





# BMJ Open Women's conceptual knowledge about breast cancer screening and overdiagnosis in Norway: a cross-sectional study

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**To cite:** Tsuruda KM, Veierød MB, Houssami N, *et al.* Women's conceptual knowledge about breast cancer screening and overdiagnosis in Norway: a cross-sectional study. *BMJ Open* 2021;**11**:e052121. doi:10.1136/bmjopen-2021-052121

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2021-052121>).

Received 12 April 2021  
Accepted 08 November 2021



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## ABSTRACT

**Objective** To investigate conceptual knowledge about mammographic screening among Norwegian women.

**Design** We administered a cross-sectional, web-based survey. We used multiple-choice questions and a grading rubric published by a research group from Australia.

**Setting** Our Norwegian-language survey was open from April to June 2020 and targeted women aged 45–74 years.

**Participants** 2033 women completed our questionnaire. We excluded 13 women outside the target age range and 128 women with incomplete data. Responses from 1892 women were included in the final study sample.

**Primary and secondary outcome measures** The questionnaire focused on women's knowledge about the breast cancer mortality reduction, false positive results and overdiagnosis associated with mammographic screening. The primary outcome was the mean number of marks assigned in each of the three themes and overall. There were three potential marks for questions about breast cancer mortality, one for false positives and six for overdiagnosis.

**Results** Most women (91.7%) correctly reported that screened women are less likely to die of breast cancer than non-screened women. 39.7% of women reported having heard of a 'false positive screening result' and 86.2% identified the term's definition; 51.3% of women had heard of 'overdiagnosis' and 14.8% identified the term's definition. The mean score was 2.59 of 3 for questions about breast cancer mortality benefit and 0.93 of 1 for the question about false positive screening results. It was 2.23 of 6 for questions about overdiagnosis.

**Conclusions** Most participants correctly answered questions about the breast cancer mortality benefit and false positive results associated with screening. The proportion of correct responses to questions about overdiagnosis was modest, indicating that conceptual knowledge about overdiagnosis was lower. Qualitative studies that can obtain in-depth information about women's understanding of overdiagnosis may help improve Norwegian-language information about this challenging topic.

## Strengths and limitations of this study

- Our study is the largest and one of the first to document Norwegian women's conceptual knowledge about breast cancer overdiagnosis.
- We reported women's responses to individual questions about mammographic screening, which provided a more nuanced view of their knowledge.
- Participants in our study were more likely to be knowledgeable about and/or interested in breast cancer screening than women in the general population, which could limit the generalisability of our findings.

## INTRODUCTION

Population-based mammographic screening programmes aim to reduce breast cancer mortality through early detection of the disease. Contemporary screening programmes increasingly value women's autonomy and endorse the notion that women ought to be supported in making an informed choice whether to participate.<sup>1</sup> To this end, the European breast cancer guidelines encourage screening programmes to provide women with information about the benefits and harms of screening.<sup>1,2</sup> However, communicating information about screening is challenging. Although there is no consensus regarding what should be communicated or how to do so, a number of programmes have been criticised for providing insufficient or unbalanced information.<sup>3–8</sup>

One criticism has been that programmes have omitted or not fully described the risks associated with detecting slow-growing tumours that might not cause symptoms during a woman's lifetime, so-called overdiagnosis.<sup>5,7</sup> However, overdiagnosis was not generally considered a major harm associated with mammographic screening until the late 1990s and current knowledge about breast

cancer biology is insufficient to identify overdiagnosed individuals who are at risk of overtreatment.<sup>9</sup> Moreover, the epidemiological definition of overdiagnosis is challenging to operationalise, and population-based estimates of overdiagnosis are sensitive to study methodology and therefore wide-ranging.<sup>10–13</sup>

Academics disagree about how the potential harms of overdiagnosis ought to be compared with other harms and benefits of screening and there is no clear best way to communicate this complex information to women.<sup>14–15</sup> However, knowledge about overdiagnosis may affect how women think about and value mammographic screening, making it important in their decision whether to attend screening.<sup>16–18</sup> A 2018 systematic review of literature from countries in the International Cancer Screening Network's breast cancer division reported that less than 50% of women were aware of overdiagnosis in a quarter of studies published during 1992–2017.<sup>19</sup>

The population-based screening programme BreastScreen Norway aims to provide balanced, evidence-based information to the women it serves. The information material it sends with screening invitations has always described the breast cancer mortality benefit and risk of false positive screening results, and has described the concept of overdiagnosis since 2009.<sup>20</sup> Additional information is available on the programme's website.

Information about the extent to which women in Norway are knowledgeable about mammographic screening, overdiagnosis in particular, is scarce. This exploratory study aimed to describe conceptual knowledge among women residing in Norway about the breast cancer mortality benefit, false positive results and overdiagnosis associated with mammographic screening.

## METHODS

### Sampling and participants

In this cross-sectional study, we asked women aged 45–74 years to complete a web-based questionnaire about mammographic screening. These women are roughly in the target age group of BreastScreen Norway, which invites about 650 000 women aged 50–69 years to biennial mammographic screening and is administered by the Cancer Registry of Norway.<sup>21</sup>

We advertised the link to this open questionnaire solely through a post on the Cancer Registry's Facebook page, *Kreftsjekken* ('The cancer check'). This page targets women eligible to participate in mammographic or cervical screening (ie, aged 25–69 years) and has roughly 8200 followers, mostly women. Anyone with the link could access the survey and 2033 participants answered the questionnaire during 8 April–8 June 2020.

### Data protection and consent

Nettskjema, a secure survey platform designed by the University of Oslo, was used to administer our questionnaire.<sup>22</sup> A disclosure statement informed women about our study objective, estimated completion time and

provided contact information for the principal investigator. Further, it informed that the questionnaire was voluntary and that completing it would be deemed as consent to participate. Women were also informed that they could exit the questionnaire at any time *without* saving their responses. No incentives were offered for survey completion.

