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Røssell E-L, Bekker HL, Borgquist S, Kristiansen IV, Schonberg MA, Støvring H. *Danish women make decisions about participation in breast cancer screening prior to invitation information: an online survey using experimental methods*. Medical Decision Making (Accepted March 2024)

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Almost all Danish women of pre-screening age wanted to participate in breast cancer screening suggesting that information at the time of screening invitation may be too late to support informed decision-making.

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Abstract

Introduction: At mammography screening invitation, the Danish Health Authority recommends women aged 50-69 to make an informed decision about whether or not to be screened. Previous studies have shown that women have very positive attitudes about screening participation. Therefore, we hypothesized that Danish women may already have decided to participate in breast cancer screening prior to receiving their screening invitation at age 50.

Methods: We invited a random sample of 2,952 Danish women 44-49 years (pre-screening age) to complete an online questionnaire about barriers to informed screening decision-making using the official digital mailbox system in Denmark. We asked participants about their screening intentions using three different questions to which women were randomized: 1) Screening presented as an opportunity; 2) as a choice; and 3) as an opportunity plus a question about women's stage of decision-making. All women completed questions about background characteristics, intended participation in the screening program, use and impact of screening information, and preferences for the decision-making process. Data were linked to sociodemographic register data.

Results: A total of 790 (26.8%) women participated in the study. Hereof, 97% (95% CI: 96%-98%) reported that they wanted to participate in breast cancer screening when invited at age 50. When presented with the choice compared to the opportunity framing, more women rejected screening. When asked about their stage of decision-making, the majority (87%) had already made a decision about screening participation and were unlikely to change their mind.

Conclusion: In our study, almost all women of pre-screening age wanted to participate in breast cancer screening suggesting that providing information at the time of screening invitation may be too late to support informed decision-making.

Word count (max 275 words): 272

Highlights (2-4 short bullet points)

- Almost all women of pre-screening age (44-49 years) in our study wanted to participate in the Danish national mammography screening program starting at age 50.
- Early decision-making represents a barrier for informed decision-making as women in this study had intentions to participate in breast cancer screening prior to official screening invitation and, therefore, providing information at the time of screening invitation may be too late to support informed decision-making.
- Very few women rejected screening participation; however, more women rejected screening when the information was framed as an active choice between having or declining breast cancer screening (continue with usual care) compared to only presenting the option of screening with no description of the alternative.
- Two-thirds of women reading the screening information in this study had unchanged attitudes toward screening after reading the presented information.

Introduction

Breast cancer screening is offered in many countries worldwide (1) and is recommended by the World Health Organization (2) and the Danish Health Authority (DHA) (3). However, breast cancer screening is the subject of an ongoing debate as it involves both potential benefits and harms (4). The benefits of screening are associated with reduced breast cancer mortality through early detection and treatment; harms are related to overdiagnosis, overtreatment (4), as well as false positive (5,6), and false negative screening results (3,7). Informed decision-making (4), shared decision-making (2), and the use of decision aid interventions are recommended to support women's choices about breast cancer screening participation (8) and to preserve individual autonomy and integrity (9). Due to the uncertainty about both benefits and harms of screening, there is a specific need for improved, transparent, and objective information about risks and probabilities (4).

Previous studies report widespread enthusiasm toward breast and other cancer screening programs (10-13). Several factors are associated with a positive attitude toward cancer screening programs including strong *a priori* held beliefs about the value of screening (14-17); worry or fear of breast cancer (12,15,17,18); information about a personal risk of cancer, reassurance (19,20), or even a desire for personal health information available through screening (10,12); a moral obligation to be screened (15,21,22); and pressure to participate from family or friends (16,18). Further, women's judgements about screening-related facts seem to be biased in favor of screening. As an example, perceived magnitude of breast cancer mortality benefits is overestimated (23), and weighted higher than harms (20,24,25). Moreover, information is rejected if it conflicts with established beliefs (12,15,16,25,26). These factors challenge well-informed screening decision-making solely based on facts presented at screening invitation. In addition, beliefs about screening are formed prior to invitation (14-17), information is disregarded (12,15,16,25,26) and decision-making is part of a social and cultural context (16,22). Thus, women's decision to participate and screening values seem to be formed prior to receiving screening information (16). Therefore, it is likely that women are not making fully informed decisions about participation at the time of screening invitation.

