



Women's responses to information about overdiagnosis in the UK breast cancer screening programme: a qualitative study

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3 **Women's responses to information about overdiagnosis in the UK breast cancer screening**
4 **programme: a qualitative study**
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ABSTRACT

Objectives To explore the influence of overdiagnosis information on women's decisions about mammography.

Design A qualitative focus group study with purposive sampling and thematic analysis, in which overdiagnosis information was presented.

Setting Community and university settings in London.

Participants 40 women within the breast screening age range (50-71 years) including attenders and non-attenders.

Results Women expressed surprise at the possible extent of overdiagnosis and recognised the information as important, although many struggled to interpret the numerical data. Overdiagnosis was viewed as less personally relevant than the possibility of 'under-diagnosis' (false negatives), and often considered to be an issue for follow-up care decisions rather than screening participation. Women also expressed concern that information on overdiagnosis could deter others from attending screening, although they themselves rarely saw it as a deterrent. Few felt that they would make a different screening decision.

Conclusions Women regard it as important to be informed about overdiagnosis to get a complete picture of the risks and benefits of mammography, but the results of this study indicate that it may not influence their attitudes towards screening. The results also highlight the challenge of communicating the individual significance of information derived from population-level modelling.

ARTICLE SUMMARY*Article focus*

- How do women respond to information about overdiagnosis in breast cancer screening?
- What impact does such information have on women's decision-making about future screening?

Key messages

- Most women were surprised by the existence and extent of overdiagnosis in breast screening
- Numerical information about rates of overdiagnosis was often poorly understood
- Women wanted to be informed about overdiagnosis whether or not it would affect their screening decisions

Strengths and limitations of this study

- This is the first study in the UK to address this issue
- The generalizability of the findings has yet to be investigated

INTRODUCTION

The controversy over the risks and benefits of breast cancer screening has been played out in the public media¹ as well as the medical press.²⁻⁵ It prompted an independent review of the research evidence on breast cancer screening in the UK⁶ which reported its findings in October 2012.⁷ As part of the debate, the information about breast screening provided by the National Health Service (NHS) has been criticised as one-sided.⁸ A key concern is that the risk of overdiagnosis is not adequately reflected in the information that is given to the public.⁹ However, given the complexity of interpreting results obtained from modelling population patterns of screening and mortality, and the difficulties of applying population level results to individual decision-making, there may be challenges in communicating this information, particularly given the range of estimates about the risk of overdiagnosis. The UK review reported estimates between 9.7% and 29.4% across three trials,⁷ depending on the denominator used, and other studies have reported higher and lower figures.³

At present it is unclear whether women would like to have numerical information on overdiagnosis and whether they would take it into account in making breast screening decisions. Survey results in the US and Europe have indicated considerable enthusiasm for screening and a tendency for the public to over-estimate the benefits of mammography.^{10,11} Tolerance of false positive results also seems high, with one US study finding that even among women who had experienced a false positive mammogram, a third believed that $\geq 10,000$ false positives would be acceptable to save one life from breast cancer.¹² The issue of overdiagnosis and unnecessary treatment is probably less well understood by the public. The same US study found that only 7% of women were aware of non-progressive breast cancer, but after a brief explanation of ductal carcinoma in situ and the risk of over-treatment, 60% wanted to take this information into account when deciding about mammography screening.¹² This indicates the importance of providing information on overdiagnosis, although in the survey context only a very brief description could be given and it is possible that more considered responses would be different.

In a recent UK study of the public's preferences for information on cancer screening, most people said they would like all available information about risks of screening as well as benefits,¹³ although qualitative research has shown that when risk information is included in a screening information leaflet, the UK public can be critical; arguing that if the NHS thinks people should go for screening, they should give unambiguous messages and not 'frighten people off' with stories of rare risks and

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3 the complexities of follow up.¹⁴ Some studies have also found women to be sceptical about the
4 motivation behind questioning the benefits of mammography.¹⁵ Crucial to taking forward new
5 approaches to breast screening information is to gain an understanding of women's perspective on
6 the idea of 'overdiagnosis', and to work out how to provide this information in a manner that is
7 understandable and not likely to undermine equality of access.
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12 Within the current debate about overdiagnosis, the voice of the users of the screening programme,
13 women themselves, has been largely silent. The one study to date examined Australian women's
14 responses to detailed information on overdiagnosis and a range of estimates of its prevalence.¹⁶ The
15 results showed that although women generally lacked prior awareness of the issue, they were able
16 to understand it when information was provided in the form of an audiovisual presentation. The
17 impact of the information on future screening intentions varied widely between women and was
18 also different depending on the prevalence of overdiagnosis presented.
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24 The present study used similar qualitative methods to elicit British women's reactions to the notion
25 of overdiagnosis and examine the effect they felt it might have on their decision-making about
26 mammography participation. The UK context is important because of the media attention there had
27 already been to the overdiagnosis issue at the time of this study. We also focused on the impact of
28 relatively brief information on overdiagnosis, to reflect the kind that might be provided in a
29 screening information leaflet.
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35 36 37 **METHODS**

38 39 40 **Methodological approach**

41 Focus groups were used to explore women's existing knowledge and experience, and elicit dynamic
42 responses to potentially new information on overdiagnosis.¹⁷ The group context allowed women to
43 reflect on and respond to one another's comments. A qualitative analysis allowed us to identify
44 common themes.
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48 49 50 **Participants**

51 Six focus groups were conducted with women in the mammography screening age range (50-71
52 years). All women spoke fluent English, none had a personal history of cancer, and none worked in
53 occupations related to cancer or cancer screening. Women were recruited from a specialist
54 participant recruitment agency, community groups, mailing lists, and adverts circulated by email to
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3 achieve a sample with a range of ethnicities, and marital and socioeconomic status (SES). Ethical
4 approval was obtained (UCL Research Ethics Committee: ref 3162/002).
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8 **Data collection**

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10 Groups were conducted at UCL or a suitable community venue and facilitated by an experienced
11 qualitative researcher with a second researcher acting as observer. In designing the discussion
12 guide, emphasis was placed on constructing open-ended, non-directive questions and using a
13 funnelling approach with questions moving from the general to the more focused (see
14 supplementary material for the discussion guide).¹⁸ The aim was to generate discussion and elicit
15 views on overdiagnosis. To open the discussion, participants were invited to discuss their own
16 experiences of decision-making about mammography. They were asked to read the relevant pages
17 of the current NHS breast screening leaflet¹⁹ to remind them of the information currently provided
18 about benefits and risks of screening, which includes a statement on overdiagnosis.¹ We then
19 provided brief information on overdiagnosis (see Box 1) and women were asked to discuss it and to
20 consider how it might affect their views of breast screening. The analysis presented here focuses on
21 women's responses to this new information. Group discussions were digitally recorded and
22 transcribed verbatim.
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32 **Box 1 – Description of overdiagnosis (read aloud to participants during group discussion)**

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34 It's been suggested that some of the breast cancers that get diagnosed through breast screening are
35 so slow-growing that they would not have caused any problems. But because we can't yet tell which
36 kind of cancer is the slow-growing kind, the woman receives the usual treatment for breast cancer
37 (e.g. surgery). Of all women who go for breast screening, about 8 in 1000 are diagnosed with cancer.
38 It's very hard to know what proportion of cancers diagnosed in the screening programme are of the
39 slow-growing type and the experts disagree at the moment. The estimates have varied from 1 in 8 of
40 women who are diagnosed to 3 in 8.
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47 The description of overdiagnosis presented to the focus groups was developed in consultation with
48 experts. We used 8 out of 1000 cancer diagnoses as a starting point, as this information is currently
49 included in the NHS leaflet.¹⁹ The range of 1 to 3 overdiagnoses out of 8 cancers detected
50 corresponds to a rate of overdiagnosis of 12.5-37.5%, broadly consistent with the conclusions of the
51 UK review.⁷ The wording was designed to be understandable to women of all educational
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56 ¹ The bullet point on overdiagnosis reads 'Screening can find cancers which are treated but which may not
57 otherwise have been found during your lifetime.'
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3 backgrounds. To make it easier, we used the term 'slow-growing cancer' because it is used by the
4 public and has been used in previous overdiagnosis research.¹⁰ We chose to use brief information to
5 reflect the level of detail women might be given in a written leaflet.
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9 10 **Analysis**

11 Verbatim transcripts were analysed thematically using guidelines outlined by Braun and Clarke.²⁰
12 Two researchers read all the transcripts independently and generated initial codes. These were then
13 collated into potential themes. A thematic map of the analysis was produced by each researcher
14 and these were refined through group discussion with all authors. All transcripts were then re-read
15 using the final thematic map and adjustments were made following further group discussion. We
16 used NVivo version 9 to code the data, and analysis continued into the write-up stage using the
17 themes and verbatim examples to produce a narrative of women's experiences of the topic. Only
18 sections of the analysis concerned with overdiagnosis are reported here. Demographic data were
19 analysed using SPSS version 15.²¹
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27 **RESULTS**

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30 A total of 40 women took part in six discussion groups; the number of women per group ranged
31 from four to nine. Demographic characteristics of the sample are shown in Table 1. Focus groups
32 lasted an average of 75 minutes (range 51-93 minutes).
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37 Themes emerged relating to women's previous experiences and beliefs about breast screening, and
38 their attitudes to false positive results. As these issues are well-documented in the existing
39 literature,^{12;22;23} we focus here specifically on responses to the overdiagnosis information. Two main
40 themes were identified: 1) 'Making sense of the concept of overdiagnosis', 2) 'Implications of
41 overdiagnosis information' (see Box 2).
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Box 2 – Thematic structure

1) Making sense of the concept of overdiagnosis

- Confusion
- How do they know?
- Emotional responses
- Cynicism
- Referring to experts

2) Implications of overdiagnosis information

- Erring on the side of caution
- Right to know
- Overdiagnosis as a treatment issue
- Impact on screening decisions

Making sense of the concept of overdiagnosis

In the initial discussions of mammography screening, overdiagnosis was mentioned in four out of six groups, but was only widely known-about in one group. The few women who had heard about the issue tended to find it somewhat off-putting and one said that negative information about breast screening in the media, including on overdiagnosis, had influenced her intentions to attend.

I just haven't felt like going again ... I read everything and there hasn't been very good reports that I've read recently, in the past five years basically, so I haven't been again (P5)

After reading the information on the risks and benefits of breast screening in the NHS leaflet, some women recalled seeing it before while others had little recollection of it and were unaware of the risk information. The analysis here focuses on responses to the information in Box 1, which encompassed a number of themes.

Confusion

Many women found the statistical information on overdiagnosis difficult to understand. The challenge of making sense of the numerical information was implicit in some participants' responses but was also mentioned explicitly. In response to the information that between one and three cancers out of every eight diagnosed would never have caused a problem, one woman said:

Well, one or three isn't a great number ... Well, one isn't. Three is, because that's nearly fifty per cent, but one isn't. (P28)

Table 1: Demographic characteristics of the sample

	N (%)
Age (mean (SD); range)	58.5 (5.4); 50-71
Ethnic group	
White	27 (67.5)
Black	6 (15.0)
Asian	5 (12.5)
Mixed	1 (2.5)
Other	1 (2.5)
Marital status	
Married/cohabiting/civil partnership	15 (37.5)
Single/never married	12 (30.0)
Divorced/widowed	13 (32.5)
Highest level of education	
University degree	21 (52.5)
A-levels/ONC/BTEC/Other Further Education	11 (27.5)
O-level or none	7 (17.5)
Missing	1 (2.5)
Time since last mammogram	
3 years or less (as recommended)	29 (72.5)
4-9 years	4 (10.0)
10 years or more	3 (7.5)
Never screened	2 (5.0)
Screened, but time since last screen missing	2 (5.0)
Ever called back for further tests?	
Yes	5 (12.5)
No	33 (82.5)
N/A – never had a mammogram	2 (5.0)

Her assumption that a higher number is preferable reveals her lack of understanding about what has been said. In another group, participants struggled to respond to the information that had been read to them:

P11: It's hard to say really.

P10: I don't know what to say about that.

P7: Yeah, it feels a bit, well, it's only some, so, well, that's good because it's only five [that need treatment] but I don't know. (Group 2)

Emotional responses

Some women expressed shock at the level of overdiagnosis and the implications for over-treatment, with women in two of the groups voicing more concern about unnecessary treatment than had been evident at earlier stages of the discussion. Some said they would be angry to discover that they had been unnecessarily treated for cancer ('*I'd have their guts for garters'* (P7)). Others highlighted the side-effects of treatment they had witnessed in friends and family and expressed dismay at the prospect of anyone having to go through that unnecessarily. There was also concern for the financial cost to the NHS and for the wasted time and energy of NHS staff.

P27: I don't know, but four out of ten! As you say one out of ten is quite a lot. Four out of ten is horrendous.

P22: Scary!

P21: And I also think about the waste of funds and resources when they could be used for people that genuinely need it ... I'm quite shocked at what you've told me today. (Group 4)

Cynicism

In five of the six focus groups, some cynicism was expressed about the statistical information.