Our questionnaire was configured to save only women's responses and survey completion time. Cookies were not used while the survey was in progress and internet protocol addresses and other personal identifiers were not saved. The disclosure statement also informed women of these details. All questions had closed-form responses and women could use a back button to change their previous answers. The resulting anonymous study data were stored and analysed on a secure server at the Cancer Registry of Norway.

### Questionnaire

Age (5-year age groups from 40 to 74 years) was asked first as the only mandatory question to identify women outside the target age range. Other sociodemographic questions were asked at the end of the questionnaire. These covered highest completed formal education (none, elementary school, high school, ≤4 years' college/university, >4 years' college/university, other post-secondary), birth country (Norway or other) and region of residence.

Table 1 describes the remaining questionnaire content, divided into non-graded (background) and graded conceptual questions. All questions were asked on separate pages, unless otherwise noted in the table. In the set of background questions, women were asked to indicate whether they had previously searched for information about mammographic screening and, if so, where. Further, women were asked to choose the definition of mammographic screening from two alternatives ('Mammographic screening is having a mammogram when you haven't noticed a lump or other breast cancer symptoms' or 'Mammographic screening is having a mammogram when you have noticed a lump or other breast cancer symptoms'). They were also asked if they had heard of a 'false positive screening result', 'overdiagnosis' or 'overdetection'. The last background question presented definitions for a false positive screening result and overdiagnosis and asked women to choose the one that corresponded to a 'false positive screening result'. The definition-based questions were derived from previous research.<sup>23</sup>

The graded conceptual questions were based on 9 out of 10 conceptual questions described by Hersch *et al.*<sup>23</sup> These multiple-choice and true/false questions covered three themes associated with screening: breast cancer mortality benefit (two questions), false positive screening results (one question) and overdiagnosis (six questions). We interpreted women's answers to these questions as a reflection of their conceptual knowledge.<sup>23</sup>

We excluded the question on whether 'screening finds harmless cancers more often than it prevents death'

**Table 1** Translated survey questions and potential responses; graded conceptual knowledge was assessed based on a published questionnaire and rubric\*

Thematic category	Survey question	Response format	Marks if correct
<b>Background questions</b>			
Not assigned	Have you ever searched for information about mammographic screening?	<ul style="list-style-type: none"> <li>▶ Yes, a lot</li> <li>▶ Yes, some</li> <li>▶ No</li> <li>▶ Can't remember/unsure</li> </ul>	Not applicable
Not assigned	Where have you searched for information about mammographic screening? (conditional question based on answer to previous question; multiple responses possible)	<ul style="list-style-type: none"> <li>▶ Family doctor/other health personnel</li> <li>▶ Friends and family</li> <li>▶ Cancer Registry of Norway/BreastScreen Norway's website</li> <li>▶ Other websites</li> <li>▶ Scientific literature</li> <li>▶ Books</li> <li>▶ Newspapers and periodicals</li> <li>▶ Other</li> </ul>	Not applicable
Not assigned	Choose the sentence you think is correct.	<ul style="list-style-type: none"> <li>▶ Mammographic screening is having a mammogram when you haven't noticed a lump or other breast cancer symptoms*</li> <li>▶ Mammographic screening is having a mammogram when you have noticed a lump or other breast cancer symptoms</li> <li>▶ Unsure</li> </ul>	Not applicable
Not assigned	Have you ever heard of these three terms?† <ul style="list-style-type: none"> <li>▶ False positive screening results</li> <li>▶ Overdiagnosis</li> <li>▶ Overdetection</li> </ul>	<ul style="list-style-type: none"> <li>▶ Yes</li> <li>▶ No</li> <li>▶ Unsure</li> </ul>	Not applicable
Not assigned	Choose the sentence you think best describes 'false positive screening results'.	<ul style="list-style-type: none"> <li>▶ Abnormal findings on a screening mammogram, but where additional examination doesn't find breast cancer*</li> <li>▶ Breast cancer that would have never been detected if a woman hadn't attended screening</li> <li>▶ Unsure</li> </ul>	Not applicable
<b>Graded questions</b>			
Breast cancer mortality benefit	Who do you think has the highest chance of dying from breast cancer?	<ul style="list-style-type: none"> <li>▶ Women who attend screening for breast cancer/ mammographic screening</li> <li>▶ Women who do NOT attend screening for breast cancer/ mammographic screening*</li> <li>▶ Unsure</li> </ul>	2
	Can mammographic screening detect all breast cancers?	<ul style="list-style-type: none"> <li>▶ Yes</li> <li>▶ No*</li> <li>▶ Unsure</li> </ul>	1
False positive screening results	Will all women who have abnormal findings on a screening mammogram be diagnosed with breast cancer?	<ul style="list-style-type: none"> <li>▶ Yes</li> <li>▶ No*</li> <li>▶ Unsure</li> </ul>	1
Overdiagnosis	Who do you think has the highest chance of being diagnosed with breast cancer?	<ul style="list-style-type: none"> <li>▶ Women who attend screening for breast cancer/ mammographic screening*</li> <li>▶ Women who do NOT attend screening for breast cancer/ mammographic screening</li> <li>▶ Unsure</li> </ul>	1
	Cross off the sentences you think are true.	(Correct if not crossed off) All breast cancers will eventually lead to sickness and death if they are not diagnosed and treated‡	1
		(Correct if not crossed off) Doctors can distinguish harmful breast cancer that needs treatment from 'nice' breast cancer that doesn't need treatment with certainty‡	1

Continued

Table 1 Continued

Thematic category	Survey question	Response format	Marks if correct
		(Correct if crossed off) Slow-growing breast cancers that are treated even though they would not have caused sickness exist*‡	1
		(Correct if crossed off) Mammographic screening leads to the diagnosis of slow-growing tumours and unnecessary treatment*‡	1
	Choose the definition you think best describes 'overdiagnosis'.	<ul style="list-style-type: none"> <li>▶ Abnormal findings on a screening mammogram, but where additional examination doesn't find breast cancer</li> <li>▶ Breast cancer that would have never been detected if a woman had not attended screening*</li> <li>▶ Unsure</li> </ul>	1

Correct answers are marked with an asterisk (\*).