In our previous study of Danish women, more than 80% wanted to participate in a hypothetical breast cancer screening even when there was no reduction in mortality, and there were potential harms related to unnecessary treatment (13). While the setup was hypothetical, the findings suggest that enthusiasm for screening in Denmark is stronger than previously

thought and that decisions might be based more on prior screening attitudes than on presented screening information. Denmark as well as the other Nordic countries is characterized by a high level of trust in authorities (27). However, compared to the other Nordic countries with public health care systems and national screening programs, Denmark has a higher mammography screening uptake (83% in 2020-2021) (28), than both Norway (76% in 2021) (29) and Sweden (79% in 2019-2020) (30). Research suggests that the invitation information for cancer screening in Denmark (16,20) and other countries (31) is framed positively and presented as an opportunity to attend rather than an active choice between screening and not screening. Few leaflets provide balanced information about both benefits and harms of cancer screening, describe explicitly the alternative option to continue without screening, or mention trade-offs between screening and usual care options (32).

Based on the factors challenging women's screening decision-making process as well as the context of screening information and invitation in Denmark, the predefined study hypothesis was that standard screening information would not impact women's decision-making, as the majority of Danish women have already made their decision about participation prior to receiving the invitation for mammography screening. We hypothesized that 80% of women would want to participate in screening when the invitation information was framed as an opportunity to have screening, reflecting the percentage of women who had already made their decision about screening prior to receiving the invitation. We hypothesized that 70% of women would want to participate in screening when the invitation was framed as a choice between screening or not screening, reflecting the impact of framing breast cancer screening as a choice between options and consideration of trade-offs between perceived harms or benefits for both screening or not screening (33). The study further explores the use and impact of screening information in women's decision-making, preferences for screening decision-making and screening recommendations, and decision certainty measured by the "Stage of Decision Making" questionnaire (34).

Methods

This study is the third and last study of a project investigating women's decision-making, participation, and use of screening information when invited to the Danish national mammography screening program (13,35). The project aim is to provide evidence-based recommendations to inform women about breast cancer screening in Denmark. This cross-

sectional survey study of Danish women of pre-screening age (44-49 years) investigated barriers to informed decision-making concerning breast cancer screening by investigating screening decision prior to invitation, certainty about screening participation, use and impact of screening information, and preferences for the decision-making process.

Study population and design

We intended to invite a random sample of 3,000 women aged 44-49 and residents in Denmark in May 2022 to participate. Women were randomly selected by the Danish Health Data Authority using individual civil registration numbers assigned to all in Denmark (36). Information about the study and questionnaire were forwarded to the invited women using the official digital mailbox system in Denmark (e-Boks). The information included a link to access the online questionnaire, and login information. The information and questionnaire were only offered in Danish. Prior to participation, women had to consent to handling of their personal information. We invited women to participate between June and August 2022 and one reminder was sent in case of non-response. Women who did not have access to e-Boks were excluded (n=48) and the invited sample thus consisted of 2,952 women.

Using the individual civil registration numbers, we obtained the most recent data on socioeconomic status (based on employment data from 2020), educational level, civil status, municipality, and whether the person was an immigrant, descendant (born in Denmark by non-Danish parents) or of Danish origin (at least one parent born in Denmark and Danish citizen) (data from 2021). These sociodemographic variables were selected in accordance with previous studies of screening participation (37).

Intervention and randomization

Participants were randomized to one of three interventions: 1) Opportunity frame (presentation of the option to have screening, with no other alternative), 2) Choice frame (presentation of the option to have screening and an option of usual care with no screening), and 3) Stage of Decision Making questionnaire (34) (question about their stage of decision-making followed by the opportunity frame to have screening). Texts for each randomization group is shown in Figure 1. Women were randomized to the three groups using a parallel design and an allocation ratio of 1:1:1 using block randomization with block size of four.

The main hypothesis and research questions were developed based on the literature on cancer screening, decision science theory (33,34), and the Theory of Planned Behavior (38). According to the Theory of Planned Behavior, individual screening behavior is determined

by the intention toward screening as well as actual control over the present situation. Furthermore, the intention is determined by individual attitudes toward screening, subjective norms (in society and personal network), and perceived behavioral control (38). This theory has been applied in previous studies (16,39,40).