Well, I'm very sceptical about statistics generally because I've seen them manipulated to prove what the person using them wishes to prove. (P2)

In particular, some women feared that statistical data supporting the risks of mammography could be used to justify a cost-cutting exercise in which the NHS Breast Screening Programme might be restricted or withdrawn. Many women became protective of the screening programme at this stage in the face of what was perceived to be a threat to the service.

I would hate to see funding for screening of breast cancer being removed because, even though I might not go for it, it's a choice and it's good to have the choice, and I think that choice is very, very important and such a vital thing you know (P3).

Referring to experts

Once women had an understanding of the concept of overdiagnosis they began to refer to experts in two ways: first to question how scientists know that this phenomenon exists and then to express their trust in health experts.

Women often questioned the statistical information they had been given.

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3 *How do they know? How have they arrived at those figures, then? Because is it just literally*
4 *at the end of chemo, they go 'Yeah, it's still there, or no, it's...?'* (P22)
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8 When it was explained that an individual woman would not know that her treatment had been
9 unnecessary, participants began to question the basis of the information. Where women asked
10 these questions, facilitators explained that statistical modelling is used to estimate levels of
11 overdiagnosis. Not surprisingly, many participants found this difficult to understand.
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14 *I mean if this is all done on modelling, what's it modelled on? Is it that when they remove*
15 *things they find different things within it, but you have to have it removed to know that? ...*
16 *Or is it that it's all coming through post-mortems and things?* (P27)
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21 Some participants wondered if doctors would choose not to treat a suspected slow-growing cancer,
22 alluding to an implicit fear of under-treatment.
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24 *Because doctors aren't infallible are they? ... Some will be more cautious than others, some*
25 *will want to err on the side of not doing very much surgery and only doing as little as they*
26 *can get away with until there is an indication that more is needed.* (P37)
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30 Others felt that surgeons 'like to wield their knives' (P19) and might be inclined to operate rather
31 than try alternative approaches.
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35 However, there was also widespread trust in health experts, which was expressed in all groups.
36 There was trust in doctors, scientists and the NHS breast screening programme to utilise new
37 knowledge or improved technology to ameliorate the risk of overdiagnosis and unnecessary
38 treatment in the future.
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42 *P5: I think that my having heard all this now, I mean [I am] more educated about it and I*
43 *would say now that I just have a trust that the NHS wouldn't haul us all out if statistically*
44 *there wasn't some evidence that, by and large, some people get saved, you know, and that*
45 *not many people get disadvantaged.*
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48 *P4: I have some trust to some extent because I think it's evidence-based treatment, isn't it?*
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50 (Group 1)
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Implications of overdiagnosis information

Erring on the side of caution

As women discussed the implications of the information about overdiagnosis, a broad consensus emerged that overdiagnosis and false positives were strongly preferred to any risk of underdiagnosis. Some women saw overdiagnosis and false positives as evidence that the screening programme was thorough in its detection of cancer. False positives in this context were considered to be acceptable despite the short-term worry of being recalled, of which some women had personal experience. In contrast, women were extremely concerned about false negatives and the risk that cancer might be missed or treatment delayed.

Well for me it's life or death, really, so there is no question that I would want to go for screening and have treatment as appropriate, because there are unknowns. We don't know if it is fast growing or slow growing. So I would want to have treatment with advice and stay alive basically. (P37)

Right to know

There was, however, a strong belief that women should be given information about overdiagnosis. Participants felt the information should be 'part of my decision' to attend for screening and, in the event of a breast cancer diagnosis, to be part of their decision about treatment. One participant talked about informed decision-making:

Yes but it's a question of ... awareness. It's a question of giving us the information ... And letting us process it ourselves and letting us make an informed decision. The facts. (P19)

Another recognised the variation in the amount of information that different people might want:

You can't deny people who want to know just because others don't. (P26)

Overdiagnosis as a treatment issue

Many women struggled to see information on overdiagnosis as relevant to their decision-making about screening. Much of the discussion was around treatment decisions for screen-detected cancers. Women were concerned about unnecessary treatment but were also keen to treat cancer.

I mean, just think, they would say to you 'You've got it but we don't think it's going to come to anything and so you don't have to have treatment if you don't want to'. That doesn't make sense to me. If someone says 'You've got a cancer', you say 'Right, let's do something about it.' (P34)

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4 In general, the risk of under-treatment of cancer was seen as much greater than the risk of over-
5
6 treatment.
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8 9 Impact on screening decisions

10 At the end of the groups, most women retained their initial perspectives on attending screening.
11 Previous attenders maintained that '*I'd still have a mammogram, yeah*'. The reasons cited included
12 reassurance that they do not have cancer, a desire to know if cancer is present and to increase the
13 chances of an earlier diagnosis and more successful treatment. The information on overdiagnosis
14 did not seem to have affected their core beliefs about screening.
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19 *I would still go, you know, it's better knowing than not knowing... At least I know that, it*
20 *gives me time to plan ... things or what to do next. So I would rather have it done. It*
21 *wouldn't change my view at all.* (P17)
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25 Despite the majority of screening decisions being unaffected, a few women did describe a change in
26 attitude. One participant who initially described mammograms as 'very good' and 'very important'
27 responded to the overdiagnosis information by saying 'That puts you off going at all doesn't it?' and
28 later 'I find that very worrying, to have an operation when you didn't need to' (P12). Another who
29 had recently attended for screening said
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34 *I'm in the clear at the moment [because of just having been screened] and I'm wondering*
35 *whether I do want to go again actually.* (P40)
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39 Women who had never attended screening or had ceased to attend also tended to maintain their
40 view although, perhaps surprisingly, one woman thought that following the discussion, she would
41 consider attending in future.
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44 *As I said, I haven't had an invitation for so many years that it is something that you don't*
45 *even think about really ... so I, you know, will gather ... more information and make another*
46 *informed decision about whether I will or not go. I mean it's my choice at the end of the day*
47 *so no one can force me to go there ... I will have another think about it seriously.* (P19)
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50 51 DISCUSSION

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54 In this qualitative study, we identified widespread lack of awareness of the risk of overdiagnosis in
55 breast cancer screening among screening-eligible women. When provided with information about
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3 the range of risks of overdiagnosis and unnecessary treatment, they were often shocked and
4 surprised, but most of those who had previously participated in screening maintained a positive
5 attitude to the programme, preferring the risk of over-treatment to the risk of under-treatment.
6 Given that no individual would know that her treatment had been unnecessary, women expressed
7 an overwhelming preference to err on the side of caution. Some also regarded the information as
8 relevant to choices about treatment rather than screening. In a few cases, however, women were
9 put off by the information and felt that it might deter them from future screening attendance. Our
10 findings are strikingly similar to a recent Australian study,¹⁶ despite differences in the way that
11 information on overdiagnosis was presented. This suggests that similar communication challenges
12 will be faced across countries where breast screening is offered.
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21 The study benefitted from the inclusion of women within the breast screening age range, around
22 70% of whom had been screened within the last three years, which is broadly in line with national
23 coverage data.²⁴ Women willing to attend a discussion group on mammography may generally be
24 more pro-screening than the general population and this may be a limitation of our study, although
25 this concern is mitigated by the fact that our groups included women in the screening age range who
26 had never attended or were overdue for screening. The use of focus groups allowed the complex
27 issues surrounding overdiagnosis to be explored and discussed in a more detailed way than is
28 possible using survey methodology, but larger-scale work will be needed to establish the
29 generalizability of the findings. Our participants found it difficult to understand the brief explanation
30 of overdiagnosis that we provided, and there is an urgent need to develop clear and concise
31 methods of conveying both the concept and its prevalence in a written format to provide to women
32 by post.
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42 The themes we identified included some that have been described before. We found that women
43 had a desire to be provided with all the available information on risks,¹³ although this was tempered
44 by concern that risk information may put 'other people' off screening.¹⁴ The theme of viewing
45 others as being more risk averse or easily deterred is common in qualitative research and
46 researchers are uncertain whether this is a coded way of expressing personal concern or a reflection
47 of broader identity beliefs that tend to represent the self as stronger than others in many respects.
48 In this case, the fact that women expressed few additional doubts about attendance despite
49 prolonged discussion of the issues tends to support the latter view. Some women also expressed
50 scepticism about any suggestion of shortcomings of mammography, which is consistent with the
51 finding that even women with interval cancer diagnoses tend to maintain trust in the screening
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3 programme and to see their own cases as exceptions to an otherwise effective programme.²⁵
4 Interpreted within the framework of Fuzzy Trace Theory,²⁶ this could be seen as due to women
5 holding a strong 'gist' representation that early detection is good and finding it difficult to integrate
6 complex verbatim information about overdiagnosis into that gist; causing them to retain their
7 original beliefs.
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13 The finding that women generally preferred to be overdiagnosed than underdiagnosed is consistent
14 with previous findings of high tolerance levels of false positive results¹² and a fear of false negative
15 results;²⁷ in other words they value sensitivity over specificity, which has been found in other
16 screening as well as diagnostic contexts.^{28,29} But this is the first study, to our knowledge, to have
17 explicitly explored the notion of overtreatment in the UK breast screening context.
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22 The study has two broad implications. First, it highlights the difficulty of communicating the
23 concept of overdiagnosis to non-statisticians. Confusion was common and women found the idea
24 that the estimates of overdiagnosis are based on statistical modelling extremely difficult to
25 understand. Further work is needed to develop ways of conveying this type of information clearly.
26
27 Secondly, although women felt the information was important, it generally had little impact on their
28 beliefs about screening and their future intentions to participate. More work will be needed to see
29 whether this finding generalises to the wider population and whether the impact of information on
30 overdiagnosis differs across socioeconomic groups.
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3 **Ethical approval:** The study was approved by the UCL Research Ethics committee (ref: 3162/002).
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6 **Funding:** The study was commissioned and funded by the Cancer Research UK Information
7
8 Department.
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11 **Role of the sponsor and funder:** The study was commissioned by Cancer Research UK to explore
12 responses to overdiagnosis in breast cancer screening. The funder was not involved in carrying out
13 the study, or in the analysis and interpretation of the data.
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17 **Data sharing:** The discussion guide used in the study is available as supplementary material.
18 Anonymised transcripts will be made available to interested researchers.
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38 **Competing interests:** All authors have completed the ICMJE uniform disclosure form at
39 www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and
40 declare: no support from any organisation for the submitted work; no financial relationship with any
41 organisations that might have an interest in the submitted work in the previous three years; no
42 other relationships or activities that could appear to have influenced the submitted work.
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50 checked the transcripts. ED and KW carried out initial coding of the data. All the authors were
51 involved in discussion of the thematic framework, further analysis and interpretation, and in the
52 drafting of the paper. JWar is the guarantor.
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REFERENCES

- (1) Baum M. Breast screening should be scrapped. *The Guardian* 2 August 2011.
- (2) Duffy SW, Tabar L, Olsen AH. Absolute numbers of lives saved and overdiagnosis in breast cancer screening, from a randomized trial and from the Breast Screening Programme in England. *J Med Screen* 2010;**17**:106.
- (3) Jorgensen KJ, Gotzsche PC. Overdiagnosis in publicly organised mammography screening programmes: systematic review of incidence trends. *BMJ* 2009;**339**:b2587.
- (4) Woolf SH, Harris R. The harms of screening: new attention to an old concern. *JAMA* 2012;**307**:565-566.
- (5) Baum M, Thornton H, Gotzsche PC, Bewley S, Jorgensen KJ, Barratt A et al. Breast cancer awareness month. Still awaiting screening facts. *BMJ* 2010;**341**:c6152.
- (6) Richards M. Breast Cancer Screening An Independent Review Is Under Way. *BMJ* 2011;**343**:d6843.
- (7) The benefits and harms of breast cancer screening: an independent review. *Lancet* 2012;**380**(9855):1778-1786.
- (8) Gotzsche PC, Hartling OJ, Nielsen M, Brodersen J, Jorgensen KJ. Breast screening: the facts-or maybe not. *BMJ* 2009;**338**:b86.
- (9) Gotzsche PC, Nielsen M. Screening for breast cancer with mammography. *Cochrane Database Syst Rev* 2006;(4):CD001877.
- (10) Schwartz LM, Woloshin S, Fowler FJ, Welch HG. Enthusiasm for Cancer Screening in the United States. *JAMA* 2004;**291**:71-78.
- (11) Domenighetti G, Avanzo B, Egger M, Berrino F, Perneger T, Mosconi P et al. Women's perception of the benefits of mammography screening: population-based survey in four countries. *Int J Epidemiol* 2003;**32**:816-821.
- (12) Schwartz LM, Woloshin S, Sox HC, Fischhoff B, Welch HG. US women's attitudes to false positive mammography results and detection of ductal carcinoma in situ: cross sectional survey. *BMJ* 2000;**320**(7250):1635-1640.
- (13) Waller J, Macedo A, von WC, Simon AE, Jones C, Hammersley V et al. Communication about colorectal cancer screening in Britain: public preferences for an expert recommendation. *Br J Cancer* 2012;**107**:1938-1943.
- (14) Woodrow C, Watson E, Rozmovits L, Parker R, Austoker J. Public perceptions of communicating information about bowel cancer screening. *Health Expect* 2008;**11**:16-25.
- (15) Hersch J, Jansen J, Irwig L, Barratt A, Thornton H, Howard K et al. How do we achieve informed choice for women considering breast screening? *Prev Med* 2011;**53**:144-146.