\*Adapted from Hersch *et al.*<sup>23</sup>

‡These terms were shown together in a grid, and participants could select one response for each term.

‡These sentences were shown together in a grid.

because of the challenges associated with accurately determining the relative probability of these outcomes (for example, Norwegian estimates of overdiagnosis range from 0% to 75%).<sup>13 24–26</sup> We also excluded Hersch *et al.*'s frequency-based (ie, numerical) questions from our questionnaire. This decision was made because the printed information material BreastScreen Norway sent with invitations to screening provided women with contextual, not numerical, information about overdiagnosis at the time of this study. This material outlined that screening could detect slow-growing breast cancers that would never cause symptoms or be life-threatening, that this was called overdiagnosis and could lead to unnecessary treatment, and that it was not possible to know which cancers may not need treatment.<sup>20</sup>

All Norwegian (Bokmål) translations were developed by the authors, which include a native English speaker with Norwegian as a second language, and native Norwegian speakers with English as a second language. The authors also back translated the Norwegian questions.

### Patient and public involvement

The public were not involved in designing this study. The language and usability of our web-based questionnaire was tested among a pilot group of five women aged 50–69 years. We intend to share the results of this study with the public through the Cancer Registry's website and Facebook page.

### Statistical analysis

Using iterative proportional fitting (raking),<sup>27</sup> we calibrated post-stratification survey weights based on publicly available population statistics for age, education and region of residence. These statistics represented women aged ≥40 years for education and 45–74 years for region.<sup>28–30</sup> Our study variables used the same categories as the reference data and were not transformed for this process. The initial weights were set to 1 and the upper bound for raked weights was 7.

For questions where women were asked to select statements they thought were true, we assumed missing responses indicated women thought these statements were false. For questions based on the work of Hersch *et al.*, we used their rubric to identify and assign marks to correct answers.<sup>23</sup> Consequently, all responses classified as correct were assigned one mark except those to the question, 'Who do you think has the highest chance of dying from breast cancer?' which were awarded two marks (table 1).

We used frequencies and proportions (%) to describe women's responses. Sociodemographic characteristics were presented for the original and weighted samples, but all other analyses pertained to the weighted sample. To compare results from our study with previous studies,<sup>23 31</sup> we calculated the mean score in each thematic category and overall.

Two-sided Rao-Scott corrected  $\chi^2$  tests (second order correction) were used to test the presence of associations between sociodemographic variables and women's responses.<sup>32</sup> A p value of <0.05 was considered significant.

Analyses and figures were produced using Stata (V.16.1); the ipfraking package was used to calibrate survey weights. Except for the specified upper bound, we used the package's default settings.

### RESULTS

Among the 2033 women who responded to the survey, we excluded 13 (0.6%) who reported being younger than 45 years. Missing data ranged from 0 to 30 women (0%–1.5%) per question (online supplemental table S1) and we restricted our analysis to those with complete data (n=128 exclusions, 6.3%). This left responses from 1892 women in the final sample.

In the unweighted data, 69.7% of women were 50–69 years old (the target age for BreastScreen Norway) (table 2). A quarter of women (26.0%) were 45–49 years,

**Table 2** Proportion (%) of sociodemographic characteristics among participants before and after weighting, and the Norwegian female population, n=1892

Characteristic	Study sample	Weighted sample*	Norwegian population
	n (%)	n (%)	(%)
<b>Age (years)</b>			
45–49	491 (26.0)	365 (19.3)	19.3†
50–54	493 (26.1)	361 (19.1)	19.1†
55–59	371 (19.6)	324 (17.1)	17.1†
60–64	297 (15.7)	304 (16.0)	16.0†
65–69	157 (8.3)	275 (14.6)	14.6†
70–74	83 (4.4)	263 (13.9)	13.9†
<b>Formal education</b>			
Elementary school	85 (4.5)	439 (23.2)	23.2‡
High school	431 (22.8)	747 (39.5)	39.5‡
University or college, ≤4 years	574 (30.3)	513 (27.1)	27.1‡
University or college, >4 years	632 (33.4)	146 (7.7)	7.7‡
Other post-secondary	170 (9.0)	47 (2.5)	2.5‡
<b>Birthplace</b>			
Norway	1789 (94.6)	1796 (94.9)	85.7§
Other	103 (5.4)	96 (5.1)	14.3§
<b>Region</b>			
Oslo or Viken	540 (28.5)	661 (34.9)	34.9¶
Innlandet	97 (5.1)	149 (7.9)	7.9¶
Agder or Sør-Østlandet	195 (10.3)	273 (14.4)	14.4¶
Vestlandet	436 (23.0)	466 (24.7)	24.7¶
Trøndelag	188 (9.9)	163 (8.6)	8.6¶
Northern Norway	436 (23.0)	180 (9.5)	9.5¶

\*Weighted for age, education and residential region.

†Among women aged 45–74 years in 2020.<sup>28</sup>

‡Highest recorded education among women aged 40 years and older in 2018.<sup>29</sup>

§Among women of all ages in 2020.<sup>41</sup>

¶Among women aged 45–74 years in 2020.<sup>30</sup>

and 4.4% were 70–74 years. Compared with the Norwegian female population, participants were younger and more likely to have post-secondary education. After weighting, the marginal distributions of age, education and region were similar to those in the female population.