The questionnaires were tested with five women in the target age group with different educational backgrounds. Testing was carried out using individual cognitive interviews by phone or video call. The questionnaires can be found in English and Danish in Appendix I and II, respectively.

[Figure 1 about here]

Questionnaire and measures

For all women across randomization groups, the main outcome measure was intended participation in screening assessed by a 5-point Likert scale question (ranging from "I do not want to participate" to "I want to participate", there was some variation in the phrasing of the responses across questionnaire versions, see Figure 1). Otherwise, the questionnaires only differed in questions related to the framing of information group, and "Stage of Decision Making" questionnaire (see Figure 1). The first group was offered the choice framing while the two other groups were offered the opportunity framing (33). In addition, one of the two last groups were randomized to receive the validated "Stage of Decision Making" questionnaire capturing women's certainty about their screening decision (six response options) (34). "Stage of Decision Making" was translated into Danish in accordance with the World Health Organization's guidelines for forward and backward translation and discussion of each translation in an expert panel (see Appendix III for details) (41,42). The "Stage of Decision Making" questionnaire was only offered to one group because stage of decision making could possibly be influenced by framing of information (the opportunity framing was used for this randomization group because it was similar to the current screening invitation).

All three versions of the questionnaire captured age, educational level, questions related to breast cancer (history, worry, and perceived risk (12,13)), and previous mammography (no/yes with referral/yes without referral). Subsequent questions concerned reading health information in general, reading the current screening leaflet from the DHA enclosed in the Danish screening invitation (a link to the leaflet was included in the questionnaire), screening attitudes after reading the screening leaflet, preferences for decision-making and screening recommendations (four statements), and preferences for

future screening invitation (information and/or invitation letter sent at screening invitation). The whole questionnaire is presented in Appendix I. The screening leaflet from the DHA presented the screening offer including a recommendation to participate. In addition, the leaflet included information about breast cancer and screening, benefits (early treatment and reduced breast cancer mortality) and harms (overtreatment, worry and false alarm, false sense of security, and discomfort) of screening, and the expected additional tests after a positive screening result (7).

Questions on health information and the screening leaflet were as follows: How likely were women to read health information in general (5-point Likert scale ranging from "Never" to "Always"), and had women read the breast cancer screening leaflet for this questionnaire (no/yes part of it/yes all of it). Questions on screening attitudes among women responding to have read (part of) the screening leaflet captured change in attitudes toward screening (5-point Likert scale ranging from "Much more negative" to "Much more positive") and change in willingness to participate in screening (5-point Likert scale ranging from "Much less willing" to "Much more willing"). With four questions, participants were asked about their preferences for screening decision-making and screening recommendations using the following two pairs of statements: 1) seeing screening participation as their very own decision vs. thinking that they should follow recommendations from health authorities about screening participation and 2) preferring to make their own decision about screening participation based on own attitudes, values, and the information available vs. preferring that health authorities recommend whether they should participate or not. Responses to these statements were indicated on a 5-point Likert scale (ranging from "Strongly disagree" to "Strongly agree").

Sample size

Sample size calculations were based on estimates for screening uptake by framing of information groups (80% and 70%) and a power of 90%. These 80% were chosen to be similar to the participation rate in the Danish national mammography screening program (28) and the willingness to participate in our previously mentioned study of a hypothetical screening (13). The 10% difference was our best estimate in the absence of similar studies and was chosen because we considered any smaller difference to have no real importance for future implementations. A sample size of 392 women was estimated for each of the first two randomization groups (opportunity vs. choice groups, "Stage of Decision Making" for comparison). For the secondary research questions (impact of information in screening

decision-making and preferences for screening decision-making), we based sample size calculations on obtaining a standard error (SE) no larger than 2.5% for a proportion of 80%. This corresponded to a sample size of 256 women. We also performed the sample size calculation with a proportion of 50% screening uptake in the absence of similar studies, corresponding to a sample size of 400 women. As 400 was the largest of these sample sizes, this was used for the final sample size. With a participation rate of 40% (based on previous study (13)), we arrived at a study population of 1,000 women in each of the three groups, i.e., a total of 3,000 women.

Analysis and statistical methods

The main outcome of intended participation in breast cancer screening at age 50 was dichotomized as participation ("I want to participate" or "I think I want to participate") and non-participation/undecided.

