

Is greater patient involvement associated with higher satisfaction? Experimental evidence from a vignette survey

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ABSTRACT

Background Patient-centredness is an essential quality parameter of modern healthcare. Accordingly, involving patients in decisions about care is required by international laws and an increasing number of medical codes and standards. These directives are based on ethical principles of autonomy. Still, there is limited empirical knowledge about the influence of patient involvement on satisfaction with care.

Objective In a large national vignette survey, we aimed to empirically test healthcare users' satisfaction with healthcare given different degrees of patient involvement, choices made and outcomes.

Methods A web-based cross-sectional survey distributed to a randomised sample of men in Denmark aged 45–70 years. Case vignettes used prostate-specific antigen (PSA) screening for early detection of prostate cancer as a clinical model. Using a 5-point Likert scale, we measured respondents' satisfaction with care in scenarios which differed in the amount of patient involvement (ranging from no involvement, through involvement with neutral or nudged information, to shared decision-making), the decision made (PSA test or no PSA test) and clinical outcomes (no cancer detected, detection of treatable cancer and detection of non-treatable cancer).

Results Participating healthcare users tended to be more satisfied with healthcare in scenarios illustrating greater levels of patient involvement. Participants were positive towards nudging in favour of the intervention but patient involvement through shared decision-making obtained the highest satisfaction ratings (Likert rating 3.81 without any involvement vs 4.07 for shared decision-making, $p < 0.001$). Greater involvement also had an ameliorating effect on satisfaction if a non-treatable cancer was later diagnosed.

Conclusion Our study provides empirical support for the hypothesis that greater patient involvement in healthcare decision-making improves satisfaction with care irrespective of decisions made and clinical outcomes. Overall satisfaction with the care illustrated was highest when decisions were reached through shared decision-making.

INTRODUCTION

Twenty years ago, the US Committee on the Quality of Health Care proposed

six aims for quality improvement for 21st-century healthcare systems. Among others, the committee made the fundamental recommendation that healthcare should be patient-centred, *'respectful of and responsive to individual patient preferences, needs, and values'*.¹ Patient-centredness intrinsically entails giving patients *'the necessary information and the opportunity to exercise the degree of control they choose over health care decisions that affect them'*.¹ Involving patients in healthcare decision-making is more than just a caprice. Patient involvement principles have deep roots in ethical considerations about autonomy and the individual's right to self-determination.^{2,3} International human rights documents, national laws, charters of patient rights and codes of medical ethics all support patient involvement in decision-making, enforced through a legal requirement for informed consent prior to healthcare interventions.^{4,5} For example, the United Nations Committee on Economic, Social and Cultural Rights underscores the right to participate in decisions affecting one's health (cf the Covenant's article 12, 1966, and General Comment 14, 2000).⁴ Patient participation in choices about medical care is believed to enhance patient empowerment, promote ownership of choices made, improve adherence and ensure the right treatment for the right patient.^{6,7} The approach assumes that healthcare users actually want to receive pertinent information, want to be asked their opinion about management and want to be given the opportunity to participate in decision-making, a cornerstone to meeting patients' needs and expectations.¹ This assumption has

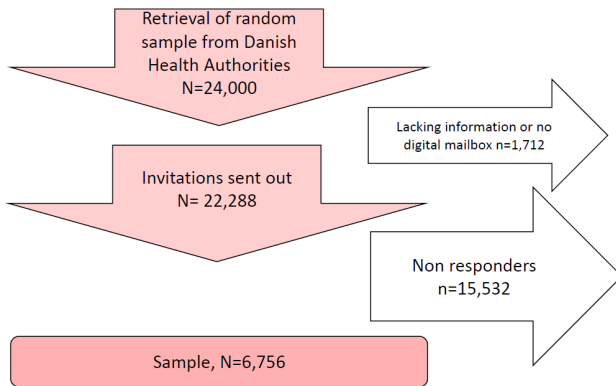


Figure 1 Flow chart illustrating inclusion of survey participants.

been repeatedly challenged by proponents of a more paternalistic model of care who advocate that making healthcare decisions is something that is exclusively vested within the health professional realm.^{8–10} Still, there is surprisingly limited and ambiguous empirical evidence on healthcare users' views towards different approaches to patient involvement. Previous studies focusing on the impact of shared decision-making (SDM) and decision aids (DAs) on patient satisfaction have provided conflicting results.¹¹ Furthermore, while the wisdom of a decision is 'put to the test' when an adverse outcome occurs, little is known about how the way in which management choices were made influences patients' assessments of care.

In a case vignette survey using hypothetical scenarios, we aimed to measure healthcare users' satisfaction with care under circumstances with different degrees of patient involvement in decision-making, different decisions made and different outcomes.

METHODS

We developed our cross-sectional survey with public and patient involvement.¹² We selected a random sample of 24 000 men aged 45–70 years from a national register held by Danish health authorities (please see the flow chart in figure 1 and below for sample size considerations). Invitations were sent across two waves and 6756 people completed the survey amounting to a 30% response rate. Compared with existing international data sets, our sample appeared reasonably representative regarding baseline sociodemographics, control preference and personality characteristics.¹³ Additionally, when comparing participants with non-responders at the national level, although older men and men living in rural areas were slightly but statistically significantly over-represented, the general population of men aged 45–70 years overall was represented very well with regard to sociodemographic characteristics.¹⁴

Clinical model

Case vignettes concerned prostate-specific antigen (PSA) screening for prostate cancer (PCa) in men. PCa

is among the most common cancers and a leading cause of cancer death among men worldwide.¹⁵ The harms of population-based PSA screening tend to outweigh the benefits.¹⁶ The PSA test sometimes misses significant cancers and also detects many clinically insignificant tumours, resulting in a high risk of overtreatment and associated irreversible adverse effects (eg, urinary incontinence, erectile dysfunction).¹⁷ Decisions about PSA screening are difficult and may depend on the information presented. As benefits and risks are finely balanced and the decision potentially has serious consequences, decision-making about PSA provides a good model for studying men's views on participation in healthcare decision-making.¹²

