

Women's responses to information about overdiagnosis in the UK breast cancer screening 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 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 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

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 of this study

- 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.

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 being 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 USA and Europe have indicated considerable enthusiasm for screening and a tendency for the public to overestimate 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 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 overtreatment, 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.

In a recent UK survey of the public's preferences for information on cancer screening (in this case it was colorectal cancer), most people, responding on a scale of 1–10, said they would like all available information about risks of screening as well as benefits.¹⁷ However, when asked more detailed and open questions in qualitative research, the UK public can be critical when risk information is included in colorectal screening information leaflets; 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 the complexities of follow-up.¹⁸ Some studies have also found women to be suspicious about the motivation behind questioning the benefits of mammography.¹⁹ To take forward new approaches to the provision of breast screening information, it is crucial to gain an understanding of women's perspective on the idea of 'overdiagnosis'. Information must be provided in a manner that is understandable and not likely to undermine equality of access.

Within the current debate about overdiagnosis, the voice of the users of the screening programme, women themselves, has been largely silent. The one study to

date examined Australian women's responses to detailed information on overdiagnosis and a range of estimates of its prevalence, using focus group methodology.²⁰ The results showed that although women generally lacked prior awareness of the issue, they were able to understand it when information was provided in the form of an audiovisual presentation. The impact of the information on future screening intentions varied widely between women and was also different depending on the prevalence of overdiagnosis presented.

The present study aimed to use qualitative methods to elicit British women's reactions to the notion of overdiagnosis and examine the effect they felt it might have on their decision-making about mammography participation. The UK context is important first, because of the media attention there had already been to the overdiagnosis issue at the time of this study^{1 21–23} and second, because of the on-going and high-profile criticism of the information provided to women in the UK about the breast screening programme.^{5 8 24} We focused on the impact of relatively brief information on overdiagnosis, to reflect the kind that might be provided in a screening information 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 socio-economic status. 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 funneling approach with questions moving from the general to the more focused (see online 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.

The description of overdiagnosis presented to the focus groups was developed in consultation with experts. We used 8 of 1000 cancer diagnoses as a starting point, as this information is currently included in the NHS leaflet.²⁸ The range of 1–3 overdiagnoses 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

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 (eg, 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 one in eight of women who are diagnosed to three in eight.

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 V.9 to code the data, and analysis continued into the write-up stage using the themes and verbatim examples to produce a narrative of women's experiences of the topic. Only sections of the analysis concerned with overdiagnosis are reported here. Demographic data were analysed using SPSS V.15.

RESULTS

A total of 40 women took part in six discussion groups; the number of women per group ranged from four to nine. Demographic characteristics of the sample are shown in table 1. Focus groups lasted an average of

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)

75 min (range 51–93 min, depending on group dynamics and how much women had to say about the issues being discussed).

Themes emerged relating to women’s previous experiences and beliefs about breast screening, and their attitudes to false-positive results. As these issues are well documented in the existing literature,^{15 30 31} we focus here specifically on responses to the overdiagnosis information (ie, Question 6 in the discussion guide—see online supplementary material). Two main themes were identified: (1) ‘Making sense of the concept of overdiagnosis’ and (2) ‘Implications of overdiagnosis information’ (see box 2).

Making sense of the concept of overdiagnosis

In the initial discussions of mammography screening, overdiagnosis was mentioned in four 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)

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

Some women found the statistical information on overdiagnosis (box 1) difficult to understand. The challenge of making sense of the numerical information was implicit in some participants’ responses but was also mentioned explicitly. In one 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)

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

P15: I don’t understand

P19: No I don’t think she understands it a hundred per cent.

P14: 8 women have cancer.

P15: Yes

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

Emotional responses

Some women expressed shock at the level of overdiagnosis and the implications for overtreatment, 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

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

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.

How do they know? How have they arrived at those figures, then? Because is it just literally at the end of chemo, they go 'Yeah, it's still there, or no, it's...?' (P22)

When it was explained that an individual woman would not know that her treatment had been unnecessary, participants began to question the basis of the information. Where women asked these questions, facilitators explained that statistical modelling is used to estimate levels of overdiagnosis. Not surprisingly, many participants found this difficult to understand.

I mean if this is all done on modelling, what's it modelled on? Is it that when they remove things they find different things within it, but you have to have it removed to know that? ... Or is it that it's all coming through post-mortems and things? (P27)

Some participants wondered if doctors would choose not to treat a suspected slow-growing cancer, alluding to an implicit fear of undertreatment.