For all women participating in the study, distributions of women across sociodemographic and questionnaire variables were presented. Simple and multiple logistic regression analyses were used to estimate the association between intended participation and relevant variables (randomization group, reading health information in general, and reading screening information). We performed multiple logistic regression analyses adjusting for one variable at a time (in addition to variable of interest) due to very few women indicating that they did not want to participate in screening at age 50, which was part of the binary outcome. In a sensitivity analysis, we categorized the outcome, intended participation, based on only one category instead of two ("I want to participate" and not "I think I want to participate"). This was done to restrict the analysis to women who appeared more certain of their decision. We tested the assumption of linearity of log odds for logistic regression analyses for relevant variables by including each of the variables as a quadratic term.

In the secondary analyses, the three randomization groups were compared using Pearson's chi-square test. To investigate the generalizability of our findings, women responding to the questionnaire and women not responding were compared using register data and Pearson's chi-square test. Lastly, we investigated intended participation after excluding women with previous breast cancer; this did not change the results (results are not shown because this will create GDPR conflicts since women with BC were too few).

This study was registered at ClinicalTrials.gov (Identifier: NCT05444725) which included a statistical analysis plan with detailed description of all analyses. Changes to the analysis plan are described in Appendix IV. The study was also registered at Aarhus University's record of research projects (2016-051-000001, 2563). According to Danish law, approval by an Ethics Board was not required for this type of study (43).

All analyses were conducted in Stata 17 (StataCorp, College Station, TX), and estimates are reported with 95% confidence intervals (95% CI).

Results

The study response rate was 26.8% (790/2,952). Among all invited women, 48 (1.6%) could not receive the invitation letter in e-Boks. A flow diagram is presented in Figure 2.

Women responding to the questionnaire had higher educational levels, higher socioeconomic status (upper two of five income groups) and were more often of Danish origin. No differences were found for civil status and geographical region (Table 1).

[Figure 2 about here]

[Table 1 about here]

Intended participation

A total of 97% (95% CI: 96%-98%) stated that they wanted to participate in breast cancer screening when turning 50. This intended participation was associated with framing of information; the proportions were 98% (96%-100%) for the opportunity framing and 95% (92%-97%) for the choice framing (p-value 0.026). For "Stage of Decision Making" with screening presented as an opportunity, the proportion was 98% (95%-99%). In the sensitivity analysis, where only "I want to participate" was categorized as intended participation (score of 1 instead of 1 and 2), participation was higher than 85% in all groups (Table 2).

Among participants randomized to "Stage of Decision Making", 87% (82%-90%) responded that they had already made their decision about screening participation and were unlikely to change their mind; 6% (3%-9%) stated they had already made their decision but were willing to reconsider (Table 3).

Odds of intended participation were higher for the opportunity framing compared to the choice framing (unadjusted odds ratio (OR) 3.38 (1.09-10.51), p-value 0.035). When adjusting for one variable at a time, similar results were obtained (ORs varying from 3.16-3.61). The same direction of odds was observed for the "Stage of Decision Making" group, although non-significant (Table 4).

[Table 2 about here]

[Table 3 about here]

[Table 4 about here]

Impact of information in screening decision-making

When asked about reading health information in general, 46% (42%-49%) responded that they would always read health information while 38% (34%-41%) answered mostly. However, 59% (56%-63%) responded that they had not read the leaflet about breast cancer screening linked to in the questionnaire (Table 3). Of those answering that they would always read health information, 47% (41%-52%) responded that they had not read the screening leaflet (Table 5). Results based on logistic regression analysis are presented in Table 4.

Among women responding that they would participate in screening, two-thirds responded that their feelings toward breast cancer screening were unchanged after reading the screening leaflet. Almost one-third were a little more or much more positive toward screening after reading the leaflet; only 3% were more negative about screening. The pattern was the same for the question about willingness to participate in screening (Table 5).