Procedures

We used Research Electronic Data Capture¹⁸ and distributed the survey through a digital mailbox used by Danish authorities for secure communication with citizens.¹⁴ Respondents were randomised into one of 30 different scenarios. Each scenario had an identical core structure but differed regarding the degree of patient involvement (five levels from no information at all to involvement using SDM and a DA), the decision to have a PSA or not and three different outcomes (no PCa, diagnosis of a treatable PCa and diagnosis of an eventually lethal PCa). By way of example, in one scenario version, the doctor performs a PSA just telling the patient that he is doing some 'routine tests' and the patient is subsequently successfully treated for PCa. In another scenario version, the patient chooses not to have a PSA after nudged information in disfavoured of the PSA test and afterwards is diagnosed with a non-treatable PCa (please see box 1). And in yet another scenario version, the vignette patient is subject to SDM, DA and dialogue with the doctor, afterwards chooses not to have the PSA test done but later is diagnosed with a treatable PCa.

Scenarios have been previously described in more detail.¹² We chose this study design to assess the entire range of realistically occurring attitudes to patient involvement (figure 2).

Following the scenario, respondents were questioned about their satisfaction with healthcare if subject to the situation illustrated in the vignette (*'Please rate your satisfaction with the doctor's care'*; rated on a 5-point Likert scale from very dissatisfied to very satisfied). Respondents were also asked about their ability to identify with the situation described in the scenario.

Statistics and power analysis

We used the following power calculation to determine our sample size. For the primary outcome measure, 100 participants per group were required to detect a 0.45 SD (~'medium') effect between groups with a 5% risk of type 1 error and a power of 0.90 (cf group difference and SD characteristics; bidirectional two-sample homoscedastic t-test).^{19 20} We included an additional

Box 1 Extracts from one case vignette version

'Imagine that you are seeing your doctor for a "health check". The doctor asks a number of questions for symptoms such as shortness of breath, abdominal pain, etc. Your answer to all those questions is "No". The doctor also asks if there are any other issues to discuss. Your answer again is "No". Afterwards, the doctor does a stethoscopy examination of your chest. He also does a blood pressure, heart rate check-up, and a manual abdominal examination and tells you that everything seems ok.'

[...]

*'Your doctor tells you about a blood test for prostate cancer. It is called PSA. PSA is a natural enzyme produced by the male prostate gland that can be measured in blood. The test is used for diagnostics and control of prostate cancer treatment. PSA blood levels normally increase with age, prostate gland enlargement, and if the prostate is sick (eg, cancer). However, an increased PSA does not necessarily mean that you have prostate cancer. The doctor then tells you that "it is not common" to test all for prostate cancer with PSA because the test is not good enough. One can for example have increased PSA in the blood without having prostate cancer. In addition, prostate cancer may develop slowly so that you experience no prostate cancer symptoms before dying from other causes. Furthermore, the treatment of prostate cancer may have significant side effects. Therefore, the doctor would suggest himself not to have a PSA test done. **You decide not to have a PSA test done.**'*

[...]

'It appears that you have prostate cancer. During the course of treatment, you and your family get increasingly worried and see your doctor several times.'

[...]

'You subsequently have surgery aiming at totally eradicating the cancer. At first, you are informed that eradication was successful. However, you have side-effects like erectile dysfunction, urinary problems and slight fecal incontinence. Afterwards you are told that the prostate cancer is not entirely removed but unluckily has spread to other parts of the body. You receive chemo and radiation therapy but you understand that you probably will live for no more than 3 years.'

300 participants per group, totalling 12 000 participant invitations (400 participants per group in 30 groups) to compensate for non-responders (expected response rate of 25%)²¹ as well as to compensate for expected non-normality of the measurements. To address the risk of uneven response rates among groups, we obtained permission to launch up to three waves of 12 000 invitations.

Participant characteristics among the 30 different randomised vignette groups were compared by χ^2 test and reported as counts and proportions. We compared

satisfaction between groups on three levels in separate analyses. The first level signified the level of patient involvement in decision-making in five groups. The next level of 10 groups also took into account whether a PSA test was done. The last level including 30 comparisons also took into account the course of disease (box 1). For each of the three levels, comparisons were carried out by linear regression with a corresponding categorical grouping variable (with 5 categories on level of patient involvement, 10 categories on level of involvement in PSA testing and 30 categories on the third level including course of disease). We determined CIs and p values by bootstrapping with 1000 repetitions to compensate for residual non-normality as examined by quantile-quantile plots.

RESULTS

Satisfaction with medical care described in scenarios

No statistically significant differences between participant characteristics among the 30 randomised vignette groups were detected (online supplemental tables D1–D4). As one would anticipate, respondents' satisfaction with the care illustrated in scenarios waned with less favourable outcomes (from A to B and particularly to C scenarios; please see table 1). Despite many overlapping CIs there was a gradation in the score findings suggestive of more satisfaction with scenarios illustrating greater degrees of patient involvement. For example, satisfaction was statistically significantly larger if comparing no involvement to SDM and DA use ($p < 0.001$).

As shown in table 1, respondents were generally positive towards healthcare including intervention (PSA testing 'to be safe') and were generally less satisfied with scenarios in which the doctor's recommendation nudged against the intervention (PSA). Satisfaction with different scenarios is shown in figure 3.

Respondents generally reported that they were able to identify with the situations described in the vignettes with no tendency for skewness between outcome scenarios. Only 6% of respondents (377/6755) felt unable to identify with the illustrated situation.

DISCUSSION

In this large national vignette survey, participants responded to vignettes illustrating greater levels of patient involvement with higher satisfaction scores. Respondents tended to be positive towards testing and towards nudging in favour of testing ('defensive medicine'; groups 6–8) but SDM with DAs achieved the highest ratings of satisfaction with the health provider's care.