- 1
2
3 (16) Hersch J, Jansen J, Barratt A, Irwig L, Houssami N, Howard K et al. Women's views on
4 overdiagnosis in breast cancer screening: a qualitative study. *BMJ* 2013;**346**:f158.
5
6 (17) Kitzinger J. Qualitative research. Introducing focus groups. *BMJ* 1995;**311**(7000):299-302.
7
8 (18) Dickson-Swift V, James EL, Kippen S, Liamputtong P. Doing sensitive research: what
9 challenges do qualitative researchers face? *Qualitative Research* 2007;**7**:327-353.
10
11 (19) NHS breast screening. Available at:
12 <http://www.cancerscreening.nhs.uk/breastscreen/publications/nhsbsp.pdf>. 2011.
13 Department of Health; NHS Cancer Screening Programmes. [Accessed 7/2/13]
14
15 (20) Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology*
16 2006;**3**:77-101.
17
18 (21) SPSS for Windows Chicago: SPSS Inc; 2006.
19
20 (22) Webster P, Austoker J. Women's knowledge about breast cancer risk and their views of the
21 purpose and implications of breast screening--a questionnaire survey. *J Public Health*
22 2006;**28**:197-202.
23
24 (23) Engelman KK, Cizik AM, Ellerbeck EF. Women's satisfaction with their mammography
25 experience: results of a qualitative study. *Women Health* 2005;**42**:17-35.
26
27 (24) NHS The Information Centre. Breast screening programme, England 2010-2011.
28 <http://www.ic.nhs.uk/pubs/brstscreen1011> [Accessed 7/2/13]
29
30 (25) Solbjor M, Skolbekken JA, Saetnan AR, Hagen AI, Forsmo S. Mammography screening and
31 trust: The case of interval breast cancer. *Soc Sci Med* 2012;**75**:1746-1752.
32
33 (26) Reyna VF. A theory of medical decision making and health: fuzzy trace theory. *Med Decis*
34 *Making* 2008;**28**:850-865.
35
36 (27) Watson-Johnson LC, DeGroff A, Steele CB, Revels M, Smith JL, Justen E et al. Mammography
37 adherence: a qualitative study. *J Womens Health* 2011;**20**:1887-1894.
38
39 (28) Ghanouni A, Smith SG, Halligan S, Plumb A, Boone D, Magee MS et al. Public perceptions and
40 preferences for CT colonography or colonoscopy in colorectal cancer screening. *Patient Educ*
41 *Couns* 2012;**89**:116-121.
42
43 (29) von Wagner C, Halligan S, Atkin WS, Lilford RJ, Morton D, Wardle J. Choosing between CT
44 colonography and colonoscopy in the diagnostic context: a qualitative study of influences on
45 patient preferences. *Health Expect* 2009;**12**:18-26.
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Supplementary material – Discussion guide

1. Introduction**2. Decision making about mammography**

- General attitude to the concept of breast cancer screening
- Factors in the decision to go
- Is the current invitation seen as a recommendation?
- Experiences of going for mammography

3. Information in Breast Screening Leaflets

- Currently read leaflets – Why? Why not?
- Is this information wanted before being screened?
- Risk information wanted? – Why? Why not?

[Participants asked to read NHS Breast Screening leaflet. Instruction to only read p.3/4 on risks and benefits]

4. Reactions to risk information

- Aware of these risks before?
- Surprising/intuitive information – Why? Why not?
- Influence on feelings about breast screening
- Change decision to go for screening – why? Why not?

5. False positives

- (Refer to leaflet) 'A false positive is when a woman is referred for further tests (such as another mammogram or a biopsy) and is then found not to have breast cancer'. What are your thoughts on this?
- 'About 1 in 20 women are sent for further tests, but most (4 in 5) turn out not to have cancer – i.e. it's a false alarm'. What are your thoughts on this?

6. Overdiagnosis

(Refer to leaflet) 'It's been suggested that some of the breast cancers that get diagnosed through breast screening are so slow-growing that they would not have caused any problems. But because we can't yet tell which kind of cancer is the slow-growing kind, the women receives the usual treatment for breast cancer (e.g. surgery).' What are your views about this?

- Of all women who go for breast screening about 8 in 1000 are diagnosed with cancer. It's very hard to know what proportion of cancers diagnosed in the screening programme are of the slow growing type and the experts disagree at the moment. The estimates have varied from 1 in 8 of women who are diagnosed to 3 in 8. How do you feel about these figures?
 - o How would you feel about having treatment (surgery, radiotherapy, chemotherapy) for a cancer that wouldn't have been life-threatening?
 - o How do you weigh up the risk of this kind of over treatment against the possible benefits for early diagnosis?

7. Wrap-up



Women's responses to information about overdiagnosis in the UK breast cancer screening programme: a qualitative study

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3 **Women's responses to information about overdiagnosis in the UK breast cancer screening**
4 **programme: a qualitative study**
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ARTICLE SUMMARY

Article focus

- Little is known about the impact that information on overdiagnosis in mammography screening might have on women's decision-making about screening
- We used qualitative methods to explore women's responses to information on overdiagnosis in breast screening

Key messages

- The concept of overdiagnosis was unfamiliar to many participants and there was a strong belief that women should be informed about it
- Participants sometimes struggled to understand the concept of overdiagnosis and often regarded it as an issue for treatment, rather than screening decisions
- Few women felt that the information they had been given would affect their future breast screening decisions

Strengths and Limitations

- This is the first study to explore responses to overdiagnosis in breast screening in the UK and benefitted from the use of in-depth qualitative methods
- The use of the phrase 'slow-growing cancer' in our explanation of overdiagnosis may have affected women's responses

ABSTRACT

Objectives To explore the influence of overdiagnosis information on women's decisions about mammography.

Design A qualitative focus group study with purposive sampling and thematic analysis, in which overdiagnosis information was presented.

Setting Community and university settings in London.

Participants 40 women within the breast screening age range (50-71 years) including attenders and non-attenders were recruited using a recruitment agency as well as convenience sampling methods.

Results Women expressed surprise at the possible extent of overdiagnosis and recognised the information as important, although many struggled to interpret the numerical data. Overdiagnosis was viewed as less personally relevant than the possibility of 'under-diagnosis' (false negatives), and often considered to be an issue for follow-up care decisions rather than screening participation.

Women also expressed concern that information on overdiagnosis could deter others from attending screening, although they themselves rarely saw it as a deterrent. After discussing overdiagnosis, few women felt that they would make different decisions about breast screening in the future.

Conclusions Women regard it as important to be informed about overdiagnosis to get a complete picture of the risks and benefits of mammography, but the results of this study indicate that understanding overdiagnosis may not always influence women's attitudes towards participation in breast screening. The results also highlight the challenge of communicating the individual significance of information derived from population-level modelling.

INTRODUCTION

The controversy over the risks and benefits of breast cancer screening has been played out in the public media¹ as well as the medical press.²⁻⁵ It prompted an independent review of the research evidence on breast cancer screening in the UK⁶ which reported its findings in October 2012.⁷ As part of the debate, the information about breast screening provided by the National Health Service (NHS) has been criticised as one-sided.⁸ A key concern is that the risk of overdiagnosis is not adequately reflected in the information that is given to the public.⁹⁻¹² However, given the complexity of interpreting results obtained from modelling population patterns of screening and mortality, and the difficulties of applying population level results to individual decision-making, there may be challenges in communicating this information, particularly given the range of estimates about the risk of overdiagnosis. The UK review reported estimates between 9.7% and 29.4% across three trials,⁷ depending on the denominator used, and other studies have reported higher and lower figures.³

At present it is unclear whether women would like to have numerical information on overdiagnosis and whether they would take it into account in making breast screening decisions. Survey results in the US and Europe have indicated considerable enthusiasm for screening and a tendency for the public to over-estimate the benefits of mammography.^{13;14} Tolerance of false positive results also seems high, with one US study finding that even among women who had experienced a false positive mammogram, a third believed that it would be acceptable for 10,000 women or more to have false positive results in order to save one life from breast cancer.¹⁵ The issue of overdiagnosis and unnecessary treatment is probably less well understood by the public. The same US study found that only 7% of women were aware of non-progressive breast cancer, but after a brief explanation of ductal carcinoma in situ and the risk of over-treatment, 60% wanted to take this information into account when deciding about mammography screening.¹⁵ This indicates the importance of providing information on overdiagnosis, although in the survey context only a very brief description could be given. It is possible that immediate responses to survey questions on a previously unfamiliar topic may lack ecological validity and could be thought of as 'non-attitudes' in that they do not reflect any pre-existing beliefs.¹⁶ This problem could be addressed by creating an opportunity for women to discuss and reflect on their understanding of overdiagnosis and the potential impact of this information on subsequent screening decisions in a more considered and ecologically valid way.

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3 In a recent UK survey of the public's preferences for information on cancer screening (in this case it
4 was colorectal cancer), most people, responding on a scale of 1 to 10, said they would like all
5 available information about risks of screening as well as benefits.¹⁷ However, when asked more
6 detailed and open questions in qualitative research, the UK public can be critical when risk
7 information is included in colorectal screening information leaflets; arguing that if the NHS thinks
8 people should go for screening, they should give unambiguous messages and not 'frighten people
9 off' with stories of rare risks and the complexities of follow up.¹⁸ Some studies have also found
10 women to be suspicious about the motivation behind questioning the benefits of mammography.¹⁹
11 In order to take forward new approaches to the provision of breast screening information, it is
12 crucial to gain an understanding of women's perspective on the idea of 'overdiagnosis'. Information
13 must be provided in a manner that is understandable and not likely to undermine equality of access.
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22 Within the current debate about overdiagnosis, the voice of the users of the screening programme,
23 women themselves, has been largely silent. The one study to date examined Australian women's
24 responses to detailed information on overdiagnosis and a range of estimates of its prevalence, using
25 focus group methodology.²⁰ The results showed that although women generally lacked prior
26 awareness of the issue, they were able to understand it when information was provided in the form
27 on an audio-visual presentation. The impact of the information on future screening intentions
28 varied widely between women and was also different depending on the prevalence of overdiagnosis
29 presented.
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37 The present study aimed to use qualitative methods to elicit British women's reactions to the notion
38 of overdiagnosis and examine the effect they felt it might have on their decision-making about
39 mammography participation. The UK context is important firstly because of the media attention
40 there had already been to the overdiagnosis issue at the time of this study,^{1,21-23} and secondly
41 because of the on-going and high-profile criticism of the information provided to women in the UK
42 about the breast screening programme.^{5;8;24} We focused on the impact of relatively brief
43 information on overdiagnosis, to reflect the kind that might be provided in a screening information
44 leaflet.
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METHODS

Methodological approach

Focus groups were used to explore women's existing knowledge and experience, and elicit dynamic responses to potentially new information on overdiagnosis in the context of a structured discussion.²⁵ It is acknowledged that focus groups are well suited to exploring 'public' topics, such as public health interventions²⁶ and are a good way to identify 'group norms and cultural values'.²⁵ We used focus groups rather than individual interviews for this study to try to gauge the public response to information about overdiagnosis in the context of a national screening programme, and to provide participants with the opportunity to question each other and to reflect and respond to one another's comments. A qualitative analysis allowed us to identify common themes.

Participants

Six focus groups were conducted with women in the mammography screening age range (50-71 years). All women spoke fluent English, none had a personal history of cancer, and none worked in occupations related to cancer or cancer screening. Women living in and around London were recruited from a specialist participant recruitment agency, community groups, mailing lists, and adverts circulated by email to achieve a sample with a range of ethnicities, and marital and socioeconomic status (SES). Ethical approval was obtained (UCL Research Ethics Committee: ref 3162/002).