Nearly half of women (47.6%) indicated that they had previously looked up some information about mammographic screening and 4.8% reported having looked up a lot of information. Age was associated with looking up information about screening ( $p=0.004$ ), and women aged 65–69 years were the most likely to have looked up any information (65.1%; online supplemental table S2). Longer formal education was positively associated with looking up information ( $p<0.001$ ) and was highest (63.0%) among women with >4 years of university or college education (online supplemental table S3). The section about BreastScreen Norway on the Cancer Registry's website was the most commonly reported information source (used by 61.0% of women who had looked up

some information, and 85.6% of women who had looked up a lot of information).

Most women (87.9%) correctly reported that mammographic screening is having a mammogram when you have not noticed any breast cancer symptoms (table 3). Less than half of women (39.7%) reported having heard of a 'false positive screening result'; the majority (86.2%) chose the correct definition for this term (tables 3 and 4). Roughly half of women (51.3%) reported having heard of the term 'overdiagnosis'. Age was not associated with having heard of overdiagnosis ( $p=0.618$ , online supplemental table S2), in contrast, longer formal education was (31.2% for women with an elementary school education vs 78.8% among women with >4 years of university or college education;  $p<0.001$ , online supplemental table S3).

Regarding the graded conceptual questions, 91.7% of women correctly reported that screened women are less likely to die of breast cancer than non-screened women

**Table 3** Background knowledge about mammographic screening among survey participants, n=1892\*

Background knowledge†	Response alternatives‡	Correct n (%)	Incorrect n (%)	Unsure n (%)
Choose the sentence you think is correct	<ul style="list-style-type: none"> <li>▶ Mammographic screening is having a mammogram when you haven't noticed a lump or other breast cancer symptoms*</li> <li>▶ Mammographic screening is having a mammogram when you have noticed a lump or other breast cancer symptoms</li> <li>▶ Unsure</li> </ul>	1662 (87.9)	190 (10.0)	40 (2.1)
Choose the sentence you think best describes 'false positive screening results'	<ul style="list-style-type: none"> <li>▶ Abnormal findings on a screening mammogram, but where additional examination doesn't find breast cancer*</li> <li>▶ Breast cancer that would have never been detected if a woman hadn't attended screening</li> <li>▶ Unsure</li> </ul>	1632 (86.2)	128 (6.8)	132 (7.0)

\*Sample weighted for age, education and region.

†Questions adapted from Hersch *et al.*<sup>23</sup>

‡Correct response marked with an asterisk (\*).

and 75.5% correctly identified that mammographic screening cannot detect all breast cancers (table 5). Further, 93.3% of women correctly identified that not all women with abnormal findings on a screening mammogram will be diagnosed with breast cancer. The proportion of correct responses was lower for questions about overdiagnosis: 66.9% of women correctly reported that women who participate in organised screening are more likely to be diagnosed with breast cancer, and 49.0% of women correctly identified that not all breast cancers will lead to illness and death if they are not found and treated. Further, 14.8% of women chose the correct definition for the term 'overdiagnosis' (vs a definition for false positive screening results or 'unsure'). Women's responses to this question were independent of their age (p=0.178, online supplemental table S2) but associated with their formal education (p=0.013, online supplemental table S3).

Overall, the mean score for all questions about the breast cancer mortality benefit was 2.59 out of a possible 3 (figure 1A). The mean score was 0.93 out of a possible 1 for the question about false positive screening results (figure 1B), and 2.23 out of a possible 6 for questions about overdiagnosis (figure 1C). Figure 2 shows the

distribution of women's total scores—the overall mean was 5.75 out of a possible 10 marks.

## DISCUSSION

We report a cross-sectional online survey undertaken to describe conceptual knowledge of three themes in breast cancer screening among Norwegian women aged 45–75 years, using questions adapted from Hersch *et al.*<sup>23</sup> We observed that participants had good scores for knowledge about the breast cancer mortality benefit associated with screening (mean score 2.59 out of 3) and about false positive screening results (mean score 0.93 out of 1). This contrasted the modest knowledge observed in response to questions about overdiagnosis (mean score 2.23 out of 6). Women's conceptual knowledge about overdiagnosis therefore appeared to be relatively lower than that about the breast cancer mortality benefit and false positive results associated with screening.

Our study framed overdiagnosis as the detection of slow-growing or indolent breast cancers that would not have been detected in a woman's lifetime had they not attended screening. However, overdiagnosis can also occur when a competing risk of death precludes a progressive breast cancer from causing clinical symptoms. In Norway, the risk of overdiagnosis due to competing risk of death is thought to be less than 2%.<sup>33</sup> This paper thus limits its scope to discussing the former cause of overdiagnosis.

Our study results can be compared with those from randomised controlled trials that used the same graded conceptual questions and associated rubric.<sup>23 31</sup> The mean number of marks assigned in our study was comparable with the control groups in Hersch *et al.* (Australia) and Pérez-Lacasta *et al.* (Spain) for questions about the mortality benefit (2.59, 2.86 and 2.30, respectively) and false positive screening results (0.93, 1.00 and 0.95,

**Table 4** Frequency and proportion of women who reported whether they had heard of false positive screening mammograms, overdiagnosis or overdiagnosis, n=1892\*

Have you ever heard of these three terms?	Yes	No	Unsure
	n (%)	n (%)	n (%)
False positive screening results	752 (39.7)	975 (51.6)	165 (8.7)
Overdiagnosis	971 (51.3)	719 (38.0)	202 (10.7)
Overdetection	197 (10.4)	1276 (67.4)	419 (22.1)

\*Sample weighted for age, education and region.