Interpretation of findings and comparison with existing literature

Informing patients about healthcare options, their pros and cons, and involving patients in choosing among options is a *conditio sine qua non* aspect of

No information about PSA test	Nudged information against PSA test	Neutral information about PSA test	Nudged information in favour of PSA test	PSA test decision aid and discussion
<i>Patient involvement</i>				
Decision-making by provider	'Negatively manipulated' decision	'Raw' informed consent	'Positively manipulated' decision	Shared decision
Ex. no PSA or doctor performs PSA declaring that 'we do some tests'	Ex. doctor informs about PSA pros and cons but says that the doctor would not choose PSA	Ex. doctor informs about PSA pros and cons and then leaves decision with patient ('you decide!')	Ex. doctor informs about PSA pros and cons but says that the doctor would choose PSA 'to be on the safe side'	Ex. Doctor informs about PSA, decision aid use and decision is made by patient after discussion with doctor

Figure 2 Simplified model of levels of patient involvement in decisions about prostate-specific antigen (PSA).

patient-centred care, acknowledging patients' needs and ensuring attunement of healthcare provision to patients' individual preferences and concerns.¹

Similarly, any disregard thereof inherently bears the seed of incongruence with patient expectations and discontentment with care. From the patient

Involvement level	Mean (95% CI)* n=6755	Decision (group)	Mean (95% CI) n=6755	Subgroup (course)	Mean (95% CI) n=6755
No involvement	3.81 (3.77 to 3.86) P<0.001	No PSA ¹	3.87 (3.81 to 3.93)	A (no PCa)	4.09 (4.01 to 4.18)
				B (treatable PCa)	3.87 (3.76 to 3.98)
				C (non-treatable PCa)	3.61 (3.50 to 3.71)
		PSA ²	3.77 (3.70 to 3.83)	A (no PCa)	4.03 (3.93 to 4.12)
				B (treatable PCa)	3.71 (3.61 to 3.82)
				C (non-treatable PCa)	3.50 (3.37 to 3.62)
Nudging against PSA	3.68 (3.63 to 3.73) P<0.001	No PSA ³	3.60 (3.53 to 3.68)	A (no PCa)	3.98 (3.89 to 4.07)
				B (treatable PCa)	3.52 (3.39 to 3.64)
				C (non-treatable PCa)	3.33 (3.20 to 3.45)
		PSA ⁴	3.76 (3.69 to 3.83)	A (no PCa)	4.09 (4.00 to 4.18)
				B (treatable PCa)	3.70 (3.58 to 3.83)
				C (non-treatable PCa)	3.46 (3.33 to 3.58)
Neutral info (Reference)	4.00 (3.95 to 4.04)	No PSA ⁵	3.96 (3.90 to 4.02)	A (no PCa)	4.15 (4.05 to 4.24)
				B (treatable PCa)	4.04 (3.95 to 4.13)
				C (non-treatable PCa)	3.67 (3.54 to 3.79)
		PSA ⁶	4.03 (3.97 to 4.09)	A (no PCa)	4.26 (4.18 to 4.35)
				B (treatable PCa)	4.01 (3.92 to 4.11)
				C (non-treatable PCa)	3.81 (3.70 to 3.92)
Nudging for PSA	4.05 (4.02 to 4.09) P=0.040	No PSA ⁷	4.07 (4.02 to 4.13)	A (no PCa)	4.25 (4.17 to 4.34)
				B (treatable PCa)	4.16 (4.07 to 4.25)
				C (non-treatable PCa)	3.80 (3.70 to 3.90)
		PSA ⁸	4.03 (3.98 to 4.09)	A (no PCa)	4.19 (4.10 to 4.28)
				B (treatable PCa)	4.04 (3.95 to 4.13)
				C (non treatable PCa)	3.89 (3.79 to 3.98)
SDM	4.07 (4.03 to 4.11) P=0.008	No PSA ⁹	4.08 (4.03 to 4.13)	A (no PCa)	4.19 (4.10 to 4.27)
				B (treatable PCa)	4.11 (4.03 to 4.20)
				C (non treatable PCa)	3.91 (3.82 to 4.01)
		PSA ¹⁰	4.06 (4.00 to 4.12)	A (no PCa)	4.19 (4.08 to 4.29)
				B (treatable PCa)	4.10 (4.01 to 4.20)
				C (non treatable PCa)	3.89 (3.79 to 4.00)

*'1' means very dissatisfied and '5' very satisfied.

PCa, prostate cancer; PSA, prostate-specific antigen; SDM, shared decision-making.

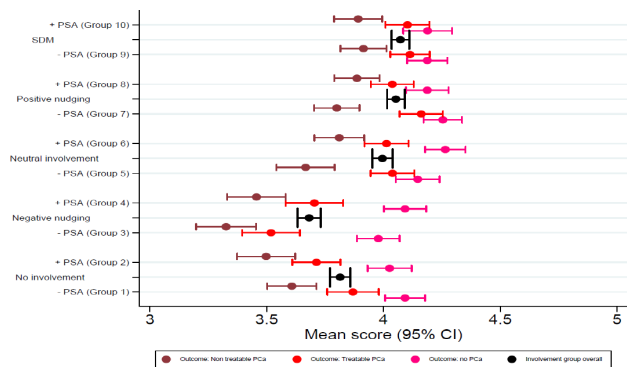


Figure 3 Respondent ratings of satisfaction with medical care illustrated in vignettes (5-point Likert scale: 1=Very dissatisfied, 2=Dissatisfied, 3=Neither satisfied nor dissatisfied, 4=Satisfied, 5=Very satisfied). PCa, prostate cancer; PSA, prostate-specific antigen; SDM, shared decision-making.

perspective, patients' understanding of healthcare options and agreement about choice of medical procedures therefore would seem fundamental to high healthcare quality. Patients may be informed through different means. In SDM, patients and healthcare providers communicate about healthcare options using the best available evidence while weighing risks and benefits and considering patients' personal preferences.⁶ DAs help to ensure accurate and consistent communication about the intervention's risks and benefits and help highlight patients' individual preferences and concerns.^{6,22} They are used in the dialogue with healthcare providers when making 'preference-sensitive' decisions where there is more than one reasonable healthcare choice. Although guidelines support the use of SDM, in clinical practice decisions about PSA screening (like most other healthcare decisions) are made with varying degrees of information provision and patient participation (figure 1).