Data collection

Groups were conducted in March and April 2012 at UCL or a suitable community venue in London, and facilitated by an experienced qualitative researcher with a second researcher acting as observer. In designing the discussion guide, emphasis was placed on constructing open-ended, non-directive questions and using a funnelling approach with questions moving from the general to the more focused (see supplementary material for the discussion guide).²⁷ The aim was to generate discussion and elicit views on overdiagnosis. To open the discussion, participants were invited to discuss their own experiences of decision-making about mammography. They were asked to read the relevant pages of the current NHS breast screening leaflet²⁸ to remind them of the information currently provided about benefits and risks of screening, which includes a statement on overdiagnosis ('Screening can find cancers which are treated but which may not otherwise have been found during your lifetime'). We then read out brief information on overdiagnosis (see Box 1)

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3 and women were asked to discuss it and to consider how it might affect their views of breast
4 screening. The information was repeated if participants requested this.
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8 **Box 1 – Description of overdiagnosis (read aloud to participants during group discussion)**

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10 It's been suggested that some of the breast cancers that get diagnosed through breast screening are
11 so slow-growing that they would not have caused any problems. But because we can't yet tell which
12 kind of cancer is the slow-growing kind, the woman receives the usual treatment for breast cancer
13 (e.g. surgery). Of all women who go for breast screening, about 8 in 1000 are diagnosed with cancer.
14 It's very hard to know what proportion of cancers diagnosed in the screening programme are of the
15 slow-growing type and the experts disagree at the moment. The estimates have varied from 1 in 8 of
16 women who are diagnosed to 3 in 8.
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23 The description of overdiagnosis presented to the focus groups was developed in consultation with
24 experts. We used 8 out of 1000 cancer diagnoses as a starting point, as this information is currently
25 included in the NHS leaflet.²⁸ The range of 1 to 3 overdiagnoses out of 8 cancers detected
26 corresponds to a rate of overdiagnosis of 12.5-37.5%, broadly consistent with the conclusions of the
27 UK review.⁷ The wording was designed to be understandable to women of all educational
28 backgrounds. We used the term 'slow-growing cancer' rather than overdiagnosis because it is
29 familiar to the public and has been used in previous overdiagnosis research.¹³ It also makes it very
30 clear that overdiagnosis relates to the detection of cancers and is therefore different from false
31 positive results, as well as being distinct from the treatment of benign conditions due to medical
32 errors. We chose to use brief information rather than a more lengthy presentation, to reflect the
33 level of detail women might be given in a written leaflet.
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42 Group discussions were digitally recorded and transcribed verbatim. Participants also completed a
43 short questionnaire assessing demographic characteristics and screening history.
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47 **Analysis**

48 Verbatim transcripts were analysed thematically using guidelines outlined by Braun and Clarke.²⁹
49 Two researchers read all the transcripts independently and generated initial codes. These were then
50 collated into potential themes. A thematic map of the analysis was produced by each researcher
51 and these were refined through group discussion with all authors. All transcripts were then re-read
52 using the final thematic map and adjustments were made following further group discussion. We
53 used NVivo version 9 to code the data, and analysis continued into the write-up stage using the
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3 themes and verbatim examples to produce a narrative of women's experiences of the topic. Only
4 sections of the analysis concerned with overdiagnosis are reported here. Demographic data were
5 analysed using SPSS version 15.
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10 11 RESULTS

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14 A total of 40 women took part in six discussion groups; the number of women per group ranged
15 from four to nine. Demographic characteristics of the sample are shown in Table 1. Focus groups
16 lasted an average of 75 minutes (range 51-93 minutes, depending on group dynamics and how much
17 women had to say about the issues being discussed).
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22 Themes emerged relating to women's previous experiences and beliefs about breast screening, and
23 their attitudes to false positive results. As these issues are well-documented in the existing
24 literature,^{15;30;31} we focus here specifically on responses to the overdiagnosis information (i.e.
25 Question 6 in the discussion guide – see supplementary material). Two main themes were
26 identified: 1) 'Making sense of the concept of overdiagnosis'; 2) 'Implications of overdiagnosis
27 information' (see Box 2).
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34 35 **Box 2 – Thematic structure**

- 36
37 1) Making sense of the concept of overdiagnosis
38 - Confusion
39 - How do they know?
40 - Emotional responses
41 - Cynicism
42 - Referring to experts
43
44 2) Implications of overdiagnosis information
45 - Erring on the side of caution
46 - Right to know
47 - Overdiagnosis as a treatment issue
48 - Impact on screening decisions
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Table 1: Demographic characteristics of the sample

	N (%)
Age (mean (SD); range)	58.5 (5.4); 50-71
Ethnic group	
White	27 (67.5)
Black	6 (15.0)
Asian	5 (12.5)
Mixed	1 (2.5)
Other	1 (2.5)
Marital status	
Married/cohabiting/civil partnership	15 (37.5)
Single/never married	12 (30.0)
Divorced/widowed	13 (32.5)
Highest level of education	
University degree	21 (52.5)
A-levels/ONC/BTEC/Other Further Education	11 (27.5)
O-level or none	7 (17.5)
Missing	1 (2.5)
Time since last mammogram	
3 years or less (as recommended)	29 (72.5)
4-9 years	4 (10.0)
10 years or more	3 (7.5)
Never screened	2 (5.0)
Screened, but time since last screen missing	2 (5.0)
Ever called back for further tests?	
Yes	5 (12.5)
No	33 (82.5)
N/A – never had a mammogram	2 (5.0)

Making sense of the concept of overdiagnosis

In the initial discussions of mammography screening, overdiagnosis was mentioned in four out of six groups, but there was only one group in which most women were familiar with the concept. The few women who had heard about the issue tended to find it somewhat discouraging and one said that negative information about breast screening in the media, including on overdiagnosis, had influenced her intentions to attend.

I just haven't felt like going again ... I read everything and there hasn't been very good reports that I've read recently, in the past five years basically, so I haven't been again (P5)

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3 After reading the information on the risks and benefits of breast screening in the NHS leaflet, some
4 women recalled seeing it before while others had little recollection of it and were unaware of the
5 risk information. The analysis here focuses on responses to the information in Box 1, which
6 encompassed a number of themes.
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9 10 11 *Confusion*

12 Some women found the statistical information on overdiagnosis (Box 1) difficult to understand. The
13 challenge of making sense of the numerical information was implicit in some participants' responses
14 but was also mentioned explicitly. In one group, participants struggled to respond to the
15 information that had been read to them:
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18 *P11: It's hard to say really.*

19 *P10: I don't know what to say about that.*

20 *P7: Yeah, it feels a bit, well, it's only some, so, well, that's good because it's only five [that
21 need treatment] but I don't know. (Group 2)*
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27 Other women did demonstrate good understanding though. In this group, one participant explained
28 the concept to another who was confused:
29

30 *P15: I don't understand*

31 *P19: No I don't think she understands it a hundred per cent.*

32 *P14: 8 women have cancer.*

33 *P15: Yes*

34 *P14: But maybe three, one two three ... don't have dangerous cancer. It doesn't matter, they
35 wouldn't have died. They would not have died without an operation. (Group 3)*
36
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39 40 41 42 43 *Emotional responses*

44 Some women expressed shock at the level of overdiagnosis and the implications for over-treatment,
45 with women in two of the groups voicing more concern about unnecessary treatment than had been
46 evident at earlier stages of the discussion. Some said they would be angry to discover that they had
47 been unnecessarily treated for cancer ('I'd have their guts for garters' (P7)). Others highlighted the
48 side-effects of treatment they had witnessed in friends and family and expressed dismay at the
49 prospect of anyone having to go through that unnecessarily. There was also concern for the
50 financial cost to the NHS and for the wasted time and energy of NHS staff.
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3 *P27: I don't know, but four out of ten! As you say one out of ten is quite a lot. Four out of*
4 *ten is horrendous.*

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6 *P22: Scary!*

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8 *P21: And I also think about the waste of funds and resources when they could be used for*
9 *people that genuinely need it ... I'm quite shocked at what you've told me today. (Group 4)*
10
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12 13 14 Cynicism

15 In five of the six focus groups, some cynicism was expressed about the statistical information.

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17 *Well, I'm very sceptical about statistics generally because I've seen them manipulated to*
18 *prove what the person using them wishes to prove. (P2)*
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22 In particular, some women feared that statistical data supporting the risks of mammography could
23 be used to justify a cost-cutting exercise in which the NHS Breast Screening Programme might be
24 restricted or withdrawn. Many women became protective of the screening programme at this stage
25 in the face of what was perceived to be a threat to the service.
26
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29 *I would hate to see funding for screening of breast cancer being removed because, even*
30 *though I might not go for it, it's a choice and it's good to have the choice, and I think that*
31 *choice is very, very important and such a vital thing you know (P3).*
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34 35 Referring to experts

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37 Once women had an understanding of the concept of overdiagnosis they began to refer to experts in
38 two ways: first to question how scientists know that this phenomenon exists and then to express
39 their trust in health experts.
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43 Women often questioned the statistical information they had been given.

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45 *How do they know? How have they arrived at those figures, then? Because is it just literally*
46 *at the end of chemo, they go 'Yeah, it's still there, or no, it's...?'* (P22)
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50 When it was explained that an individual woman would not know that her treatment had been
51 unnecessary, participants began to question the basis of the information. Where women asked
52 these questions, facilitators explained that statistical modelling is used to estimate levels of
53 overdiagnosis. Not surprisingly, many participants found this difficult to understand.
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3 *I mean if this is all done on modelling, what's it modelled on? Is it that when they remove*
4 *things they find different things within it, but you have to have it removed to know that? ...*
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6 *Or is it that it's all coming through post-mortems and things? (P27)*
7
8

9
10 Some participants wondered if doctors would choose not to treat a suspected slow-growing cancer,
11 alluding to an implicit fear of under-treatment.

12 *Because doctors aren't infallible are they? ... Some will be more cautious than others, some*
13 *will want to err on the side of not doing very much surgery and only doing as little as they*
14 *can get away with until there is an indication that more is needed. (P37)*
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19 Others felt that surgeons 'like to wield their knives' (P19) and might be inclined to operate rather
20 than try alternative approaches.
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24 However, there was also widespread trust in health experts, which was expressed in all groups.
25 There was trust in doctors, scientists and the NHS breast screening programme to utilise new
26 knowledge or improved technology to ameliorate the risk of overdiagnosis and unnecessary
27 treatment in the future.
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30 *P5: I think that my having heard all this now, I mean [I am] more educated about it and I*
31 *would say now that I just have a trust that the NHS wouldn't haul us all out if statistically*
32 *there wasn't some evidence that, by and large, some people get saved, you know, and that*
33 *not many people get disadvantaged.*
34
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37 *P4: I have some trust to some extent because I think it's evidence-based treatment, isn't it?*
38
39 (Group 1)
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43 **Implications of overdiagnosis information**

44 *Erring on the side of caution*

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46 As women discussed the implications of the information about overdiagnosis, a broad consensus
47 emerged that overdiagnosis and false positives were strongly preferred to any risk of under-
48 diagnosis. Some women saw overdiagnosis and false positives as evidence that the screening
49 programme was thorough in its detection of cancer. False positives in this context were considered
50 to be acceptable despite the short-term worry of being recalled, of which some women had personal
51 experience. In contrast, women were extremely concerned about false negatives and the risk that
52 cancer might be missed or treatment delayed.
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3 *Well for me it's life or death, really, so there is no question that I would want to go for*
4 *screening and have treatment as appropriate, because there are unknowns. We don't know*
5 *if it is fast growing or slow growing. So I would want to have treatment with advice and stay*
6 *alive basically. (P37)*
7
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10 11 *Right to know*

12 There was, however, a strong belief that women should be given information about overdiagnosis.
13 Participants felt the information should be 'part of my decision' to attend for screening and, in the
14 event of a breast cancer diagnosis, to be part of their decision about treatment. One participant
15 talked about informed decision-making:
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18 *Yes but it's a question of ... awareness. It's a question of giving us the information ... And*
19 *letting us process it ourselves and letting us make an informed decision. The facts. (P19)*
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24 Another recognised the variation in the amount of information that different people might want:
25

26 *You can't deny people who want to know just because others don't. (P26)*
27
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29 *Overdiagnosis as a treatment issue*

30 Many women struggled to see information on overdiagnosis as relevant to their decision-making
31 about screening. Much of the discussion was around treatment decisions for screen-detected
32 cancers. Women were concerned about unnecessary treatment but were also keen to treat cancer.
33

34 *I mean, just think, they would say to you 'You've got it but we don't think it's going to come*
35 *to anything and so you don't have to have treatment if you don't want to'. That doesn't*
36 *make sense to me. If someone says 'You've got a cancer', you say 'Right, let's do something*
37 *about it.'* (P34)
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43 In general, the risk of under-treatment of cancer was seen as much greater than the risk of over-
44 treatment.
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46

47 *Impact on screening decisions*

48 At the end of the groups, most women retained their initial perspectives on attending screening.
49 Previous attenders maintained that *'I'd still have a mammogram, yeah'*. The reasons cited included
50 reassurance that they do not have cancer, a desire to know if cancer is present and to increase the
51 chances of an earlier diagnosis and more successful treatment. The information on overdiagnosis
52 did not seem to have affected their core beliefs about screening.
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3 *I would still go, you know, it's better knowing than not knowing... At least I know that, it*
4 *gives me time to plan ... things or what to do next. So I would rather have it done. It*
5 *wouldn't change my view at all. (P17)*
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10 Despite the majority of screening decisions being unaffected, a few women did describe a change in
11 attitude. One participant who initially described mammograms as 'very good' and 'very important'
12 responded to the overdiagnosis information by saying 'That puts you off going at all doesn't it?' and
13 later 'I find that very worrying, to have an operation when you didn't need to' (P12). Another who
14 had recently attended for screening said

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16
17 *I'm in the clear at the moment [because of just having been screened] and I'm wondering*
18 *whether I do want to go again actually. (P40)*
19
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22 Women who had never attended screening or had ceased to attend also tended to maintain their
23 view although, perhaps surprisingly, one woman thought that following the discussion, she would
24 consider attending in future.

