
Living situation, Number (%)							0.37
With parent(s)/caretaker(s)	2	(0.4)	2	(1)	0	(0)	
Alone	96	(19)	71	(21)	25	(16)	
Together with a partner, without children	172	(34)	111	(32)	61	(38)	
Together with a partner, with children	213	(43)	144	(42)	69	(43)	
Without a partner, with children	18	(4)	14	(4)	4	(3)	
Time spent reading the leaflet in minutes, <i>mean (SD)</i>	4.1	(7)	5.9	(8)	0.3	(0.3)	NA
Self-reported answer 'yes' to the question: 'Did you read the leaflet?' <i>Number (%)</i>	452	(90)	342	(100)	110	(69)	NA
Reported that the leaflet was clear, <i>Number</i> (%)	429	(86)	323	(94)	106	(67)	0.43
Thought about doing a PSA-test, <i>Number</i> (%)	170	(34)	118	(35)	52	(33)	0.66
Did do a PSA-test before, Number (%)	101	(20)	75	(22)	26	(16)	0.15

* =Respondents answered 'yes' to the question: 'did you read the leaflet?' and spent 1 minute or more on reading the leaflet.

** =Respondents answered 'no' to the question: 'did you read the leaflet? or spent less than 1 minute on reading the leaflet.

Percentages may not add to 100 because of rounding

Table 2,

Overview of knowledge items

Knowledge item (right answer: correct/ incorrect) No. correct answers (%)	All respondents n=501		Respondents who read the leaflet n=342*		Respondents who did not read the leaflet n=159 ^{**}		p-value ***
The aim of the screening program is to detect prostate cancer as early as possible. <i>(correct)</i>	479	(96)	328	(96)	151	(95)	0.41
Prostate cancer is the most common cancer among men in the Netherlands.(correct)	426	(85)	308	(90)	118	(74)	<0.001
The chance of having prostate cancer declines with aging. <i>(incorrect)</i>	449	(90)	309	(90)	140	(88)	0.72
I can have prostate cancer even if I don't have any symptoms. <i>(correct)</i>	463	(92)	328	(96)	135	(85)	0.001
Complaints when urinating, such as more frequent urination or a weak stream, are often caused by prostate cancer. <i>(incorrect)</i>	288	(58)	229	(67)	59	(37)	<0.001
I certainly have prostate cancer if the blood sample shows that I have a high PSA-value. <i>(incorrect)</i>	374	(75)	280	(82)	94	(59)	<0.001
I certainly do not have prostate cancer if the blood sample shows that I have a low PSA-value. <i>(incorrect)</i>	314	(63)	225	(66)	89	(56)	0.16
The chance of dying is lower when prostate cancer is discovered early. <i>(correct)</i>	484	(97)	333	(97)	151	(95)	0.52
A PSA-test always discovers prostate cancer. <i>(incorrect)</i>	335	(67)	253	(74)	82	(52)	<0.001
When prostate cancer is found, treatment is always needed. <i>(incorrect)</i>	263	(53)	214	(63)	49	(31)	<0.001
Because of this screening program, certain cases of prostate cancer can be found that otherwise never caused any problems. <i>(correct)</i>	402	(80)	290	(85)	112	(70)	0.002
I always get radiotherapy as treatment when further research shows that I have prostate cancer. <i>(incorrect)</i>	397	(79)	302	(88)	95	(60)	<0.001
I can stop at any moment with my participation in the screening program. <i>(correct)</i>	442	(88)	321	(94)	121	(76)	<0.001
Total of correct answers Mean, (SD)	10.2	(2.4)	10.9	(1.8)	8.8	(2.8)	< 0.001
Knowledge is categorized as sufficient if respondent correctly answered 8 out of 13 knowledge items correctly: <i>No. of respondents</i> (%)	All respondents n=501		Respondents who read the leaflet n=342 [*]		Respondents who did not read the leaflet n=159 ^{**}		p-value ^{***}
Sufficient knowledge	433	(86)	327	(96)	106	(67)	< 0.001
Insufficient knowledge	68	(13)	15	(4)	53	(33)	

* =Respondents answered 'yes' to the question: 'did you read the leaflet?' and spent 1 minute or more on reading the leaflet.

** =Respondents answered 'no' to the question: 'did you read the leaflet? or spent less than 1 minute on reading the leaflet.

*** * P-value is corrected for educational level.

Percentages may not add to 100 because of rounding

Table 3,

Overview of attitude and intended screening uptake

	All respondents n=501		Respondents w leaflet n=342*	ho read the	Respondents wh leaflet n=159 ^{**}	p-value ^{***}	
Attitude score							
No. of respondents, (%)							
Negative attitude	89	(18)	58	(17)	31	(20)	0.47
Neutral attitude	75	(15)	51	(15)	24	(15)	
Positive attitude	337	(67)	233	(68)	104	(65)	
Intended screening uptake							
No. of respondents, (%)							
Unlikely to participate	65	(13)	40	(12)	25	(16)	0.14
Undecided	49	(10)	32	(9)	17	(11)	
Likely to participate	387	(77)	270	(79)	117	(74)	

* =Respondents answered 'yes' to the question: 'did you read the leaflet?' and spent 1 minute or more on reading the leaflet.

** =Respondents answered 'no' to the question: 'did you read the leaflet? or spent less than 1 minute on reading the leaflet.

*** = P-value is corrected for educational level.

Percentages may not add to 100 because of rounding

Table 4,

Overview of Informed choice

Informed choice No. of respondents, (%)	All respondents n=501		Respondents who read the leaflet $n=342^*$		Respondents who did not read the leaflet n=159 ^{**}		p- value ^{***}
Informed choice:	338	(68)	249	(73)	89	(56)	0.001
Negative attitude and unlikely to participate	40	(8)	27	(8)	13	(8)	
Neutral attitude and undecided about participation	17	(3)	11	(3)	6	(4)	
Positive attitude and likely to participate	281	(56)	211	(62)	70	(44)	
Total of informed choices	163	(33)	93	(27)	70	(44)	
Uninformed choice due to conflicting attitude and intention:	116	(23)	83	(24)	33	(21)	
Negative attitude and likely to participate	27	(5)	19	(6)	8	(5)	
Negative attitude and undecided about participation	14	(3)	9	(3)	5	(3)	
Positive attitude and unlikely to participate	5	(1)	3	(1)	2	(1)	
Positive attitude and undecided about participation	15	(3)	12	(4)	3	(2)	
Neutral attitude and likely to participate	43	(9)	33	(10)	10	(6)	
Neutral attitude and unlikely to participate	12	(2)	7	(2)	5	(3)	
Uninformed choice due to insufficient knowledge:	47	(9)	10	(3)	37	(23)	
Negative attitude and unlikely to participate	8	(2)	3	(1)	5	(3)	
Neutral attitude and undecided about participation	3	(1)	0	(0)	3	(2)	
Positive attitude and likely to participate	36	(7)	7	(2)	29	(18)	

* =Respondents answered 'yes' to the question: 'did you read the leaflet?' and spent 1 minute or more on reading the leaflet.

** =Respondents answered 'no' to the question: 'did you read the leaflet? or spent less than 1 minute on reading the leaflet.

*** = P-value is corrected for educational level.

Percentages may not add to 100 because of rounding

Author Manuscript