To the authors' knowledge, no previous empirical investigation has examined the relationship between different levels of involvement in healthcare decision-making and satisfaction with care, while taking into account different clinical outcomes. Existing research on SDM and patients' assessment of the decision-making process have had conflicting results.^{11,23} Some studies regarding patients' satisfaction with actual healthcare provision found a positive effect of SDM on patient satisfaction and as such agree with our findings. For example, Mandelblatt and colleagues studied 718 patients with breast cancer, and found SDM to be associated with higher satisfaction with care.²⁴ Likewise, in a cross-sectional survey of 305 patients undergoing definitive radiotherapy, Shabason and colleagues found patient satisfaction to be associated with perceived SDM and patient-perceived control.²⁵ In a study of 233 patients with various cancers, Gattellari and colleagues found SDM to be positively associated with satisfaction with the consultation information received.³ In Keating *et al*'s study among 1081 patients

with breast cancer, the authors found SDM to be associated with greater satisfaction with the amount of treatment information provided,²⁶ and in Whelan *et al*'s study, use of SDM and DA was associated with higher ratings of satisfaction with decision-making compared with controls (the surgeon discussing the treatment 'in his/her usual fashion' without DA use; 5-point Likert rating difference 0.18; n=201).²⁷ Other studies have not been able to establish any association between SDM and patient satisfaction with care. Morgan *et al* found no difference between intervention and control groups totalling 240 patients with regard to satisfaction although patients became more knowledgeable, and underwent fewer interventional therapies.²⁸ Likewise, in Heisler and associates' larger study of 4198 patients with diabetes, no statistically significant association could be established between SDM use and satisfaction with provider communication,²⁹ and Edwards *et al* rather found satisfaction tended to be negatively associated with SDM use although that finding was not statistically significant (n=747).³⁰

Summed up, studies have struggled to consistently establish a positive effect on healthcare users' satisfaction through promoting patient participation. There are several conceivable explanations. One possible explanation is that patient involvement may not contribute positively to patients' experience of healthcare. Alternatively, the inability to establish the influence of patient involvement may reflect a ceiling effect.¹¹ This could also be an explanation for the relatively small Likert score differences detected in our study (see the Limitations section). As healthcare users may usually be positive towards the care they receive, measures may not detect any effect. This may be particularly true if studies do not consider healthcare users' views in situations where the outcome is poor. Studies have commonly been conducted without taking into account the actual choice (whether an intervention was opted for or not) or the outcome resulting from the choice.

In our study, only healthcare scenarios illustrating at least 'neutral' involvement of patients in decision-making succeeded in making the average respondent downright 'satisfied'. Furthermore, our study provides a careful warning against simply attempting to talk the patient out of getting an intervention. Respondents' satisfaction with care described in case vignettes was highest when patients had been actively involved in decisions and that higher satisfaction persisted even when the outcome was poor. In this regard, our findings suggest that use of SDM and DAs may promote satisfaction with care and makes healthcare users' assessment of care more robust across differing outcome scenarios. The differences in variability among outcomes (scenarios A–C) show that when patients are involved, healthcare satisfaction in non-SDM scenarios is more dependent on a positive healthcare outcome. As the outcome is not fully

under the control of the health provider, employing SDM appears to be a prudent approach to optimising healthcare users' satisfaction when making healthcare decisions. Given that greater patient involvement and SDM with DA use does not adversely affect healthcare outcomes,¹¹ and research suggests the approach to be cost-effective,³¹ there seems to be an overall gain in recommending it.

Limitations

Our study has several limitations. First, our findings only allow for tentative conclusions about the likely effect size of greater patient involvement on satisfaction in the real world. The relatively small effects found in our study may agree well with findings from studies in the real world suggesting that in general, patients may already express reserved satisfaction with healthcare (a ceiling effect; please see above¹¹). Everything depends on the perspective taken, though. Given the premise of patient-centredness, every little improvement in patients' assessment of healthcare in principle would count but our findings suggest that it may be difficult for providers to achieve consistently high satisfaction with care unless they involve patients in decision-making.

Still, it can be argued that our study using a hypothetical case vignette rather than a real-life set-up might be better suited for studying the relative likelihood of satisfaction with healthcare than for establishing an absolute measure of patient satisfaction. Similarly, it should be borne in mind that figures showing average satisfaction across outcome scenarios place equal weight on each outcome even though detection of PCa is much less common than finding no cancer with a PSA test.

The case vignette design reflects hypothetical judgements and we therefore cannot rule out that participants' behaviour might have been different in real life. This caveat, however, seems contradicted in studies comparing actual choices with stated preferences.³² Likewise, during survey development, patient and public representatives indicated that they could relate to the patient in the situations described in vignettes¹² and a large majority of survey respondents indicated that they were able to identify with the situations described in vignettes. Similarly, survey respondents were passive witnesses to the course of healthcare described in the vignettes without any ability to influence decision-making. As an alternative, they could have been offered the opportunity to, for example, decide themselves whether to have a PSA test done. This could be an attractive design in future studies although it would require specific attention to safeguarding sample size in each scenario variant to achieve enough statistical power.