**Table 5** Conceptual knowledge about the mortality benefit, false positives and overdiagnosis associated with mammographic screening, among survey participants, n=1892\*

Graded conceptual knowledge questions†	Correct response	Correct n (%)	Incorrect n (%)	Unsure n (%)
<b>Breast cancer mortality benefit</b>				
Who do you think has the highest chance of dying from breast cancer?	Women who do NOT attend screening for breast cancer/mammographic screening	1734 (91.7)	45 (2.4)	113 (6.0)
Can mammographic screening detect all breast cancers?	No	1429 (75.5)	236 (12.5)	227 (12.0)
<b>False positive screening results</b>				
Will all women who have abnormal findings on a screening mammogram be diagnosed with breast cancer?	No	1766 (93.3)	27 (1.4)	99 (5.2)
<b>Overdiagnosis</b>				
Who do you think has the highest chance of being diagnosed with breast cancer?	Women who attend screening for breast cancer/mammographic screening	1266 (66.9)	483 (25.5)	143 (7.6)
Cross off the sentences you think are true	(Correct if not crossed off) All breast cancers will eventually lead to sickness and death if they are not diagnosed and treated	927 (49.0)	965 (51.0)	Not applicable‡
	(Correct if not crossed off) Doctors can distinguish harmful breast cancer that needs treatment from 'nice' breast cancer that doesn't need treatment with certainty	586 (31.0)	1306 (69.0)	Not applicable‡
	(Correct if crossed off) Slow-growing breast cancers that are treated even though they would not have caused sickness exist	819 (43.3)	1073 (56.7)	Not applicable‡
	(Correct if crossed off) Mammographic screening leads to the diagnosis of slow-growing tumours and unnecessary treatment	345 (18.3)	1547 (81.7)	Not applicable‡
Choose the definition you think best describes 'overdiagnosis'	Breast cancer that would have never been detected if a woman had not attended screening	279 (14.8)	1289 (68.1)	323 (17.1)

\*Sample weighted for age, education and region.

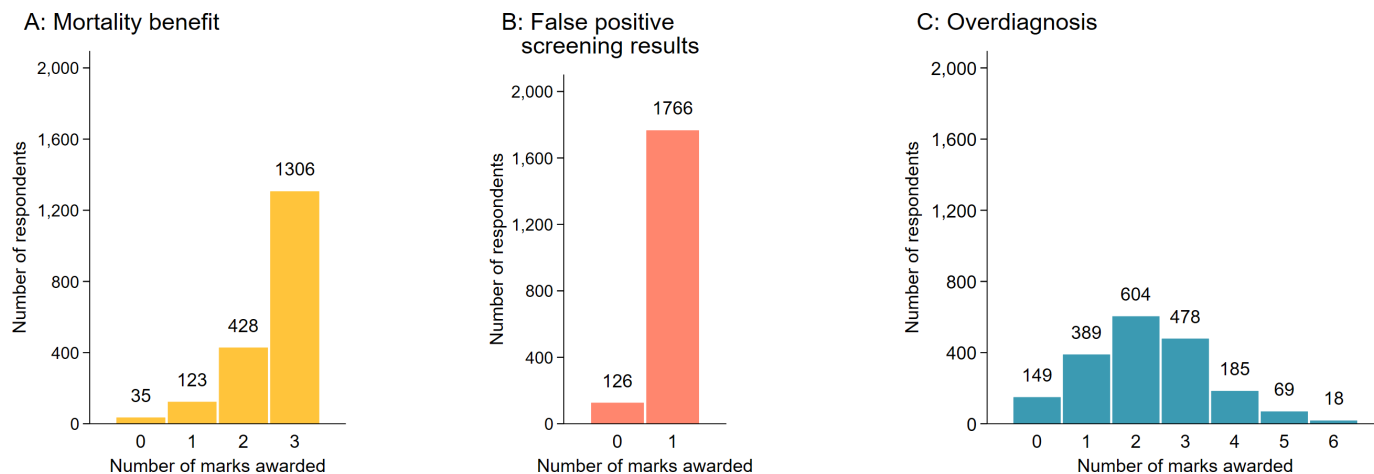
†Questions adapted from Hersch *et al.*<sup>23</sup>

‡These statements were shown together in a grid and women were asked to select the statement if they thought it was correct. If the statement was not selected, we interpreted the answer as 'false'.

respectively). The mean number of marks awarded for questions about overdiagnosis was somewhat lower in our study (2.32, 3.48 and 2.88, respectively); however, we included one fewer question than the trials. Results from an Italian study also suggest that women had less conceptual knowledge about overdiagnosis than the other two topics.<sup>34</sup> Overall, the proportion of correct answers for questions about overdiagnosis ranged from roughly 15% to 67% in our study and 12% to 76% among the control groups in the Australian and Spanish trials. Notably, the proportion of women who reported that the statement 'all breast cancers will eventually cause illness and death if they are not found and treated' as false was higher in our study (49.0%) than the control groups in Hersch *et al* and Pérez-Lacasta *et al* (33% and 24.9%, respectively).

We posit that this heterogeneity is primarily attributable to differences in study design and regional variation in women's knowledge related to differential exposure to information about screening outcomes.