[Table 5 about here]

Preferences for screening decision-making

For the two statements about screening as an actual choice, 95% and 94% of participants, respectively, agreed or strongly agreed with the statements. This indicated that participants believed that screening participation was their own decision. Moreover, it indicated that participants believed that they should follow recommendations from health authorities about screening participation (Table 3). A total of 89% (87%-91%) agreed or strongly agreed to both statements at the same time (Table 5). Regarding the two statements about preference for informed decision-making, 76% and 79% of participants, respectively, expressed agreement or strong agreement. This indicated a preference for making individual decisions about screening participation based on their own attitudes, values and available information. It also indicated a preference for recommendations on screening participation from health authorities (Table 3). A total of 59% (56%-63%) agreed or strongly agreed to both statements at the same time (Table 5).

Secondary analyses

When asked about preferences for future screening invitation, 80% (77%-82%) preferred the current invitation strategy with an information leaflet and pre-scheduled appointment and place for screening, whereas 18% (15%-20%) preferred only invitation letter and/or information but no pre-scheduled appointment and place (last two response options) (Table 3).

When investigating variation across randomization groups with respect to sociodemographic factors, thoughts about breast cancer and previous mammograms, no statistically significant differences were found (Supplementary table 1, Appendix V).

Discussion

This study showed that over 95% of participating women (aged 44-49 years) intended to participate in breast cancer screening when invited at age 50. This is a substantially larger proportion than the actual participation rate for breast cancer screening in Denmark of 83% (28). In addition, the majority of women in the study had already made a decision about screening participation before receiving the invitation and were unlikely to change their mind. This is an important finding as provision of information at the time of screening invitation may be too late to support informed decision-making. However, when provided with information framed as an active choice between having or declining breast cancer screening, the intended participation was still high (95%) but lower than for information framed as an opportunity. This finding suggested that presenting breast cancer screening as a choice between options supports more informed decisions about screening, and for a minority of women also the confidence to choose not to have screening. Lastly, 18% preferred not to receive the pre-scheduled appointment for screening.

The high willingness to participate in breast cancer screening and the certainty about this decision might be explained by a variety of factors. In particular, social norms, moral obligations or even pressure regarding screening may influence decision-making (16,22,44) as well as trust in public authorities (20,22,26). The desire to be good and responsible citizens can also influence screening participation (20,22,45). In our study, we reported intended participation both for "I want to participate" and also combined with "I think I want to participate" (main analysis). It could be argued that women responding "I think I want" did so because of social norms, moral obligations etc. Therefore, some of these women might not necessarily participate at age 50. Information to support women to make informed decisions

about breast cancer screening could include components to challenge *ex-ante* positive attitudes toward having screening.

Among women responding that they would always read health information, almost half of the women did not read the screening leaflet enclosed in the study information. This could be because women wanted to appear as good and responsible citizens taking care of their own health (22) or because they had already reached a decision and did not find the information to be essential. In addition, it could have been a challenge that the link to the leaflet was only provided in the invitation letter and not in the questionnaire (because of technicalities) but a text in the questionnaire mentioned this link and leaflet. Even if women had read the screening information, many may have attended to information that aligned with their prior knowledge and values about healthcare and screening (12,16,25). The term "perception gap" has been used to describe the conflict or cognitive dissonance between presented screening information and women's individual understanding and interpretation of the information (25). This cognitive dissonance could explain why the majority of the women in our study had not changed their opinion about screening after reading about benefits and harms in the leaflet. Hence, the impact and timing of screening information on decision making could be doubted.

Our finding that statistically significantly more women declined screening when presented with the choice framing suggests that explicitly presenting the option of screening with an alternative of usual care supports women to more actively engage with the facts and use these in the decision-making process. This suggests that presenting invitations for screening as a choice framing is more likely to meet guidance on supporting people to make informed decisions. On the other hand, it may also suggest that women do not perceive screening participation as a genuine choice given the current presentation of screening (45).

The results related to preferences for decision-making in screening partly supported the recommendation of informed decision-making in a breast cancer screening context. Most women agreed that screening participation should be an individual and informed decision. At the same time, most women also agreed that the DHA and health professionals should play a central role in screening recommendations and decision-making. These findings could be seen as contradicting screening preferences among women. However, using the MIND-IT model developed by Bekker (46,47), women's responses could instead be seen as two elements of an individual and informed decision-making process. Women might prefer making their own informed screening decisions based on both individual factors, knowledge,

and social network but at the same time use expert judgement and recommendations as part of their basis or information prior to making their final screening decision. In line with this, another study on medical screenings argues that in populations with high levels of trust in authorities such as the Danish, individual screening decisions are influenced by recommendations from those authorities and people perceive preventive health services as a means through which the welfare state attends to the well-being of its citizens (22,45).