Second, owing to population and scenarios chosen, the question arises as to the generalisability of our study. For example, our study excluded women due to

the focus on PCa. Women may differ in their views on participation in healthcare decision-making, although previous research with women with cancer suggests this is not the case.²⁴ Likewise, in this study we did not investigate deeper into groups for whom there may be variation in their response to patient involvement, such as those with lower health literacy and those who are older, both of whom might prefer a more paternalistic model. The findings of our study must be interpreted bearing in mind this caveat that also underscores the requirement for further research into the variation in involvement preferences among different groups of healthcare users. As a final point, the possibility of non-response bias must be kept in mind. Even if our comparisons with national statistics information and previously published international data suggest our sample to be reasonably representative of the socio-demographic, personality and decision control preferences of adult men, the possibility of residual bias cannot be ruled out.¹³

CONCLUSION

Expert committees, policies, health laws and codes of ethics increasingly stress patient-centredness as a key aspect of high-quality healthcare, generally requiring patient involvement in healthcare decision-making. While such an approach is strongly supported by bioethical principles maintaining patients' right to self-determination, empirical evidence on whether patients prefer participation in healthcare decision-making has been scant. In this paper, we report the results from a large national case vignette survey investigating men's preferences for participation in decision-making about having a PSA test. Results generally indicate that participants expressed higher satisfaction with healthcare scenarios describing greater patient involvement in decision-making. SDM with DAs generated the highest and most consistent ratings of satisfaction with care when taking into account different decisions and outcomes.

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data. All authors read, commented and approved the final manuscript.

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REFERENCES

- 1 The Institute of Medicine. *Crossing the quality chasm: a new health system for the 21st century*. Washington D.C, 2001.
- 2 Beauchamp TL, Childress JF. *Principles of biomedical ethics*. Seventh Edition. Oxford University Press, 2012.
- 3 Gattellari M, Butow PN, Tattersall MH. Sharing decisions in cancer care. *Soc Sci Med* 2001;52:1865–78.
- 4 General Comment No. 14 (2000), the right to the highest attainable standard of health (article 12 of the International covenant on economic, social and cultural rights), (2000).
- 5 Convention for the protection of human rights and dignity of the human being with regard to the application of biology and medicine: convention on human rights and biomedicine 1997.
- 6 Barry MJ. Shared decision making: informing and involving patients to do the right thing in health care. *J Ambul Care Manage* 2012;35:90–8.
- 7 Birkeland SF. Informed consent Obtainment, malpractice litigation, and the potential role of shared decision-making approaches. *Eur J Health Law* 2016;24:264–84.
- 8 Rosenbaum L. The Paternalism Preference--Choosing Unshared Decision Making. *N Engl J Med* 2015;373:589–92.
- 9 Hart RI, Cameron DA, Cowie FJ, et al. The challenges of making informed decisions about treatment and trial participation following a cancer diagnosis: a qualitative study involving adolescents and young adults with cancer and their caregivers. *BMC Health Serv Res* 2020;20:25.
- 10 Levinson W, Kao A, Kuby A, et al. Not all patients want to participate in decision making. A national study of public preferences. *J Gen Intern Med* 2005;20:531–5.
- 11 Stacey D, Légaré F, Lewis K, et al. Decision AIDS for people facing health treatment or screening decisions. *Cochrane Database Syst Rev* 2017;4:Cd001431.
- 12 Birkeland S, Pedersen SS, Haakonsson AK, et al. Men's view on participation in decisions about prostate-specific antigen (PSA) screening: patient and public involvement in development of a survey. *BMC Med Inform Decis Mak* 2020;20:65.
- 13 Birkeland S, Linkhorst T, Haakonsson A, et al. Representativeness of personality and involvement preferences in a web-based survey on healthcare decision-making. *BMC Health Serv Res* 2020;20:851.
- 14 Birkeland SF, Haakonsson AK, Pedersen SS, et al. Sociodemographic representativeness in a nationwide web-based survey of the view of men on involvement in health care decision-making: cross-sectional questionnaire study. *J Med Internet Res* 2020;22:e19517.
- 15 Ferlay J, Shin H-R, Bray F, et al. Estimates of worldwide burden of cancer in 2008: GLOBOCAN 2008. *Int J Cancer* 2010;127:2893–917.
- 16 Alberts AR, Schoots IG, Roobol MJ. Prostate-Specific antigen-based prostate cancer screening: past and future. *Int J Urol* 2015;22:524–32.
- 17 Schröder FH, Hugosson J, Roobol MJ, et al. Screening and prostate cancer mortality: results of the European randomised study of screening for prostate cancer (ERSPC) at 13 years of follow-up. *Lancet* 2014;384:2027–35.
- 18 Harris PA, Taylor R, Thielke R, et al. Research electronic data capture (REDCap)—a metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inform* 2009;42:377–81.
- 19 DeWitt T, Brady MK. Rethinking service recovery strategies: the effect of Rapport on consumer responses to service failure. *Journal of Service Research* 2003;6:193–207.
- 20 Altman D. *Practical statistics for medical research*. London: Chapman & Hall, 1991: 611.
- 21 Barry MJ, Wexler RM, Brackett CD, et al. Responses to a decision aid on prostate cancer screening in primary care practices. *Am J Prev Med* 2015;49:520–5.
- 22 King JS, Moulton BW. Rethinking informed consent: the case for shared medical decision-making. *Am J Law Med* 2006;32:429–501.
- 23 Joosten EAG, DeFuentes-Merillas L, de Weert GH, et al. Systematic review of the effects of shared decision-making on patient satisfaction, treatment adherence and health status. *Psychother Psychosom* 2008;77:219–26.
- 24 Mandelblatt J, Kreling B, Figueriedo M, et al. What is the impact of shared decision making on treatment and outcomes for older women with breast cancer? *J Clin Oncol* 2006;24:4908–13.
- 25 Shabason JE, Mao JJ, Frankel ES, et al. Shared decision-making and patient control in radiation oncology: implications for patient satisfaction. *Cancer* 2014;120:1863–70.
- 26 Keating NL, Guadagnoli E, Landrum MB, et al. Treatment decision making in early-stage breast cancer: should surgeons match patients' desired level of involvement? *J Clin Oncol* 2002;20:1473–9.
- 27 Whelan T, Levine M, Willan A, et al. Effect of a decision aid on knowledge and treatment decision making for breast cancer surgery: a randomized trial. *JAMA* 2004;292:435–41.
- 28 Morgan MW, Deber RB, Llewellyn-Thomas HA, et al. Randomized, controlled trial of an interactive videodisc decision aid for patients with ischemic heart disease. *J Gen Intern Med* 2000;15:685–93.