A strength of our study is that it is one of the first and the largest to document Norwegian women's conceptual knowledge about breast cancer overdiagnosis. Similar to the aforementioned trials, our survey questions focused on overdiagnosis, which is of particular ethical importance in screening. We included women aged 45–74 years, which allowed us to observe that age was not associated with having heard of overdiagnosis or correctly choosing its definition (in contrast, education was). Our study focused on women's responses to individual questions and presented histograms showing the distribution of the

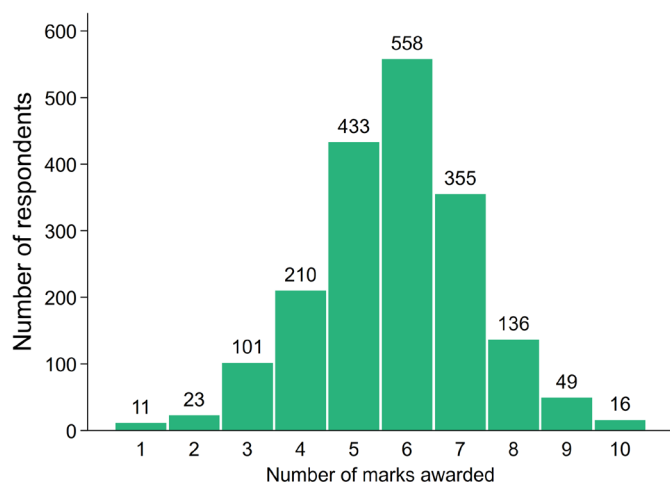


**Figure 1** Marks for correct responses in the weighted sample (n=1892) within themes investigated in this study: (A) breast cancer mortality benefit, (B) false positive screening results and (C) overdiagnosis.

number of marks assigned in each thematic category. We view this as a strength of our study because it provides a more nuanced view of women's conceptual knowledge than reporting the proportion of women who correctly answered a certain number of questions.<sup>35</sup>

A limitation of our study was that internet access was required to participate. However, in Norway, 92% of women aged 45–54 years and 60% of women aged 65–74 years used social media in October–December 2018, and >87% of residents aged 45–79 years communicate with public authorities online.<sup>36 37</sup> We assumed that all participants identified as women. Compared with the national population, younger women with longer formal education were over-represented in our sample and we calibrated and applied post-stratification weights for age, education and region of residence to overcome this selection bias. Immigrants were likely under-represented in our sample, but we did not have population statistics for adult women to calibrate weights for this variable.

Over 50% of women in the weighted sample reported that they had searched for at least some information about screening, compared with <20% among women attending



**Figure 2** Distribution of total marks assigned for correct responses in the weighted sample (n=1892).

BreastScreen Norway in 2015.<sup>38</sup> We therefore hypothesise that participants in our study were more knowledgeable about and/or interested in breast cancer screening than similarly aged women in the general population. Participants' intentions and perceptions about mammographic screening, as well as their breast cancer or screening history, could have also influenced their knowledge. Regarding the latter, most women in Norway aged 50–69 years receive invitations to BreastScreen Norway and over 80% of invited women attend the programme, so many participants likely had attended screening previously.<sup>39</sup> A limitation of our study is that we did not collect information on these factors.

The multiple-choice format used in our web-based questionnaire was chosen because it was straightforward and understandable for participants, but may have obscured some of the subtleties associated with information regarding mammographic screening. It is our view that the conceptual questions and rubric described by Hersch *et al*<sup>23</sup> are broadly accurate even though knowledge about the biology and extent of breast cancer overdiagnosis is highly debated.<sup>13</sup> However, this debate (and uncertainty) regarding estimates of overdiagnosis influenced our decision to exclude numerical questions from our questionnaire, since we would have needed to provide Norwegian reference values in our study. For example, asking participants 'If these 1000 (ordinary women who are 50 years old) have screening every 2 years for 20 years, in that time about how many will be diagnosed and treated for a breast cancer that is not harmful?' implies that a conclusive answer exists.<sup>23</sup> However, published rates of overdiagnosis in Norway range from 0% to 75%, making it difficult to select an appropriate reference value.<sup>25 26</sup> Further, BreastScreen Norway's information material has traditionally favoured contextual information about overdiagnosis; numerical information about overdiagnosis was first included in the programme's printed materials in October 2020 (after our survey was conducted).

Overall, 39.7% of participants reported having heard of a 'false positive screening result', while 51.3% of women



reported having heard of ‘overdiagnosis’. It is possible that more women had heard of overdiagnosis than false positive screening results because the latter has been intensely discussed in the Norwegian mainstream media in recent years. Most participants (86.2%) chose the correct definition for the term ‘false positive screening result’; however, 68.1% incorrectly chose the description of a false positive screening result as a definition for ‘overdiagnosis’. Given the proportions of correct responses to questions about false positive screening results, it seems plausible that survey participants were familiar with the concept of false positive screening results but mistakenly attributed it to the term overdiagnosis, which they were more familiar with. Focus group discussions about BreastScreen Norway’s information material have indicated that overdiagnosis is difficult to understand and can be confused with false positive screening results.<sup>38</sup> This has also been observed in other countries.<sup>16 17 40</sup>

## CONCLUSION

Roughly one-third of participants reported that they had looked up information about screening from BreastScreen Norway, which underlines the importance of the programme’s role in providing accessible information to women. Further, most participants responded correctly to our questions about the breast cancer mortality benefit and false positive screening results. The proportion of correct responses on the topic of overdiagnosis was lower and varied notably between questions. Qualitative studies can provide in-depth information about how women understand mammographic screening. Such studies, particularly those using serial interviews to evaluate women’s comprehension of different descriptions of overdiagnosis, can ultimately improve the information available to women about this challenging topic. Such research may be a natural next step in further describing and improving women’s knowledge about overdiagnosis in Norway.

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**Acknowledgements** We would like to thank Elisabeth Jakobsen for feedback on a draft of this manuscript.

**Contributors** Conceptualisation—KMT, NH and SH. Data curation—KMT. Formal analysis—KMT, MBV and SH. Funding acquisition—KMT, NH and SH. Investigation and methodology—KMT, MBV, GM, GGW and SH. Project administration and resources—SH. Software—KMT. Supervision—SH and MBV. Validation and visualisation—KMT, MBV and SH. Writing (original draft preparation)—KMT and SH. Writing (review and editing)—all authors. Guarantor—SH.