Because doctors aren't infallible are they? ... Some will be more cautious than others, some will want to err on the side of not doing very much surgery and only doing as little as they can get away with until there is an indication that more is needed. (P37)

Others felt that surgeons 'like to wield their knives' (P19) and might be inclined to operate rather than try alternative approaches.

However, there was also widespread trust in health experts, which was expressed in all groups. There was trust in doctors, scientists and the NHS breast screening programme to utilise new knowledge or improved technology to ameliorate the risk of overdiagnosis and unnecessary treatment in the future.

P5: I think that my having heard all this now, I mean [I am] more educated about it and I would say now that I just have a trust that the NHS wouldn't haul us all out if

statistically there wasn't some evidence that, by and large, some people get saved, you know, and that not many people get disadvantaged.

P4: I have some trust to some extent because I think it's evidence-based treatment, isn't it? (Group 1)

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)

In general, the risk of undertreatment of cancer was seen as much greater than the risk of overtreatment.

Impact on screening decisions

At the end of the groups, most women retained their initial perspectives on attending screening. Previous attenders maintained that 'I'd still have a mammogram, yeah'. The reasons cited included reassurance that they do not have cancer, a desire to know if cancer is present and to increase the chances of an earlier diagnosis and more successful treatment. The information on overdiagnosis did not seem to have affected their core beliefs about screening.

I would still go, you know, it's better knowing than not knowing... At least I know that, it gives me time to plan ... things or what to do next. So I would rather have it done. It wouldn't change my view at all. (P17)

Despite the majority of screening decisions being unaffected, a few women did describe a change in attitude. One participant who initially described mammograms as 'very good' and 'very important' responded to the overdiagnosis information by saying 'That puts you off going at all doesn't it?' and later 'I find that very worrying, to have an operation when you didn't need to' (P12). Another who had recently attended for screening said

I'm in the clear at the moment [because of just having been screened] and I'm wondering whether I do want to go again actually. (P40)

Women who had never attended screening or had ceased to attend also tended to maintain their view although, perhaps surprisingly, one woman thought that following the discussion, she would consider attending in future.

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

DISCUSSION

In this qualitative study, we identified widespread lack of awareness of the risk of overdiagnosis in breast cancer screening among screening-eligible women. When provided with information about the range of risks of overdiagnosis and unnecessary treatment, they were often shocked and surprised, initially. After these initial emotional responses, many women went on to question the basis of the estimates of overdiagnosis, sometimes expressing scepticism but usually trusting health

professionals to make appropriate decisions. Most of those who had previously participated in screening maintained a positive attitude to the programme, preferring the risk of overtreatment to the risk of undertreatment. Given that no individual would know that her treatment had been unnecessary, women expressed an overwhelming preference to err on the side of caution. Some also regarded the information as relevant to choices about treatment rather than screening. In a few cases, however, women were put off by the information and felt that it might deter them from future screening attendance. Our findings are strikingly similar to a recent Australian study,²⁰ despite differences in the way that information on overdiagnosis was presented. This suggests that similar communication challenges will be faced across countries where breast screening is offered.

The study benefitted from the inclusion of women within the breast screening age range, around 70% of whom had been screened within the last 3 years, which is broadly in line with national coverage data.³² Women willing to attend a discussion group on mammography may generally be more proscreening than the general population and this may be a limitation of our study, although this concern is mitigated by the fact that our groups included women in the screening age range who had never attended or were overdue for screening. The use of focus groups allowed the complex issues surrounding overdiagnosis to be explored and discussed within a group context, enabling us to understand more about likely public responses to information within the screening programme than would be possible using individual interviews. However, individual interviews may have been more informative in understanding women's individual responses and the way that information might be integrated into women's screening histories and experiences. Larger-scale work will be needed to establish the generalisability of the findings. In common with most qualitative research, we used non-random sampling, recruiting women using a range of methods. This, and the fact that women were recruited in and around London, may also limit the generalisability of our findings.

Our participants sometimes found it difficult to understand the brief explanation of overdiagnosis that we provided, and there is an urgent need to develop clear and concise methods of conveying both the concept and its prevalence in a written format to provide to women. The difficulties of communicating risk estimates to the lay public are well documented³³ but may be particularly challenging where epidemiological, clinical and lay perspectives differ³⁴ and where there is such wide disagreement between experts.