- 29 Heisler M, Tierney E, Ackermann RT, *et al.* Physicians' participatory decision-making and quality of diabetes care processes and outcomes: results from the triad study. *Chronic Illn* 2009;5:165–76.
- 30 Edwards A, Elwyn G, Hood K, *et al.* Patient-Based outcome results from a cluster randomized trial of shared decision making skill development and use of risk communication AIDS in general practice. *Fam Pract* 2004;21:347–54.
- 31 Kennedy ADM, Sculpher MJ, Coulter A, *et al.* A multicentre randomised controlled trial assessing the costs and benefits of using structured information and analysis of women's preferences in the management of menorrhagia. *Health Technol Assess* 2003;7:1–76.
- 32 Herrmann A, Sanson-Fisher R, Hall A, *et al.* A discrete choice experiment to assess cancer patients' preferences for when and how to make treatment decisions. *Support Care Cancer* 2018;26:1215–20.

Supplementary table D1

Age distribution by vignette (Involvement level/Decision/Course). Test for difference in distribution P= 0.965.

Involvement level/Decision/Course	Age 45-49	Age 50-54	Age 55-59	Age 60-64	Age 65-70
No involvement/No PSA/no PCa	26 (11%)	47 (20%)	47 (20%)	50 (21%)	68 (29%)
No involvement/No PSA/treatable PCa	27 (12%)	26 (12%)	52 (23%)	53 (24%)	64 (29%)
No involvement/No PSA/non treatable PCa	29 (14%)	39 (19%)	43 (21%)	42 (20%)	56 (27%)
No involvement/PSA/no PCa	30 (11%)	56 (21%)	52 (19%)	54 (20%)	75 (28%)
No involvement/PSA/treatable PCa	30 (12%)	49 (20%)	50 (20%)	49 (20%)	66 (27%)
No involvement/PSA/non treatable PCa	25 (12%)	37 (18%)	45 (21%)	42 (20%)	62 (29%)
Nudging against PSA/No PSA/no PCa	27 (12%)	49 (21%)	41 (18%)	52 (23%)	59 (26%)
Nudging against PSA/No PSA/treatable PCa	39 (16%)	43 (18%)	53 (22%)	53 (22%)	55 (23%)
Nudging against PSA/No PSA/non treatable PCa	25 (11%)	44 (19%)	46 (20%)	48 (21%)	67 (29%)
Nudging against PSA/PSA/no PCa	31 (13%)	48 (20%)	52 (22%)	59 (25%)	48 (20%)
Nudging against PSA/PSA/treatable PCa	33 (14%)	43 (19%)	43 (19%)	47 (20%)	64 (28%)
Nudging against PSA/PSA/non treatable PCa	34 (16%)	41 (19%)	39 (18%)	37 (17%)	66 (30%)
Neutral info/No PSA/no PCa	35 (16%)	35 (16%)	46 (20%)	43 (19%)	66 (29%)
Neutral info/No PSA/treatable PCa	28 (12%)	44 (19%)	50 (21%)	50 (21%)	61 (26%)
Neutral info/No PSA/non treatable PCa	32 (16%)	29 (14%)	34 (17%)	44 (22%)	62 (31%)
Neutral info/PSA/no PCa	26 (12%)	40 (18%)	41 (19%)	60 (27%)	52 (24%)
Neutral info/PSA/treatable PCa	27 (12%)	53 (23%)	55 (24%)	48 (21%)	47 (20%)
Neutral info/PSA/non treatable PCa	33 (15%)	37 (17%)	40 (18%)	45 (20%)	67 (30%)
Nudging for PSA/No PSA/no PCa	33 (14%)	41 (18%)	47 (21%)	51 (22%)	56 (25%)
Nudging for PSA/No PSA/treatable PCa	45 (20%)	43 (19%)	40 (17%)	44 (19%)	57 (25%)
Nudging for PSA/No PSA/non treatable PCa	32 (14%)	43 (19%)	42 (18%)	53 (23%)	60 (26%)
Nudging for PSA/PSA/no PCa	39 (19%)	40 (19%)	39 (19%)	37 (18%)	53 (25%)
Nudging for PSA/PSA/treatable PCa	36 (15%)	37 (16%)	54 (23%)	45 (19%)	66 (28%)
Nudging for PSA/PSA/non treatable PCa	28 (13%)	31 (14%)	48 (22%)	48 (22%)	65 (30%)
SDM/No PSA/no PCa	31 (12%)	43 (16%)	58 (22%)	54 (21%)	75 (29%)
SDM/No PSA/treatable PCa	29 (13%)	43 (19%)	50 (23%)	36 (16%)	63 (29%)
SDM/No PSA/non treatable PCa	27 (13%)	37 (18%)	46 (22%)	44 (21%)	56 (27%)
SDM/PSA/no PCa	30 (15%)	36 (18%)	40 (20%)	41 (21%)	49 (25%)
SDM/PSA/treatable PCa	39 (18%)	36 (17%)	40 (19%)	40 (19%)	59 (28%)
SDM/PSA/non treatable PCa	29 (15%)	35 (18%)	35 (18%)	37 (19%)	58 (30%)

Supplementary table D2

Home municipality type distribution by vignette (Involvement level/Decision/Course). Test for difference in distribution $P=0.651$.