**Funding** This work was supported by the Dam Foundation via the Norwegian Breast Cancer Society (grant number 2018/FO201362 to KMT). NH receives

research support through a National Health and Medical Research Council (NHMRC) Investigator (Leader) Grant (#1194410).

**Competing interests** SH is the head of BreastScreen Norway. The other authors declare no competing interests.

**Patient consent for publication** Not required.

**Ethics approval** The survey data used in this study were considered anonymous and this quality improvement project was therefore exempt from review from our local privacy ombudsman and local research ethics board (REC South East C; 2019/1291).

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data availability statement** Data are available in a public, open access repository. Data are available upon reasonable request. The questionnaire data in this article can be requested from the Cancer Registry of Norway’s data delivery unit: <https://www.kreftregisteret.no/en/The-Registries/data-delivery-unit/>. The population-based data for Norwegian women used to create survey weights are publicly available: (1) Age distribution: Statistics Norway. Population. Table 2: Population by sex, age and marital status (per 1 January) (updated 27 February 2020; accessed 24 March 2020). Available from: <https://www.ssb.no/befolkning/statistikker/folkemengde/aar-per-1-januar>. (2) Education: Statistics Norway. Educational attainment of the population. Table 1: Age groups and educational attainment (updated 27 February 2020; accessed 24 March 2020). Available from: <https://www.ssb.no/utniv/>. (3) Region of residence: Statistics Norway. Population. 07459: Population, by sex and one-year age groups (M) 1986–2020 (updated 27 February 2020; accessed 24 March 2020). Available from: <https://www.ssb.no/statbank/table/07459/>. Immigration statistics reported in table 2 are also publicly available: Immigrants and Norwegian-born to immigrant parents: Statistics Norway. 05182: Persons, by immigration category and sex (C) 1970–2020 (updated 9 March 2020; accessed 24 March 2020). Available from: <https://www.ssb.no/en/statbank/table/05182/>.

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**Table S1:** Missing data per question (*unweighted* sample after excluding women < 45 and ≥ 75; n = 2020). Questions and answers were adapted from published research<sup>a</sup>; correct answers are marked with an asterisk where applicable

Question	Response format	Missing n (%)
<b>Sociodemographic</b>		
Which age group do you belong to?	- Under 45 - 45–49 - 50–54 - 55–59 - 60–64 - 65–69 - 70–74 - 75 or older	0
What is your highest level of completed formal education?	- None - Elementary school - High school - University or college, ≤ 4 years - University or college, > 4 years - Other post-secondary - Prefer not to say <sup>b</sup>	26 (1.3)
Where were you born?	- Norway - Other - Prefer not to say <sup>b</sup>	6 (0.3)
Where in Norway do you live?	- Oslo or Viken - Innlandet - Agder or Sør-Østlandet - Vestlandet - Trøndelag - Northern Norway - Prefer not to say <sup>b</sup>	15 (0.7)
<b>Background</b>		
Have you ever searched for information about mammographic screening?	- Yes, a lot - Yes, some - No - Can't remember/unsure	2 (0.1)
Where have you searched for information about mammographic screening? (Multiple options can be selected)	- Family doctor/other health personnel - Friends and family - Cancer Registry of Norway/BreastScreen Norway's website - Other websites - Scientific literature - Books - Newspapers and periodicals - Other	0 (0.0)
Choose the sentence you think is correct	- Mammographic screening is having a mammogram when you haven't noticed a lump or other breast cancer symptoms* - Mammographic screening is having a mammogram when you have noticed a lump or other breast cancer symptoms	3 (0.1)
Have you ever heard of these three terms? <sup>c</sup>	- Yes - No - Unsure	False positives 21 (1.0)
- False positive screening results		Overdiagnosis 21 (1.0)
- Overdiagnosis		Overdetection 30 (1.5)
- Overdetection		
Choose the sentence you think best describes "false positive screening results"	- Abnormal findings on a screening mammogram, but where additional examination doesn't find breast cancer* - Breast cancer that would have never been detected if a woman hadn't attended screening - Unsure	8 (0.4)

<b>Graded</b>		
<b>Breast cancer mortality benefit</b>		
Who do you think has the highest chance of dying from breast cancer?	- Women who attend screening for breast cancer/mammographic screening - Women who do NOT attend screening for breast cancer/mammographic screening* - Unsure	15 (0.7)
Can mammographic screening detect all breast cancers?	- Yes - No* - Unsure	4 (0.2)
<b>False positive screening results</b>		
Will all women who have abnormal findings on a screening mammogram be diagnosed with breast cancer?	- Yes - No* - Unsure	10 (0.5)
<b>Overdiagnosis</b>		
Who do you think has the highest chance of being diagnosed with breast cancer?	- Women who attend screening for breast cancer/mammographic screening* - Women who do NOT attend screening for breast cancer/mammographic screening - Unsure	3 (0.1)
Cross off the sentences you think are true <sup>d</sup>	[Correct if not crossed off] All breast cancers will eventually lead to sickness and death if they are not diagnosed and treated	NA <sup>d</sup>
	[Correct if not crossed off] Doctors can distinguish harmful breast cancer that needs treatment from "nice" breast cancer that doesn't need treatment with certainty	NA <sup>d</sup>
	[Correct if crossed off] Slow growing breast cancers that are treated even though they would not have caused sickness exist*	NA <sup>d</sup>
	[Correct if crossed off] Mammographic screening leads to the diagnosis of slow growing tumours and unnecessary treatment*	NA <sup>d</sup>
Choose the definition you think best describes "overdiagnosis"	- Abnormal findings on a screening mammogram, but where additional examination doesn't find breast cancer - Breast cancer that would have never been detected if a woman hadn't attended screening* - Unsure	14 (0.7)

<sup>a</sup> Hersch J, Barratt A, Jansen J, et al. Use of a decision aid including information on overdetection to support informed choice about breast cancer screening: a randomised controlled trial. *The Lancet*. 2015;385(9978):1642-52.