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27 *As I said, I haven't had an invitation for so many years that it is something that you don't*
28 *even think about really ... so I, you know, will gather ... more information and make another*
29 *informed decision about whether I will or not go. I mean it's my choice at the end of the day*
30 *so no one can force me to go there ... I will have another think about it seriously. (P19)*
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34 35 DISCUSSION

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38 In this qualitative study, we identified widespread lack of awareness of the risk of overdiagnosis in
39 breast cancer screening among screening-eligible women. When provided with information about
40 the range of risks of overdiagnosis and unnecessary treatment, they were often shocked and
41 surprised, initially. After these initial emotional responses, many women went on to question the
42 basis of the estimates of overdiagnosis, sometimes expressing scepticism but usually trusting health
43 professionals to make appropriate decisions. Most of those who had previously participated in
44 screening maintained a positive attitude to the programme, preferring the risk of over-treatment to
45 the risk of under-treatment. Given that no individual would know that her treatment had been
46 unnecessary, women expressed an overwhelming preference to err on the side of caution. Some
47 also regarded the information as relevant to choices about treatment rather than screening. In a
48 few cases, however, women were put off by the information and felt that it might deter them from
49 future screening attendance. Our findings are strikingly similar to a recent Australian study,²⁰
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3 despite differences in the way that information on overdiagnosis was presented. This suggests that
4 similar communication challenges will be faced across countries where breast screening is offered.
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10 The study benefitted from the inclusion of women within the breast screening age range, around
11 70% of whom had been screened within the last three years, which is broadly in line with national
12 coverage data.³² Women willing to attend a discussion group on mammography may generally be
13 more pro-screening than the general population and this may be a limitation of our study, although
14 this concern is mitigated by the fact that our groups included women in the screening age range who
15 had never attended or were overdue for screening. The use of focus groups allowed the complex
16 issues surrounding overdiagnosis to be explored and discussed within a group context, enabling us
17 to understand more about likely public responses to information within the screening programme
18 than would be possible using individual interviews. However, individual interviews may have been
19 more informative in understanding women's individual responses and the way that information
20 might be integrated into women's screening histories and experiences. Larger-scale work will be
21 needed to establish the generalizability of the findings. In common with most qualitative research,
22 we used non-random sampling, recruiting women using a range of methods. This, and the fact that
23 women were recruited in and around London, may also limit the generalizability of our findings.
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34 Our participants sometimes found it difficult to understand the brief explanation of overdiagnosis
35 that we provided, and there is an urgent need to develop clear and concise methods of conveying
36 both the concept and its prevalence in a written format to provide to women. The difficulties of
37 communicating risk estimates to the lay public are well documented³³ but may be particularly
38 challenging where epidemiological, clinical and lay perspectives differ³⁴ and where there is such wide
39 disagreement between experts.
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45 We chose to use the term 'slow-growing' to describe cancers that are over-treated in the screening
46 programme as this has been used in previous survey work.¹³ There is on-going debate about how
47 best to communicate the concept of overdiagnosis to a lay audience. The citizen's jury carried out as
48 part of the current review of NHS information materials found that women preferred the term
49 'overtreatment' to 'overdiagnosis',³⁵ while the recent Australian study²⁰ used 'overdetection' (both
50 these were published after our study had been completed). To our knowledge, no empirical data
51 are available on the impact that using these different terms has on responses to the information.
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53 However it is possible that the image of a slow-growing cancer could have led our participants to
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3 think about receiving a cancer diagnosis and may have caused them to focus on treatment rather
4 than screening decisions. The terms 'overdetection' and 'overdiagnosis' may make it easier to
5 consider the concept in more abstract terms. But we felt it was important for women to realise that
6 the cancers being overdiagnosed in the screening programme do represent malignant disease, as
7 distinct from false positive results. Further research is needed to identify the best way to describe
8 the phenomenon.
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14 The themes we identified included some that have been described before. We found that women
15 had a desire to be provided with all the available information on risks,¹⁷ although this was tempered
16 by concern that risk information may put 'other people' off screening.¹⁸ The theme of viewing
17 others as being more risk averse or easily deterred has been found in other qualitative studies¹⁸ and
18 it is unclear whether this is a coded way of expressing personal concern or a reflection of broader
19 identity beliefs that tend to represent the self as stronger than others in many respects. There is
20 evidence that people evaluate risk differently when considering themselves and when considering
21 others, tending to be more risk averse when considering other people.³⁶ It is possible, therefore,
22 that women in our study were cautious of anything that might deter others from attending
23 screening. Some women also expressed scepticism about any suggestion of shortcomings of
24 mammography, which is consistent with the finding that even women with interval cancer diagnoses
25 tend to maintain trust in the screening programme and to see their own cases as exceptions to an
26 otherwise effective programme.³⁷
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37 The finding that women generally preferred to be overdiagnosed than underdiagnosed is consistent
38 with previous survey findings of high tolerance levels of false positive results¹⁵ and a fear of false
39 negative results identified in qualitative work;³⁸ in other words women appear to value sensitivity
40 over specificity, which has been found in qualitative studies in other screening as well as diagnostic
41 contexts.^{39;40} But this is the first study, to our knowledge, to have explicitly explored the notion of
42 overdiagnosis in the UK breast screening context.
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48 The study has two broad implications. First, it highlights the difficulty of communicating the
49 concept of overdiagnosis to non-statisticians. Confusion was common and women found the idea
50 that the estimates of overdiagnosis are based on statistical modelling extremely difficult to
51 understand. Further work is needed to develop ways of conveying this type of information clearly,
52 especially given moves towards a policy of informed participation in screening.⁴⁰ Secondly, although
53 women felt the information was important, it generally had little impact on their beliefs about
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3 screening and their future intentions to participate. More work will be needed to see whether this
4 finding generalises to the wider population and whether the impact of information on overdiagnosis
5 differs across socioeconomic groups.
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5

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16 **Data sharing:** The discussion guide used in the study is available as supplementary material.
17 Anonymised transcripts will be made available to interested researchers.
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19

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52 drafting of the paper. JWar is the guarantor.
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6
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8
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14 **Previous work:** There have been no previous publications from this study.
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REFERENCES

- (1) Baum M. Breast screening should be scrapped. *The Guardian* 2011.
- (2) Duffy SW, Tabar L, Olsen AH. Absolute numbers of lives saved and overdiagnosis in breast cancer screening, from a randomized trial and from the Breast Screening Programme in England. *Journal of Medical Screening* 2010; 17(2):106.
- (3) Jorgensen KJ, Gotzsche PC. Overdiagnosis in publicly organised mammography screening programmes: systematic review of incidence trends. *British Medical Journal* 2009; 339.
- (4) Woolf SH, Harris R. The harms of screening: new attention to an old concern. *JAMA* 2012; 307(6):565-566.
- (5) Baum M, Thornton H, Gotzsche PC, Bewley S, Jorgensen KJ, Barratt A et al. Breast cancer awareness month. Still awaiting screening facts. *BMJ* 2010; 341:c6152.
- (6) Richards M. Breast Cancer Screening An Independent Review Is Under Way. *British Medical Journal* 2011; 343.
- (7) The benefits and harms of breast cancer screening: an independent review. *Lancet* 2012; 380(9855):1778-1786.
- (8) Gotzsche PC, Hartling OJ, Nielsen M, Brodersen J, Jorgensen KJ. Breast screening: the facts-or maybe not. *British Medical Journal* 2009; 338.
- (9) Gotzsche PC, Nielsen M. Screening for breast cancer with mammography. *Cochrane Database Syst Rev* 2006;(4):CD001877.
- (10) Gummersbach E, Piccoliori G, Zerbe CO, Altiner A, Othman C, Rose C et al. Are women getting relevant information about mammography screening for an informed consent: a critical appraisal of information brochures used for screening invitation in Germany, Italy, Spain and France. *Eur J Public Health* 2010; 20(4):409-414.
- (11) Zapka JG, Geller BM, Bulliard JL, Fracheboud J, Sancho-Garnier H, Ballard-Barbash R. Print information to inform decisions about mammography screening participation in 16 countries with population-based programs. *Patient Educ Couns* 2006; 63(1-2):126-137.
- (12) Jorgensen KJ, Gotzsche PC. Content of invitations for publicly funded screening mammography. *BMJ* 2006; 332(7540):538-541.
- (13) Schwartz LM, Woloshin S, Fowler FJ, Welch HG. Enthusiasm for Cancer Screening in the United States. *JAMA: The Journal of the American Medical Association* 2004; 291(1):71-78.
- (14) Domenighetti G, Avanzo B, Egger M, Berrino F, Perneger T, Mosconi P et al. Women's perception of the benefits of mammography screening: population-based survey in four countries. *International Journal of Epidemiology* 2003; 32(5):816-821.
- (15) Schwartz LM, Woloshin S, Sox HC, Fischhoff B, Welch HG. US women's attitudes to false positive mammography results and detection of ductal carcinoma in situ: cross sectional survey. *BMJ* 2000; 320(7250):1635-1640.

- 1
2
3 (16) Cicourel A. Interviews, surveys and the problem of ecological validity. *American Sociologist* 1982; 17(11):20.
4
5
6 (17) Waller J, Macedo A, von WC, Simon AE, Jones C, Hammersley V et al. Communication about
7 colorectal cancer screening in Britain: public preferences for an expert recommendation. *Br J*
8 *Cancer* 2012; 107(12):1938-1943.
9
10 (18) Woodrow C, Watson E, Rozmovits L, Parker R, Austoker J. Public perceptions of
11 communicating information about bowel cancer screening. *Health Expectations* 2008;
12 11(1):16-25.
13
14 (19) Hersch J, Jansen J, Irwig L, Barratt A, Thornton H, Howard K et al. How do we achieve
15 informed choice for women considering breast screening? *Preventive Medicine* 2011;
16 53(3):144-146.
17
18 (20) Hersch J, Jansen J, Barratt A, Irwig L, Houssami N, Howard K et al. Women's views on
19 overdiagnosis in breast cancer screening: a qualitative study. *BMJ* 2013; 346:f158.
20
21 (21) Bowater D. Breast cancer screening 'can no longer be justified'. The Telegraph 2012 Jan 21.
22
23 (22) Lakhani N. Claims of breast cancer screening success are dishonest, say critics . The
24 Independent 2011 Sep 1.
25
26 (23) Haywood L. Breast screening does save lives... we're the proof. The Sun 2011 Oct 27.
27
28 (24) Mayor S. Critics attack new NHS breast screening leaflet for failing to address harms. *BMJ*
29 2010; 341:c7267.
30
31 (25) Kitzinger J. Qualitative research. Introducing focus groups. *BMJ* 1995; 311(7000):299-302.
32
33 (26) Guest G, Namey EE, Mitchell ML. Collecting Qualitative Data. London: Sage; 2013.
34
35 (27) Dickson-Swift V, James EL, Kippen S, Liamputtong P. Doing sensitive research: what
36 challenges do qualitative researchers face? *Qualitative Research* 2007; 7(3):327-353.
37
38 (28) NHS breast screening. Available at:
39 <http://www.cancerscreening.nhs.uk/breastscreen/publications/nhsbsp.pdf>. 2011.
40 Department of Health; NHS Cancer Screening Programmes.
41
42 (29) Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology*
43 2006; 3(2):77-101.
44
45 (30) Webster P, Austoker J. Women's knowledge about breast cancer risk and their views of the
46 purpose and implications of breast screening--a questionnaire survey. *J Public Health (Oxf)*
47 2006; 28(3):197-202.
48
49 (31) Engelman KK, Cizik AM, Ellerbeck EF. Women's satisfaction with their mammography
50 experience: results of a qualitative study. *Women Health* 2005; 42(4):17-35.
51
52 (32) NHS The Information Centre. Breast screening programme, England 2010-2011.
53 <http://www.ic.nhs.uk/pubs/brstscreen1011>. 2012.
54
55
56
57
58
59
60

- 1
2
3 (33) Fagerlin A, Zikmund-Fisher BJ, Ubel PA. Helping patients decide: ten steps to better risk
4 communication. *J Natl Cancer Inst* 2011; 103(19):1436-1443.
5
6 (34) Adelsward V, Sachs L. The meaning of 6.8: numeracy and normality in health information
7 talks. *Soc Sci Med* 1996; 43(8):1179-1187.
8
9 (35) Hawkes N. "Citizens' jury" disagrees over whether screening leaflet should put reassurance
10 before accuracy. *BMJ* 2012; 345:e8047.
11
12 (36) Zikmund-Fisher BJ, Sarr B, Fagerlin A, Ubel PA. A matter of perspective: choosing for others
13 differs from choosing for yourself in making treatment decisions. *J Gen Intern Med* 2006;
14 21(6):618-622.
15
16 (37) Solbjor M, Skolbekken JA, Saetnan AR, Hagen AI, Forsmo S. Mammography screening and
17 trust: The case of interval breast cancer. *Soc Sci Med* 2012; 75(10):1746-1752.
18
19 (38) Watson-Johnson LC, DeGross A, Steele CB, Revels M, Smith JL, Justen E et al. Mammography
20 adherence: a qualitative study. *J Womens Health (Larchmt)* 2011; 20(12):1887-1894.
21
22 (39) Ghanouni A, Smith SG, Halligan S, Plumb A, Boone D, Magee MS et al. Public perceptions and
23 preferences for CT colonography or colonoscopy in colorectal cancer screening. *Patient Educ*
24 *Couns* 2012; 89(1):116-121.
25
26 (40) von Wagner C, Halligan S, Atkin WS, Lilford RJ, Morton D, Wardle J. Choosing between CT
27 colonography and colonoscopy in the diagnostic context: a qualitative study of influences on
28 patient preferences. *Health Expect* 2009; 12(1):18-26.
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Supplementary material – Discussion guide

1. Introduction**2. Decision making about mammography**

- General attitude to the concept of breast cancer screening
- Factors in the decision to go
- Is the current invitation seen as a recommendation?
- Experiences of going for mammography

3. Information in Breast Screening Leaflets

- Currently read leaflets – Why? Why not?
- Is this information wanted before being screened?
- Risk information wanted? – Why? Why not?