Involvement level/Decision/Course	Urban	Rural	Urban-rural	Outskirts
No involvement/No PSA/no PCa	86 (36%)	74 (31%)	53 (22%)	25 (11%)
No involvement/No PSA/treatable PCa	98 (44%)	66 (30%)	33 (15%)	25 (11%)
No involvement/No PSA/non treatable PCa	89 (43%)	72 (34%)	32 (15%)	16 (8%)
No involvement/PSA/no PCa	116 (43%)	76 (28%)	46 (17%)	29 (11%)
No involvement/PSA/treatable PCa	110 (45%)	59 (24%)	45 (18%)	30 (12%)
No involvement/PSA/non treatable PCa	87 (41%)	67 (32%)	44 (21%)	13 (6%)
Nudging against PSA/No PSA/no PCa	85 (37%)	61 (27%)	59 (26%)	23 (10%)
Nudging against PSA/No PSA/treatable PCa	113 (47%)	67 (28%)	40 (16%)	23 (9%)
Nudging against PSA/No PSA/non treatable PCa	95 (41%)	73 (32%)	31 (13%)	31 (13%)
Nudging against PSA/PSA/no PCa	105 (44%)	70 (29%)	34 (14%)	29 (12%)
Nudging against PSA/PSA/treatable PCa	102 (44%)	68 (30%)	35 (15%)	25 (11%)
Nudging against PSA/PSA/non treatable PCa	93 (43%)	72 (33%)	34 (16%)	18 (8%)
Neutral info/No PSA/no PCa	93 (41%)	67 (30%)	41 (18%)	24 (11%)
Neutral info/No PSA/treatable PCa	100 (43%)	66 (28%)	43 (18%)	24 (10%)
Neutral info/No PSA/non treatable PCa	81 (40%)	64 (32%)	40 (20%)	16 (8%)
Neutral info/PSA/no PCa	89 (41%)	67 (31%)	47 (21%)	16 (7%)
Neutral info/PSA/treatable PCa	96 (42%)	72 (31%)	43 (19%)	19 (8%)
Neutral info/PSA/non treatable PCa	88 (40%)	81 (36%)	32 (14%)	21 (9%)
Nudging for PSA/No PSA/no PCa	99 (43%)	67 (29%)	40 (18%)	22 (10%)
Nudging for PSA/No PSA/treatable PCa	98 (43%)	70 (31%)	41 (18%)	20 (9%)
Nudging for PSA/No PSA/non treatable PCa	88 (38%)	66 (29%)	47 (20%)	29 (13%)
Nudging for PSA/PSA/no PCa	84 (40%)	64 (31%)	33 (16%)	27 (13%)
Nudging for PSA/PSA/treatable PCa	92 (39%)	84 (35%)	31 (13%)	31 (13%)
Nudging for PSA/PSA/non treatable PCa	94 (43%)	64 (29%)	36 (16%)	26 (12%)
SDM/No PSA/no PCa	102 (39%)	85 (33%)	40 (15%)	34 (13%)
SDM/No PSA/treatable PCa	101 (46%)	55 (25%)	44 (20%)	21 (10%)
SDM/No PSA/non treatable PCa	90 (43%)	57 (27%)	38 (18%)	25 (12%)
SDM/PSA/no PCa	81 (41%)	55 (28%)	36 (18%)	24 (12%)
SDM/PSA/treatable PCa	92 (43%)	68 (32%)	36 (17%)	18 (8%)
SDM/PSA/non treatable PCa	81 (42%)	65 (34%)	29 (15%)	19 (10%)

Supplementary table D3

Work status and civil status distribution by vignette (Involvement level/Decision/Course). Test for difference in distribution $P=0.118$ for work status and $P=0.460$ for civil status.

Involvement level/Decision/Course	Student	Unemployed	Working	Pension	Partner, living together	Partner, not living together	Single
No involvement/No PSA/no PCa	0 (0%)	7 (3%)	149 (63%)	82 (34%)	182 (76%)	14 (6%)	42 (18%)
No involvement/No PSA/treatable PCa	0 (0%)	9 (4%)	141 (64%)	72 (32%)	164 (74%)	12 (5%)	46 (21%)
No involvement/No PSA/non treatable PCa	0 (0%)	6 (3%)	135 (65%)	68 (33%)	164 (78%)	11 (5%)	34 (16%)
No involvement/PSA/no PCa	1 (0%)	8 (3%)	172 (64%)	86 (32%)	221 (83%)	11 (4%)	35 (13%)
No involvement/PSA/treatable PCa	2 (1%)	10 (4%)	162 (66%)	70 (29%)	183 (75%)	14 (6%)	47 (19%)
No involvement/PSA/non treatable PCa	1 (0%)	9 (4%)	134 (64%)	67 (32%)	173 (82%)	6 (3%)	32 (15%)
Nudging against PSA/No PSA/no PCa	0 (0%)	5 (2%)	152 (67%)	71 (31%)	180 (79%)	9 (4%)	39 (17%)
Nudging against PSA/No PSA/treatable PCa	0 (0%)	8 (3%)	170 (70%)	65 (27%)	199 (82%)	10 (4%)	34 (14%)
Nudging against PSA/No PSA/non treatable PCa	1 (0%)	6 (3%)	146 (63%)	77 (33%)	182 (79%)	9 (4%)	39 (17%)
Nudging against PSA/PSA/no PCa	0 (0%)	12 (5%)	172 (72%)	54 (23%)	188 (79%)	12 (5%)	38 (16%)
Nudging against PSA/PSA/treatable PCa	1 (0%)	4 (2%)	150 (65%)	75 (33%)	176 (77%)	16 (7%)	38 (17%)
Nudging against PSA/PSA/non treatable PCa	0 (0%)	8 (4%)	142 (65%)	67 (31%)	168 (77%)	10 (5%)	39 (18%)
Neutral info/No PSA/no PCa	0 (0%)	9 (4%)	154 (68%)	62 (28%)	171 (76%)	15 (7%)	39 (17%)
Neutral info/No PSA/treatable PCa	0 (0%)	5 (2%)	165 (71%)	63 (27%)	195 (84%)	10 (4%)	28 (12%)
Neutral info/No PSA/non treatable PCa	1 (0%)	12 (6%)	123 (61%)	65 (32%)	156 (78%)	8 (4%)	37 (18%)
Neutral info/PSA/no PCa	0 (0%)	12 (5%)	146 (67%)	61 (28%)	182 (83%)	9 (4%)	28 (13%)
Neutral info/PSA/treatable PCa	1 (0%)	16 (7%)	160 (70%)	53 (23%)	187 (81%)	10 (4%)	33 (14%)
Neutral info/PSA/non treatable PCa	2 (1%)	4 (2%)	146 (66%)	70 (32%)	172 (77%)	9 (4%)	41 (18%)
Nudging for PSA/No PSA/no PCa	0 (0%)	8 (4%)	156 (68%)	64 (28%)	173 (76%)	14 (6%)	41 (18%)
Nudging for PSA/No PSA/treatable PCa	0 (0%)	12 (5%)	155 (68%)	62 (27%)	188 (82%)	10 (4%)	31 (14%)
Nudging for PSA/No PSA/non treatable PCa	0 (0%)	14 (6%)	150 (65%)	66 (29%)	185 (80%)	7 (3%)	38 (17%)
Nudging for PSA/PSA/no PCa	0 (0%)	10 (5%)	137 (66%)	61 (29%)	169 (81%)	5 (2%)	34 (16%)
Nudging for PSA/PSA/treatable PCa	0 (0%)	15 (6%)	159 (67%)	64 (27%)	198 (83%)	9 (4%)	31 (13%)
Nudging for PSA/PSA/non treatable PCa	1 (0%)	4 (2%)	137 (62%)	78 (35%)	166 (75%)	15 (7%)	39 (18%)
SDM/No PSA/no PCa	0 (0%)	9 (3%)	168 (64%)	84 (32%)	216 (83%)	7 (3%)	38 (15%)
SDM/No PSA/treatable PCa	0 (0%)	9 (4%)	144 (65%)	68 (31%)	177 (80%)	9 (4%)	35 (16%)
SDM/No PSA/non treatable PCa	0 (0%)	4 (2%)	134 (64%)	72 (34%)	170 (81%)	17 (8%)	23 (11%)
SDM/PSA/no PCa	0 (0%)	10 (5%)	123 (63%)	63 (32%)	154 (79%)	8 (4%)	34 (17%)
SDM/PSA/treatable PCa	0 (0%)	2 (1%)	140 (65%)	72 (34%)	181 (85%)	10 (5%)	23 (11%)
SDM/PSA/non treatable PCa	0 (0%)	4 (2%)	123 (63%)	67 (35%)	150 (77%)	7 (4%)	37 (19%)