<sup>b</sup> Interpreted as missing

<sup>c</sup> These terms were shown together in a grid, and participants could select a response for each term.

<sup>d</sup> These statements were shown together in a grid and women were asked to select the statement if they thought it was correct. If the statement was not selected, we interpreted the answer as "false". As a result, there were no missing data for these questions.

**Table S2:** Frequencies and proportions (%) of women's answers to selected questions stratified by five year age group (*weighted* sample, n=1892)

Question	Age, n (%) <sup>a</sup>						Total
	45–49	50–54	55–59	60–64	65–69	70–74	
<b>Have you ever searched for information about mammographic screening?</b>							
- Yes, some	147 (40.3)	174 (48.3)	149 (46.0)	142 (46.7)	163 (59.1)	125 (47.7)	901 (47.6)
- Yes, a lot	9 (2.4)	14 (4.0)	16 (5.1)	15 (5.0)	16 (6.0)	19 (7.2)	90 (4.8)
- No	201 (55.0)	154 (42.6)	139 (42.9)	110 (36.3)	93 (33.8)	100 (38.1)	797 (42.1)
- Can't remember/unsure	8 (2.3)	18 (5.1)	20 (6.1)	36 (12.0)	3 (1.1)	19 (7.1)	105 (5.5)
<b>Have you ever heard of the term "overdiagnosis"?</b>							
- Yes	176 (48.3)	187 (51.9)	175 (53.9)	170 (56.1)	136 (49.2)	127 (48.4)	971 (51.3)
- No	156 (42.6)	138 (38.1)	125 (38.6)	87 (28.5)	112 (40.7)	102 (38.8)	719 (38.0)
- Unsure	33 (9.1)	36 (9.9)	24 (7.5)	47 (15.4)	28 (10.1)	34 (12.8)	202 (10.7)
<b>Choose the definition you think best describes "overdiagnosis"<sup>b</sup></b>							
- [Incorrect] Abnormal findings on a screening mammogram, but where additional examination doesn't find breast cancer	214 (58.7)	222 (61.6)	244 (75.3)	231 (76.2)	190 (69.1)	187 (71.1)	1289 (68.1)
- [Correct] Breast cancer that would have never been detected if a woman hadn't attended screening	66 (18.0)	60 (16.5)	40 (12.4)	36 (11.8)	43 (15.5)	36 (13.5)	279 (14.8)
- Unsure	85 (23.3)	79 (21.9)	40 (12.3)	36 (12.0)	42 (15.4)	41 (15.4)	323 (17.1)

<sup>a</sup>Weighted frequencies and proportions were estimated separately. Some totals may not add up to 1892 due to rounding.

<sup>b</sup> Question and answers adapted from Hersch J, Barratt A, Jansen J, et al. Use of a decision aid including information on overdiagnosis to support informed choice about breast cancer screening: a randomised controlled trial. *The Lancet*. 2015;385(9978):1642-52.

**Table S3:** Frequencies and proportions (%) of women's answers to selected questions stratified by highest completed formal education (*weighted* sample, n = 1892).

Question	Highest completed formal education, n (%) <sup>a</sup>					Total
	Elementary school	High school	University or college, ≤ 4 years	University or college, > 4 years	Other post-secondary	
<b>Have you ever searched for information about mammographic screening?</b>						
- Yes, some	169 (38.5)	353 (47.2)	277 (54.1)	76 (52.3)	25 (53.3)	901 (47.6)
- Yes, a lot	15 (3.3)	12 (1.5)	43 (8.4)	16 (10.7)	5 (10.6)	90 (4.8)
- No	233 (53.2)	335 (44.8)	164 (32.0)	49 (33.7)	15 (32.5)	797 (42.1)
- Can't remember/unsure	22 (5.0)	48 (6.4)	28 (5.5)	5 (3.3)	2 (3.6)	105 (5.5)
<b>Have you ever heard of the term "overdiagnosis"?</b>						
- Yes	137 (31.2)	333 (44.6)	358 (69.9)	115 (78.8)	28 (59.6)	971 (51.3)
- No	237 (54.1)	324 (43.3)	119 (23.2)	23 (15.9)	16 (33.7)	719 (38.0)
- Unsure	65 (14.8)	90 (12.1)	36 (6.9)	8 (5.3)	3 (6.7)	202 (10.7)
<b>Choose the definition you think best describes "overdiagnosis"<sup>b</sup></b>						
- [Incorrect] Abnormal findings on a screening mammogram, but where additional examination doesn't find breast cancer	262 (59.7)	507 (67.8)	372 (72.5)	114 (78.0)	35 (73.1)	1289 (68.1)
- [Correct] Breast cancer that would have never been detected if a woman hadn't attended screening	74 (16.8)	94 (12.6)	79 (15.5)	24 (16.6)	8 (16.0)	279 (14.8)
- Unsure	103 (23.5)	146 (19.5)	61 (12.0)	8 (5.5)	5 (10.9)	323 (17.1)

<sup>a</sup>Weighted counts and proportions were estimated separately. Some totals may not add up to 1892 due to rounding.

<sup>b</sup> Question and answers adapted from Hersch J, Barratt A, Jansen J, et al. Use of a decision aid including information on overdetection to support informed choice about breast cancer screening: a randomised controlled trial. *The Lancet*. 2015;385(9978):1642-52