[Participants asked to read NHS Breast Screening leaflet. Instruction to only read p.3/4 on risks and benefits]

4. Reactions to risk information

- Aware of these risks before?
- Surprising/intuitive information – Why? Why not?
- Influence on feelings about breast screening
- Change decision to go for screening – why? Why not?

5. False positives

- (Refer to leaflet) 'A false positive is when a woman is referred for further tests (such as another mammogram or a biopsy) and is then found not to have breast cancer'. What are your thoughts on this?
- 'About 1 in 20 women are sent for further tests, but most (4 in 5) turn out not to have cancer – i.e. it's a false alarm'. What are your thoughts on this?

6. Overdiagnosis

(Refer to leaflet) 'It's been suggested that some of the breast cancers that get diagnosed through breast screening are so slow-growing that they would not have caused any problems. But because we can't yet tell which kind of cancer is the slow-growing kind, the women receives the usual treatment for breast cancer (e.g. surgery).' What are your views about this?

- Of all women who go for breast screening about 8 in 1000 are diagnosed with cancer. It's very hard to know what proportion of cancers diagnosed in the screening programme are of the slow growing type and the experts disagree at the moment. The estimates have varied from 1 in 8 of women who are diagnosed to 3 in 8. How do you feel about these figures?
 - o How would you feel about having treatment (surgery, radiotherapy, chemotherapy) for a cancer that wouldn't have been life-threatening?
 - o How do you weigh up the risk of this kind of over treatment against the possible benefits for early diagnosis?

7. Wrap-up

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3 **Women's responses to information about overdiagnosis in the UK breast cancer screening**
4 **programme: a qualitative study**
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ARTICLE SUMMARY

Article focus

- Little is known about the impact that information on overdiagnosis in mammography screening might have on women's decision-making about screening
- We used qualitative methods to explore women's responses to information on overdiagnosis in breast screening

Key messages

- The concept of overdiagnosis was unfamiliar to many participants and there was a strong belief that women should be informed about it
- Participants sometimes struggled to understand the concept of overdiagnosis and often regarded it as an issue for treatment, rather than screening decisions
- Few women felt that the information they had been given would affect their future breast screening decisions

Strengths and Limitations

- This is the first study to explore responses to overdiagnosis in breast screening in the UK and benefitted from the use of in-depth qualitative methods
- The use of the phrase 'slow-growing cancer' in our explanation of overdiagnosis may have affected women's responses

ABSTRACT

Objectives To explore the influence of overdiagnosis information on women's decisions about mammography.

Design A qualitative focus group study with purposive sampling and thematic analysis, in which overdiagnosis information was presented.

Setting Community and university settings in London.

Participants 40 women within the breast screening age range (50-71 years) including attenders and non-attenders were recruited using a recruitment agency as well as convenience sampling methods.

Results Women expressed surprise at the possible extent of overdiagnosis and recognised the information as important, although many struggled to interpret the numerical data. Overdiagnosis was viewed as less personally relevant than the possibility of 'under-diagnosis' (false negatives), and often considered to be an issue for follow-up care decisions rather than screening participation.

Women also expressed concern that information on overdiagnosis could deter others from attending screening, although they themselves rarely saw it as a deterrent. After discussing overdiagnosis, few women felt that they would make different decisions about breast screening in the future.

Conclusions Women regard it as important to be informed about overdiagnosis to get a complete picture of the risks and benefits of mammography, but the results of this study indicate that understanding overdiagnosis may not always influence women's attitudes towards participation in breast screening. The results also highlight the challenge of communicating the individual significance of information derived from population-level modelling.

INTRODUCTION

The controversy over the risks and benefits of breast cancer screening has been played out in the public media¹ as well as the medical press.²⁻⁵ It prompted an independent review of the research evidence on breast cancer screening in the UK⁶ which reported its findings in October 2012.⁷ As part of the debate, the information about breast screening provided by the National Health Service (NHS) has been criticised as one-sided.⁸ A key concern is that the risk of overdiagnosis is not adequately reflected in the information that is given to the public.⁹⁻¹² However, given the complexity of interpreting results obtained from modelling population patterns of screening and mortality, and the difficulties of applying population level results to individual decision-making, there may be challenges in communicating this information, particularly given the range of estimates about the risk of overdiagnosis. The UK review reported estimates between 9.7% and 29.4% across three trials,⁷ depending on the denominator used, and other studies have reported higher and lower figures.³

At present it is unclear whether women would like to have numerical information on overdiagnosis and whether they would take it into account in making breast screening decisions. Survey results in the US and Europe have indicated considerable enthusiasm for screening and a tendency for the public to over-estimate the benefits of mammography.^{13;14} Tolerance of false positive results also seems high, with one US study finding that even among women who had experienced a false positive mammogram, a third believed that **it would be acceptable for 10,000 women or more to have false positive results in order to save one life from breast cancer.**¹⁵ The issue of overdiagnosis and unnecessary treatment is probably less well understood by the public. The same US study found that only 7% of women were aware of non-progressive breast cancer, but after a brief explanation of ductal carcinoma in situ and the risk of over-treatment, 60% wanted to take this information into account when deciding about mammography screening.¹⁵ This indicates the importance of providing information on overdiagnosis, although in the survey context only a very brief description could be given. **It is possible that immediate responses to survey questions on a previously unfamiliar topic may lack ecological validity and could be thought of as 'non-attitudes' in that they do not reflect any pre-existing beliefs.**¹⁶ **This problem could be addressed by creating an opportunity for women to discuss and reflect on their understanding of overdiagnosis and the potential impact of this information on subsequent screening decisions in a more considered and ecologically valid way.**

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3 In a recent UK survey of the public's preferences for information on cancer screening (in this case it
4 was colorectal cancer), most people, responding on a scale of 1 to 10, said they would like all
5 available information about risks of screening as well as benefits.¹⁷ However, when asked more
6 detailed and open questions in qualitative research, the UK public can be critical when risk
7 information is included in colorectal screening information leaflets; arguing that if the NHS thinks
8 people should go for screening, they should give unambiguous messages and not 'frighten people
9 off' with stories of rare risks and the complexities of follow up.¹⁸ Some studies have also found
10 women to be suspicious about the motivation behind questioning the benefits of mammography.¹⁹
11 In order to take forward new approaches to the provision of breast screening information, it is
12 crucial to gain an understanding of women's perspective on the idea of 'overdiagnosis'. Information
13 must be provided in a manner that is understandable and not likely to undermine equality of access.

21
22 Within the current debate about overdiagnosis, the voice of the users of the screening programme,
23 women themselves, has been largely silent. The one study to date examined Australian women's
24 responses to detailed information on overdiagnosis and a range of estimates of its prevalence, using
25 focus group methodology.²⁰ The results showed that although women generally lacked prior
26 awareness of the issue, they were able to understand it when information was provided in the form
27 on an audio-visual presentation. The impact of the information on future screening intentions
28 varied widely between women and was also different depending on the prevalence of overdiagnosis
29 presented.

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31 The present study aimed to use qualitative methods to elicit British women's reactions to the notion
32 of overdiagnosis and examine the effect they felt it might have on their decision-making about
33 mammography participation. The UK context is important firstly because of the media attention
34 there had already been to the overdiagnosis issue at the time of this study,^{1,21-23} and secondly
35 because of the on-going and high-profile criticism of the information provided to women in the UK
36 about the breast screening programme.^{5;8;24} We focused on the impact of relatively brief
37 information on overdiagnosis, to reflect the kind that might be provided in a screening information
38 leaflet.

METHODS

Methodological approach

Focus groups were used to explore women's existing knowledge and experience, and elicit dynamic responses to potentially new information on overdiagnosis in the context of a structured discussion.²⁵ It is acknowledged that focus groups are well suited to exploring 'public' topics, such as public health interventions²⁶ and are a good way to identify 'group norms and cultural values'.²⁵ We used focus groups rather than individual interviews for this study to try to gauge the public response to information about overdiagnosis in the context of a national screening programme, and to provide participants with the opportunity to question each other and to reflect and respond to one another's comments. A qualitative analysis allowed us to identify common themes.

Participants

Six focus groups were conducted with women in the mammography screening age range (50-71 years). All women spoke fluent English, none had a personal history of cancer, and none worked in occupations related to cancer or cancer screening. Women living in and around London were recruited from a specialist participant recruitment agency, community groups, mailing lists, and adverts circulated by email to achieve a sample with a range of ethnicities, and marital and socioeconomic status (SES). Ethical approval was obtained (UCL Research Ethics Committee: ref 3162/002).

Data collection

Groups were conducted in March and April 2012 at UCL or a suitable community venue in London, and facilitated by an experienced qualitative researcher with a second researcher acting as observer. In designing the discussion guide, emphasis was placed on constructing open-ended, non-directive questions and using a funnelling approach with questions moving from the general to the more focused (see supplementary material for the discussion guide).²⁷ The aim was to generate discussion and elicit views on overdiagnosis. To open the discussion, participants were invited to discuss their own experiences of decision-making about mammography. They were asked to read the relevant pages of the current NHS breast screening leaflet²⁸ to remind them of the information currently provided about benefits and risks of screening, which includes a statement on overdiagnosis ('Screening can find cancers which are treated but which may not otherwise have been found during your lifetime'). We then read out brief information on overdiagnosis (see Box 1)

and women were asked to discuss it and to consider how it might affect their views of breast screening. The information was repeated if participants requested this.

Box 1 – Description of overdiagnosis (read aloud to participants during group discussion)

It's been suggested that some of the breast cancers that get diagnosed through breast screening are so slow-growing that they would not have caused any problems. But because we can't yet tell which kind of cancer is the slow-growing kind, the woman receives the usual treatment for breast cancer (e.g. surgery). Of all women who go for breast screening, about 8 in 1000 are diagnosed with cancer. It's very hard to know what proportion of cancers diagnosed in the screening programme are of the slow-growing type and the experts disagree at the moment. The estimates have varied from 1 in 8 of women who are diagnosed to 3 in 8.

The description of overdiagnosis presented to the focus groups was developed in consultation with experts. We used 8 out of 1000 cancer diagnoses as a starting point, as this information is currently included in the NHS leaflet.²⁸ The range of 1 to 3 overdiagnoses out of 8 cancers detected corresponds to a rate of overdiagnosis of 12.5-37.5%, broadly consistent with the conclusions of the UK review.⁷ The wording was designed to be understandable to women of all educational backgrounds. We used the term 'slow-growing cancer' rather than overdiagnosis because it is familiar to the public and has been used in previous overdiagnosis research.¹³ It also makes it very clear that overdiagnosis relates to the detection of cancers and is therefore different from false positive results, as well as being distinct from the treatment of benign conditions due to medical errors. We chose to use brief information rather than a more lengthy presentation, to reflect the level of detail women might be given in a written leaflet.

Group discussions were digitally recorded and transcribed verbatim. Participants also completed a short questionnaire assessing demographic characteristics and screening history.