Supplementary table D4

Presence of chronic disease and experiences with prostate cancer distribution by vignette (Involvement level/Decision/Course). Test for difference in distribution $P=0.309$ for chronic disease and $P=0.338$ for experience with examination or tests for prostate cancer.

Involvement level/Decision/Course	No chronic disease	Chronic disease	No experience with PCa examination or test	PCa examination or test experience
No involvement/No PSA/no PCa	120 (50%)	118 (50%)	63 (26%)	175 (74%)
No involvement/No PSA/treatable PCa	117 (53%)	105 (47%)	44 (20%)	178 (80%)
No involvement/No PSA/non treatable PCa	123 (59%)	86 (41%)	38 (18%)	171 (82%)
No involvement/PSA/no PCa	166 (62%)	101 (38%)	50 (19%)	217 (81%)
No involvement/PSA/treatable PCa	133 (55%)	111 (45%)	55 (23%)	189 (77%)
No involvement/PSA/non treatable PCa	122 (58%)	89 (42%)	36 (17%)	175 (83%)
Nudging against PSA/No PSA/no PCa	133 (58%)	95 (42%)	47 (21%)	181 (79%)
Nudging against PSA/No PSA/treatable PCa	144 (59%)	99 (41%)	39 (16%)	204 (84%)
Nudging against PSA/No PSA/non treatable PCa	133 (58%)	97 (42%)	45 (20%)	185 (80%)
Nudging against PSA/PSA/no PCa	143 (60%)	95 (40%)	41 (17%)	197 (83%)
Nudging against PSA/PSA/treatable PCa	139 (60%)	91 (40%)	45 (20%)	185 (80%)
Nudging against PSA/PSA/non treatable PCa	136 (63%)	81 (37%)	44 (20%)	173 (80%)
Neutral info/No PSA/no PCa	126 (56%)	99 (44%)	43 (19%)	182 (81%)
Neutral info/No PSA/treatable PCa	130 (56%)	103 (44%)	48 (21%)	185 (79%)
Neutral info/No PSA/non treatable PCa	111 (55%)	90 (45%)	49 (24%)	152 (76%)
Neutral info/PSA/no PCa	120 (55%)	99 (45%)	45 (21%)	174 (79%)
Neutral info/PSA/treatable PCa	141 (61%)	89 (39%)	35 (15%)	195 (85%)
Neutral info/PSA/non treatable PCa	141 (64%)	81 (36%)	46 (21%)	176 (79%)
Nudging for PSA/No PSA/no PCa	136 (60%)	92 (40%)	48 (21%)	180 (79%)
Nudging for PSA/No PSA/treatable PCa	129 (56%)	100 (44%)	31 (14%)	198 (86%)
Nudging for PSA/No PSA/non treatable PCa	135 (59%)	95 (41%)	47 (20%)	183 (80%)
Nudging for PSA/PSA/no PCa	129 (62%)	79 (38%)	36 (17%)	172 (83%)
Nudging for PSA/PSA/treatable PCa	150 (63%)	88 (37%)	55 (23%)	183 (77%)
Nudging for PSA/PSA/non treatable PCa	137 (62%)	83 (38%)	53 (24%)	167 (76%)
SDM/No PSA/no PCa	155 (59%)	106 (41%)	57 (22%)	204 (78%)
SDM/No PSA/treatable PCa	134 (61%)	87 (39%)	39 (18%)	182 (82%)
SDM/No PSA/non treatable PCa	126 (60%)	84 (40%)	41 (20%)	169 (80%)
SDM/PSA/no PCa	112 (57%)	84 (43%)	38 (19%)	158 (81%)
SDM/PSA/treatable PCa	142 (66%)	72 (34%)	39 (18%)	175 (82%)
SDM/PSA/non treatable PCa	114 (59%)	80 (41%)	36 (19%)	158 (81%)