Both recommendations from authorities and pre-scheduled appointments are framing effects used to increase participation (22). In this study, 18% preferred not to receive the pre-scheduled appointment at screening invitation. In addition, pre-scheduled appointments have been criticized for bypassing informed consent (32). Based on a Norwegian study on breast cancer screening, women perceived the pre-scheduled appointment as if the screening decision was already made (48).

Comparison with other studies

In the U.S. and Great Britain, population-based surveys found widespread enthusiasm for screening as almost 90% indicated that routine cancer screening for healthy people is almost always a good idea (10,11). Strong enthusiasm for cancer screening was also found in two studies on hypothetical cancer screenings with no reduction in mortality, only potential harms (12,13).

A European survey found that 95% were more likely to participate or had not changed their decision regarding future participation in breast cancer screening after being informed about both screening benefits and harms (49). In addition, a study of Norwegian and American women found that additional information on benefits and harms of cervical cancer screening did not significantly impact women's intention to participate in screening (50). This is similar to our finding that almost all women did not change or were more positive toward screening after reading the screening leaflet. It could be questioned whether women understood screening harms. However, in our previous study of a hypothetical breast cancer screening, we informed about potential harms (and no benefits) and more than two-thirds seemed to understand the information and generally wanted to participate in the screening regardless (13).

An Australian study of cervical cancer screening found that women wanted to be involved in decision-making concerning screening and that the majority wanted information about both benefits and harms prior to screening participation (51). In our study, Danish women also seemed to have a clear preference for receiving screening information when

receiving the invitation for breast cancer screening. Furthermore, most women in our study indicated that they wanted to decide themselves whether to participate in screening.

Strengths and limitations

A major strength of this study was the invitation of a random sample of women in Denmark with sociodemographic register data available on all invited. However, a limitation was the low participation rate (26.8%). Responding women differed from non-responding women by having a higher educational level, being in higher income groups, and more frequently of Danish origin. In addition, women completing the questionnaire may be more pro-screening than non-respondents. This could explain why the proportion intending to participate in screening was higher than the actual participation rate in the national screening program of 83% in 2020-2021 (28). We did not have information on invited women's breast cancer risk, only self-reported information on previous mammograms. However, based on Danish numbers, a very small proportion in this age group are expected to be at increased risk of breast cancer due to hereditary factors. The findings can be generalized to countries with a similar national mammography screening program and health care system such as the other Nordic countries. However, there can be some differences with and without pre-scheduled screening appointments and co-payments for these countries. Lastly, when comparing the choice and opportunity framings, the provision of the DHA screening leaflet to both groups may have diluted the framing contrast, as screening is clearly recommended. Thus, the choice framing appeared to be more pro-screening and less of a choice than intended if women read the screening leaflet. On the other hand, the choice framing might have been slightly more negative than intended because of inclusion of information about always contacting GP in case of symptoms, also when regularly attending screening (see Figure 1). This information was not included in the text for the two other randomization groups; however, the information was part of the DHA screening leaflet presented to all groups. A more pro screening choice framing would likely dilute the difference between the choice and the opportunity framing while the more negative framing mentioning GP would result in a larger difference between the two framing groups.

Conclusion

In our study, almost all women in a pre-screening age group (44-49 years) with a high certainty wanted to participate in breast cancer screening when invited at age 50. This may represent a barrier to informed decision-making concerning screening as it suggests that providing information at the time of the screening invitation may be too late to support

informed decision-making. Moreover, as many women did not read screening information and/or did not change their opinion about screening after reading the enclosed information leaflet from the DHA. Lastly, intended participation in screening was associated with framing of information. Thus, in future screening information, the screening option could be presented together with the alternative of usual care with no screening (choice framing) to support more engaged and informed decision-making among women invited to breast cancer screening.

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(See Title Page for Acknowledgements)

Data is not available to other researchers due to confidentiality regulations when using data from Statistics Denmark and personal information collected through a questionnaire.

Conflicts of interest

The authors have no conflicts of interest to declare.

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Figure legends

Figure 1. Text for each of the three randomization groups (the rest of the questionnaire was the same)

Figure 2. Flow diagram