Analysis

Verbatim transcripts were analysed thematically using guidelines outlined by Braun and Clarke.²⁹ Two researchers read all the transcripts independently and generated initial codes. These were then collated into potential themes. A thematic map of the analysis was produced by each researcher and these were refined through group discussion with all authors. All transcripts were then re-read using the final thematic map and adjustments were made following further group discussion. We used NVivo version 9 to code the data, and analysis continued into the write-up stage using the

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3 themes and verbatim examples to produce a narrative of women's experiences of the topic. Only
4 sections of the analysis concerned with overdiagnosis are reported here. Demographic data were
5 analysed using SPSS version 15.
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10 11 RESULTS

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14 A total of 40 women took part in six discussion groups; the number of women per group ranged
15 from four to nine. Demographic characteristics of the sample are shown in Table 1. Focus groups
16 lasted an average of 75 minutes (range 51-93 minutes, depending on group dynamics and how much
17 women had to say about the issues being discussed).
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22 Themes emerged relating to women's previous experiences and beliefs about breast screening, and
23 their attitudes to false positive results. As these issues are well-documented in the existing
24 literature,^{15;30;31} we focus here specifically on responses to the overdiagnosis information (i.e.
25 Question 6 in the discussion guide – see supplementary material). Two main themes were
26 identified: 1) 'Making sense of the concept of overdiagnosis'; 2) 'Implications of overdiagnosis
27 information' (see Box 2).
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34 35 Box 2 – Thematic structure

- 36
37 1) Making sense of the concept of overdiagnosis
38 - Confusion
39 - How do they know?
40 - Emotional responses
41 - Cynicism
42 - Referring to experts
43
44 2) Implications of overdiagnosis information
45 - Erring on the side of caution
46 - Right to know
47 - Overdiagnosis as a treatment issue
48 - Impact on screening decisions
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Table 1: Demographic characteristics of the sample

	N (%)
Age (mean (SD); range)	58.5 (5.4); 50-71
Ethnic group	
White	27 (67.5)
Black	6 (15.0)
Asian	5 (12.5)
Mixed	1 (2.5)
Other	1 (2.5)
Marital status	
Married/cohabiting/civil partnership	15 (37.5)
Single/never married	12 (30.0)
Divorced/widowed	13 (32.5)
Highest level of education	
University degree	21 (52.5)
A-levels/ONC/BTEC/Other Further Education	11 (27.5)
O-level or none	7 (17.5)
Missing	1 (2.5)
Time since last mammogram	
3 years or less (as recommended)	29 (72.5)
4-9 years	4 (10.0)
10 years or more	3 (7.5)
Never screened	2 (5.0)
Screened, but time since last screen missing	2 (5.0)
Ever called back for further tests?	
Yes	5 (12.5)
No	33 (82.5)
N/A – never had a mammogram	2 (5.0)

Making sense of the concept of overdiagnosis

In the initial discussions of mammography screening, overdiagnosis was mentioned in four out of six groups, but **there was only one group in which most women were familiar with the concept**. The few women who had heard about the issue tended to find it somewhat **discouraging** and one said that negative information about breast screening in the media, including on overdiagnosis, had influenced her intentions to attend.

I just haven't felt like going again ... I read everything and there hasn't been very good reports that I've read recently, in the past five years basically, so I haven't been again (P5)

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3 After reading the information on the risks and benefits of breast screening in the NHS leaflet, some
4 women recalled seeing it before while others had little recollection of it and were unaware of the
5 risk information. The analysis here focuses on responses to the information in Box 1, which
6 encompassed a number of themes.
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9 10 11 *Confusion*

12 **Some** women found the statistical information on overdiagnosis (**Box 1**) difficult to understand. The
13 challenge of making sense of the numerical information was implicit in some participants' responses
14 but was also mentioned explicitly. In one group, participants struggled to respond to the
15 information that had been read to them:
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18 *P11: It's hard to say really.*

19 *P10: I don't know what to say about that.*

20 *P7: Yeah, it feels a bit, well, it's only some, so, well, that's good because it's only five [that
21 need treatment] but I don't know. (Group 2)*

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27 **Other women did demonstrate good understanding though. In this group, one participant explained**
28 **the concept to another who was confused:**

29 *P15: I don't understand*

30 *P19: No I don't think she understands it a hundred per cent.*

31 *P14: 8 women have cancer.*

32 *P15: Yes*

33 *P14: But maybe three, one two three ... don't have dangerous cancer. It doesn't matter, they
34 wouldn't have died. They would not have died without an operation. (Group 3)*

35 36 37 38 *Emotional responses*

39 Some women expressed shock at the level of overdiagnosis and the implications for over-treatment,
40 with women in two of the groups voicing more concern about unnecessary treatment than had been
41 evident at earlier stages of the discussion. Some said they would be angry to discover that they had
42 been unnecessarily treated for cancer ('I'd have their guts for garters' (P7)). Others highlighted the
43 side-effects of treatment they had witnessed in friends and family and expressed dismay at the
44 prospect of anyone having to go through that unnecessarily. There was also concern for the
45 financial cost to the NHS and for the wasted time and energy of NHS staff.
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3 *P27: I don't know, but four out of ten! As you say one out of ten is quite a lot. Four out of*
4 *ten is horrendous.*

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6 *P22: Scary!*

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8 *P21: And I also think about the waste of funds and resources when they could be used for*
9 *people that genuinely need it ... I'm quite shocked at what you've told me today. (Group 4)*
10

11 12 13 14 *Cynicism*

15 In five of the six focus groups, some cynicism was expressed about the statistical information.

16
17 *Well, I'm very sceptical about statistics generally because I've seen them manipulated to*
18 *prove what the person using them wishes to prove. (P2)*
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22 In particular, some women feared that statistical data supporting the risks of mammography could
23 be used to justify a cost-cutting exercise in which the NHS Breast Screening Programme might be
24 restricted or withdrawn. Many women became protective of the screening programme at this stage
25 in the face of what was perceived to be a threat to the service.
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29 *I would hate to see funding for screening of breast cancer being removed because, even*
30 *though I might not go for it, it's a choice and it's good to have the choice, and I think that*
31 *choice is very, very important and such a vital thing you know (P3).*
32
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34 35 *Referring to experts*

36 Once women had an understanding of the concept of overdiagnosis they began to refer to experts in
37 two ways: first to question how scientists know that this phenomenon exists and then to express
38 their trust in health experts.
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43 Women often questioned the statistical information they had been given.

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45 *How do they know? How have they arrived at those figures, then? Because is it just literally*
46 *at the end of chemo, they go 'Yeah, it's still there, or no, it's...?' (P22)*
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50 When it was explained that an individual woman would not know that her treatment had been
51 unnecessary, participants began to question the basis of the information. Where women asked
52 these questions, facilitators explained that statistical modelling is used to estimate levels of
53 overdiagnosis. Not surprisingly, many participants found this difficult to understand.
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3 *I mean if this is all done on modelling, what's it modelled on? Is it that when they remove*
4 *things they find different things within it, but you have to have it removed to know that? ...*
5
6 *Or is it that it's all coming through post-mortems and things? (P27)*
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10 Some participants wondered if doctors would choose not to treat a suspected slow-growing cancer,
11 alluding to an implicit fear of under-treatment.

12 *Because doctors aren't infallible are they? ... Some will be more cautious than others, some*
13 *will want to err on the side of not doing very much surgery and only doing as little as they*
14 *can get away with until there is an indication that more is needed. (P37)*
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19 Others felt that surgeons 'like to wield their knives' (P19) and might be inclined to operate rather
20 than try alternative approaches.
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24 However, there was also widespread trust in health experts, which was expressed in all groups.
25 There was trust in doctors, scientists and the NHS breast screening programme to utilise new
26 knowledge or improved technology to ameliorate the risk of overdiagnosis and unnecessary
27 treatment in the future.
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30 *P5: I think that my having heard all this now, I mean [I am] more educated about it and I*
31 *would say now that I just have a trust that the NHS wouldn't haul us all out if statistically*
32 *there wasn't some evidence that, by and large, some people get saved, you know, and that*
33 *not many people get disadvantaged.*
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37 *P4: I have some trust to some extent because I think it's evidence-based treatment, isn't it?*
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39 (Group 1)
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43 **Implications of overdiagnosis information**

44 *Erring on the side of caution*

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46 As women discussed the implications of the information about overdiagnosis, a broad consensus
47 emerged that overdiagnosis and false positives were strongly preferred to any risk of under-
48 diagnosis. Some women saw overdiagnosis and false positives as evidence that the screening
49 programme was thorough in its detection of cancer. False positives in this context were considered
50 to be acceptable despite the short-term worry of being recalled, of which some women had personal
51 experience. In contrast, women were extremely concerned about false negatives and the risk that
52 cancer might be missed or treatment delayed.
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3 *Well for me it's life or death, really, so there is no question that I would want to go for*
4 *screening and have treatment as appropriate, because there are unknowns. We don't know*
5 *if it is fast growing or slow growing. So I would want to have treatment with advice and stay*
6 *alive basically. (P37)*
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10 *Right to know*

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12 There was, however, a strong belief that women should be given information about overdiagnosis.
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14 Participants felt the information should be 'part of my decision' to attend for screening and, in the
15 event of a breast cancer diagnosis, to be part of their decision about treatment. One participant
16 talked about informed decision-making:
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18 *Yes but it's a question of ... awareness. It's a question of giving us the information ... And*
19 *letting us process it ourselves and letting us make an informed decision. The facts. (P19)*
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24 Another recognised the variation in the amount of information that different people might want:
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26 *You can't deny people who want to know just because others don't. (P26)*
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29 *Overdiagnosis as a treatment issue*

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31 Many women struggled to see information on overdiagnosis as relevant to their decision-making
32 about screening. Much of the discussion was around treatment decisions for screen-detected
33 cancers. Women were concerned about unnecessary treatment but were also keen to treat cancer.
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35 *I mean, just think, they would say to you 'You've got it but we don't think it's going to come*
36 *to anything and so you don't have to have treatment if you don't want to'. That doesn't*
37 *make sense to me. If someone says 'You've got a cancer', you say 'Right, let's do something*
38 *about it.'* (P34)
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44 In general, the risk of under-treatment of cancer was seen as much greater than the risk of over-
45 treatment.
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47 *Impact on screening decisions*

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49 At the end of the groups, most women retained their initial perspectives on attending screening.
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51 Previous attenders maintained that '*I'd still have a mammogram, yeah*'. The reasons cited included
52 reassurance that they do not have cancer, a desire to know if cancer is present and to increase the
53 chances of an earlier diagnosis and more successful treatment. The information on overdiagnosis
54 did not seem to have affected their core beliefs about screening.
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3 *I would still go, you know, it's better knowing than not knowing... At least I know that, it*
4 *gives me time to plan ... things or what to do next. So I would rather have it done. It*
5 *wouldn't change my view at all. (P17)*
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10 Despite the majority of screening decisions being unaffected, a few women did describe a change in
11 attitude. One participant who initially described mammograms as 'very good' and 'very important'
12 responded to the overdiagnosis information by saying 'That puts you off going at all doesn't it?' and
13 later 'I find that very worrying, to have an operation when you didn't need to' (P12). Another who
14 had recently attended for screening said

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17 *I'm in the clear at the moment [because of just having been screened] and I'm wondering*
18 *whether I do want to go again actually. (P40)*
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22 Women who had never attended screening or had ceased to attend also tended to maintain their
23 view although, perhaps surprisingly, one woman thought that following the discussion, she would
24 consider attending in future.
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27 *As I said, I haven't had an invitation for so many years that it is something that you don't*
28 *even think about really ... so I, you know, will gather ... more information and make another*
29 *informed decision about whether I will or not go. I mean it's my choice at the end of the day*
30 *so no one can force me to go there ... I will have another think about it seriously. (P19)*
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34 35 DISCUSSION

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38 In this qualitative study, we identified widespread lack of awareness of the risk of overdiagnosis in
39 breast cancer screening among screening-eligible women. When provided with information about
40 the range of risks of overdiagnosis and unnecessary treatment, they were often shocked and
41 surprised, initially. After these initial emotional responses, many women went on to question the
42 basis of the estimates of overdiagnosis, sometimes expressing scepticism but usually trusting health
43 professionals to make appropriate decisions. Most of those who had previously participated in
44 screening maintained a positive attitude to the programme, preferring the risk of over-treatment to
45 the risk of under-treatment. Given that no individual would know that her treatment had been
46 unnecessary, women expressed an overwhelming preference to err on the side of caution. Some
47 also regarded the information as relevant to choices about treatment rather than screening. In a
48 few cases, however, women were put off by the information and felt that it might deter them from
49 future screening attendance. Our findings are strikingly similar to a recent Australian study,²⁰
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3 despite differences in the way that information on overdiagnosis was presented. This suggests that
4 similar communication challenges will be faced across countries where breast screening is offered.
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10 The study benefitted from the inclusion of women within the breast screening age range, around
11 70% of whom had been screened within the last three years, which is broadly in line with national
12 coverage data.³² Women willing to attend a discussion group on mammography may generally be
13 more pro-screening than the general population and this may be a limitation of our study, although
14 this concern is mitigated by the fact that our groups included women in the screening age range who
15 had never attended or were overdue for screening. The use of focus groups allowed the complex
16 issues surrounding overdiagnosis to be explored and discussed within a group context, enabling us
17 to understand more about likely public responses to information within the screening programme
18 than would be possible using individual interviews. However, individual interviews may have been
19 more informative in understanding women's individual responses and the way that information
20 might be integrated into women's screening histories and experiences. Larger-scale work will be
21 needed to establish the generalizability of the findings. In common with most qualitative research,
22 we used non-random sampling, recruiting women using a range of methods. This, and the fact that
23 women were recruited in and around London, may also limit the generalizability of our findings.
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34 Our participants sometimes found it difficult to understand the brief explanation of overdiagnosis
35 that we provided, and there is an urgent need to develop clear and concise methods of conveying
36 both the concept and its prevalence in a written format to provide to women. The difficulties of
37 communicating risk estimates to the lay public are well documented³³ but may be particularly
38 challenging where epidemiological, clinical and lay perspectives differ³⁴ and where there is such wide
39 disagreement between experts.
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45 We chose to use the term 'slow-growing' to describe cancers that are over-treated in the screening
46 programme as this has been used in previous survey work.¹³ There is on-going debate about how
47 best to communicate the concept of overdiagnosis to a lay audience. The citizen's jury carried out as
48 part of the current review of NHS information materials found that women preferred the term
49 'overtreatment' to 'overdiagnosis',³⁵ while the recent Australian study²⁰ used 'overdetection' (both
50 these were published after our study had been completed). To our knowledge, no empirical data
51 are available on the impact that using these different terms has on responses to the information.
52 However it is possible that the image of a slow-growing cancer could have led our participants to
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3 think about receiving a cancer diagnosis and may have caused them to focus on treatment rather
4 than screening decisions. The terms 'overdetection' and 'overdiagnosis' may make it easier to
5 consider the concept in more abstract terms. But we felt it was important for women to realise that
6 the cancers being overdiagnosed in the screening programme do represent malignant disease, as
7 distinct from false positive results. Further research is needed to identify the best way to describe
8 the phenomenon.
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14 The themes we identified included some that have been described before. We found that women
15 had a desire to be provided with all the available information on risks,¹⁷ although this was tempered
16 by concern that risk information may put 'other people' off screening.¹⁸ The theme of viewing
17 others as being more risk averse or easily deterred has been found in other qualitative studies¹⁸ and
18 it is unclear whether this is a coded way of expressing personal concern or a reflection of broader
19 identity beliefs that tend to represent the self as stronger than others in many respects. There is
20 evidence that people evaluate risk differently when considering themselves and when considering
21 others, tending to be more risk averse when considering other people.³⁶ It is possible, therefore,
22 that women in our study were cautious of anything that might deter others from attending
23 screening. Some women also expressed scepticism about any suggestion of shortcomings of
24 mammography, which is consistent with the finding that even women with interval cancer diagnoses
25 tend to maintain trust in the screening programme and to see their own cases as exceptions to an
26 otherwise effective programme.³⁷
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37 The finding that women generally preferred to be overdiagnosed than underdiagnosed is consistent
38 with previous survey findings of high tolerance levels of false positive results¹⁵ and a fear of false
39 negative results identified in qualitative work;³⁸ in other words women appear to value sensitivity
40 over specificity, which has been found in qualitative studies in other screening as well as diagnostic
41 contexts.^{39;40} But this is the first study, to our knowledge, to have explicitly explored the notion of
42 overdiagnosis in the UK breast screening context.
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48 The study has two broad implications. First, it highlights the difficulty of communicating the
49 concept of overdiagnosis to non-statisticians. Confusion was common and women found the idea
50 that the estimates of overdiagnosis are based on statistical modelling extremely difficult to
51 understand. Further work is needed to develop ways of conveying this type of information clearly,
52 especially given moves towards a policy of informed participation in screening.⁴⁰ Secondly, although
53 women felt the information was important, it generally had little impact on their beliefs about
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3 screening and their future intentions to participate. More work will be needed to see whether this
4 finding generalises to the wider population and whether the impact of information on overdiagnosis
5 differs across socioeconomic groups.
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For peer review only

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3 **Ethical approval:** The study was approved by the UCL Research Ethics committee (ref: 3162/002).
4
5

6 **Funding:** The study was commissioned and funded by the Cancer Research UK Information
7 Department.
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11 **Role of the sponsor and funder:** The study was commissioned by Cancer Research UK to explore
12 responses to overdiagnosis in breast cancer screening. The funder was not involved in carrying out
13 the study, or in the analysis and interpretation of the data.
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17 **Data sharing:** The discussion guide used in the study is available as supplementary material.
18 Anonymised transcripts will be made available to interested researchers.
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REFERENCES

- (1) Baum M. Breast screening should be scrapped. *The Guardian* 2011.
- (2) Duffy SW, Tabar L, Olsen AH. Absolute numbers of lives saved and overdiagnosis in breast cancer screening, from a randomized trial and from the Breast Screening Programme in England. *Journal of Medical Screening* 2010; 17(2):106.
- (3) Jorgensen KJ, Gotzsche PC. Overdiagnosis in publicly organised mammography screening programmes: systematic review of incidence trends. *British Medical Journal* 2009; 339.
- (4) Woolf SH, Harris R. The harms of screening: new attention to an old concern. *JAMA* 2012; 307(6):565-566.
- (5) Baum M, Thornton H, Gotzsche PC, Bewley S, Jorgensen KJ, Barratt A et al. Breast cancer awareness month. Still awaiting screening facts. *BMJ* 2010; 341:c6152.
- (6) Richards M. Breast Cancer Screening An Independent Review Is Under Way. *British Medical Journal* 2011; 343.
- (7) The benefits and harms of breast cancer screening: an independent review. *Lancet* 2012; 380(9855):1778-1786.
- (8) Gotzsche PC, Hartling OJ, Nielsen M, Brodersen J, Jorgensen KJ. Breast screening: the facts-or maybe not. *British Medical Journal* 2009; 338.
- (9) Gotzsche PC, Nielsen M. Screening for breast cancer with mammography. *Cochrane Database Syst Rev* 2006;(4):CD001877.
- (10) Gummersbach E, Piccoliori G, Zerbe CO, Altiner A, Othman C, Rose C et al. Are women getting relevant information about mammography screening for an informed consent: a critical appraisal of information brochures used for screening invitation in Germany, Italy, Spain and France. *Eur J Public Health* 2010; 20(4):409-414.
- (11) Zapka JG, Geller BM, Bulliard JL, Fracheboud J, Sancho-Garnier H, Ballard-Barbash R. Print information to inform decisions about mammography screening participation in 16 countries with population-based programs. *Patient Educ Couns* 2006; 63(1-2):126-137.
- (12) Jorgensen KJ, Gotzsche PC. Content of invitations for publicly funded screening mammography. *BMJ* 2006; 332(7540):538-541.
- (13) Schwartz LM, Woloshin S, Fowler FJ, Welch HG. Enthusiasm for Cancer Screening in the United States. *JAMA: The Journal of the American Medical Association* 2004; 291(1):71-78.
- (14) Domenighetti G, Avanzo B, Egger M, Berrino F, Perneger T, Mosconi P et al. Women's perception of the benefits of mammography screening: population-based survey in four countries. *International Journal of Epidemiology* 2003; 32(5):816-821.
- (15) Schwartz LM, Woloshin S, Sox HC, Fischhoff B, Welch HG. US women's attitudes to false positive mammography results and detection of ductal carcinoma in situ: cross sectional survey. *BMJ* 2000; 320(7250):1635-1640.

- 1
2
3 (16) Cicourel A. Interviews, surveys and the problem of ecological validity. *American Sociologist* 1982; 17(11):20.
4
5
6 (17) Waller J, Macedo A, von WC, Simon AE, Jones C, Hammersley V et al. Communication about
7 colorectal cancer screening in Britain: public preferences for an expert recommendation. *Br J*
8 *Cancer* 2012; 107(12):1938-1943.
9
10 (18) Woodrow C, Watson E, Rozmovits L, Parker R, Austoker J. Public perceptions of
11 communicating information about bowel cancer screening. *Health Expectations* 2008;
12 11(1):16-25.
13
14 (19) Hersch J, Jansen J, Irwig L, Barratt A, Thornton H, Howard K et al. How do we achieve
15 informed choice for women considering breast screening? *Preventive Medicine* 2011;
16 53(3):144-146.
17
18 (20) Hersch J, Jansen J, Barratt A, Irwig L, Houssami N, Howard K et al. Women's views on
19 overdiagnosis in breast cancer screening: a qualitative study. *BMJ* 2013; 346:f158.
20
21 (21) Bowater D. Breast cancer screening 'can no longer be justified'. *The Telegraph* 2012 Jan 21.
22
23 (22) Lakhani N. Claims of breast cancer screening success are dishonest, say critics . *The*
24 *Independent* 2011 Sep 1.
25
26 (23) Haywood L. Breast screening does save lives... we're the proof. *The Sun* 2011 Oct 27.
27
28 (24) Mayor S. Critics attack new NHS breast screening leaflet for failing to address harms. *BMJ*
29 2010; 341:c7267.
30
31 (25) Kitzinger J. Qualitative research. Introducing focus groups. *BMJ* 1995; 311(7000):299-302.
32
33 (26) Guest G, Namey EE, Mitchell ML. *Collecting Qualitative Data*. London: Sage; 2013.
34
35 (27) Dickson-Swift V, James EL, Kippen S, Liangputtong P. Doing sensitive research: what
36 challenges do qualitative researchers face? *Qualitative Research* 2007; 7(3):327-353.
37
38 (28) NHS breast screening. Available at:
39 <http://www.cancerscreening.nhs.uk/breastscreen/publications/nhsbsp.pdf>. 2011.
40 Department of Health; NHS Cancer Screening Programmes.
41
42 (29) Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology*
43 2006; 3(2):77-101.
44
45 (30) Webster P, Austoker J. Women's knowledge about breast cancer risk and their views of the
46 purpose and implications of breast screening--a questionnaire survey. *J Public Health (Oxf)*
47 2006; 28(3):197-202.
48
49 (31) Engelman KK, Cizik AM, Ellerbeck EF. Women's satisfaction with their mammography
50 experience: results of a qualitative study. *Women Health* 2005; 42(4):17-35.
51
52 (32) NHS The Information Centre. Breast screening programme, England 2010-2011.
53 <http://www.ic.nhs.uk/pubs/brstscreen1011>. 2012.
54
55
56
57
58
59
60

- 1
2
3 (33) Fagerlin A, Zikmund-Fisher BJ, Ubel PA. Helping patients decide: ten steps to better risk
4 communication. *J Natl Cancer Inst* 2011; 103(19):1436-1443.
5
6 (34) Adelsward V, Sachs L. The meaning of 6.8: numeracy and normality in health information
7 talks. *Soc Sci Med* 1996; 43(8):1179-1187.
8
9 (35) Hawkes N. "Citizens' jury" disagrees over whether screening leaflet should put reassurance
10 before accuracy. *BMJ* 2012; 345:e8047.
11
12 (36) Zikmund-Fisher BJ, Sarr B, Fagerlin A, Ubel PA. A matter of perspective: choosing for others
13 differs from choosing for yourself in making treatment decisions. *J Gen Intern Med* 2006;
14 21(6):618-622.
15
16 (37) Solbjor M, Skolbekken JA, Saetnan AR, Hagen AI, Forsmo S. Mammography screening and
17 trust: The case of interval breast cancer. *Soc Sci Med* 2012; 75(10):1746-1752.
18
19 (38) Watson-Johnson LC, DeGross A, Steele CB, Revels M, Smith JL, Justen E et al. Mammography
20 adherence: a qualitative study. *J Womens Health (Larchmt)* 2011; 20(12):1887-1894.
21
22 (39) Ghanouni A, Smith SG, Halligan S, Plumb A, Boone D, Magee MS et al. Public perceptions and
23 preferences for CT colonography or colonoscopy in colorectal cancer screening. *Patient Educ*
24 *Couns* 2012; 89(1):116-121.
25
26 (40) von Wagner C, Halligan S, Atkin WS, Lilford RJ, Morton D, Wardle J. Choosing between CT
27 colonography and colonoscopy in the diagnostic context: a qualitative study of influences on
28 patient preferences. *Health Expect* 2009; 12(1):18-26.
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Supplementary material – Discussion guide

1. Introduction**2. Decision making about mammography**

- General attitude to the concept of breast cancer screening
- Factors in the decision to go
- Is the current invitation seen as a recommendation?
- Experiences of going for mammography

3. Information in Breast Screening Leaflets

- Currently read leaflets – Why? Why not?
- Is this information wanted before being screened?
- Risk information wanted? – Why? Why not?

[Participants asked to read NHS Breast Screening leaflet. Instruction to only read p.3/4 on risks and benefits]

4. Reactions to risk information

- Aware of these risks before?
- Surprising/intuitive information – Why? Why not?
- Influence on feelings about breast screening
- Change decision to go for screening – why? Why not?

5. False positives

- (Refer to leaflet) ‘A false positive is when a woman is referred for further tests (such as another mammogram or a biopsy) and is then found not to have breast cancer’. What are your thoughts on this?
- ‘About 1 in 20 women are sent for further tests, but most (4 in 5) turn out not to have cancer – i.e. it’s a false alarm’. What are your thoughts on this?

6. Overdiagnosis

(Refer to leaflet) ‘It’s been suggested that some of the breast cancers that get diagnosed through breast screening are so slow-growing that they would not have caused any problems. But because we can’t yet tell which kind of cancer is the slow-growing kind, the women receives the usual treatment for breast cancer (e.g. surgery).’ What are your views about this?

- Of all women who go for breast screening about 8 in 1000 are diagnosed with cancer. It’s very hard to know what proportion of cancers diagnosed in the screening programme are of the slow growing type and the experts disagree at the moment. The estimates have varied from 1 in 8 of women who are diagnosed to 3 in 8. How do you feel about these figures?
 - o How would you feel about having treatment (surgery, radiotherapy, chemotherapy) for a cancer that wouldn’t have been life-threatening?
 - o How do you weigh up the risk of this kind of over treatment against the possible benefits for early diagnosis?

7. Wrap-up