We chose to use the term 'slow-growing' to describe cancers that are overtreated in the screening programme as this has been used in previous survey work.¹³ There is on-going debate about how best to communicate the concept of overdiagnosis to a lay audience. The citizen's jury carried out as part of the current review of NHS information materials found that women preferred the

term 'overtreatment' to 'overdiagnosis',³⁵ while the recent Australian study²⁰ used 'overdetection' (both these were published after our study had been completed). To our knowledge, no empirical data are available on the impact that using these different terms has on responses to the information. However it is possible that the image of a slow-growing cancer could have led our participants to think about receiving a cancer diagnosis and may have caused them to focus on treatment rather than screening decisions. The terms 'overdetection' and 'overdiagnosis' may make it easier to consider the concept in more abstract terms. But we felt it was important for women to realise that the cancers being overdiagnosed in the screening programme do represent malignant disease, as distinct from false-positive results. Further research is needed to identify the best way to describe the phenomenon.

The themes we identified included some that have been described before. We found that women had a desire to be provided with all the available information on risks,¹⁷ although this was tempered by concern that risk information may put 'other people' off screening.¹⁸ The theme of viewing others as being more risk averse or easily deterred has been found in other qualitative studies¹⁸ and it is unclear whether this is a coded way of expressing personal concern or a reflection of broader identity beliefs that tend to represent the self as stronger than others in many respects. There is evidence that people evaluate risk differently when considering themselves and when considering others, tending to be more risk averse when considering other people.³⁶ It is possible, therefore, that women in our study were cautious of anything that might deter others from attending screening. Some women also expressed scepticism about any suggestion of shortcomings of mammography, which is consistent with the finding that even women with interval cancer diagnoses tend to maintain trust in the screening programme and to see their own cases as exceptions to an otherwise effective programme.³⁷

The finding that women generally preferred to be overdiagnosed than underdiagnosed is consistent with previous survey findings of high tolerance levels of false-positive results¹⁵ and a fear of false-negative results identified in qualitative work³⁸; in other words women appear to value sensitivity over specificity, which has been found in qualitative studies in other screening as well as diagnostic contexts.^{39 40} But this is the first study, to our knowledge, to have explicitly explored the notion of overdiagnosis in the UK breast screening context.

The study has two broad implications. First, it highlights the difficulty of communicating the concept of overdiagnosis to non-statisticians. Confusion was common and women found the idea that the estimates of overdiagnosis are based on statistical modelling extremely difficult to understand. Further work is needed to develop ways of conveying this type of information clearly, especially given moves towards a policy of informed choice in screening.⁴¹ Second, although women felt the information was

important, it generally had little impact on their beliefs about screening and their future intentions to participate. More work will be needed to see whether this finding could be generalised to the wider population and whether the impact of information on overdiagnosis differs across socioeconomic groups.

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Data sharing statement The discussion guide used in the study is available as online supplementary material. Anonymised transcripts will be made available to interested researchers.

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PEER REVIEW HISTORY

BMJ Open publishes all reviews undertaken for accepted manuscripts. Reviewers are asked to complete a checklist review form (<http://bmjopen.bmj.com/site/about/resources/checklist.pdf>) and are provided with free text boxes to elaborate on their assessment. These free text comments are reproduced below. Some articles will have been accepted based in part or entirely on reviews undertaken for other BMJ Group journals. These will be reproduced where possible.

ARTICLE DETAILS

TITLE (PROVISIONAL)	Women's responses to information about overdiagnosis in the UK breast cancer screening programme: a qualitative study
AUTHORS	Waller, Jo; Douglas, Elaine; Whitaker, Katriina; Wardle, Jane

VERSION 1 - REVIEW

REVIEWER	Dr Paul Hewitson Senior Research Officer Department of Public Health University of Oxford UK I have no competing interests.
REVIEW RETURNED	13-Feb-2013

GENERAL COMMENTS	<p>Minor point, but further information (refs) for why focus group methodology rather than interviewing for this type of research topic may be useful.</p> <p>Please note: unless I'm reading the last question wrong, a 'no' is good, and a 'yes' would be bad - there is no requirement for supplemental documents for this paper.</p> <p>Abstract No comments</p> <p>Introduction Clear and concise introduction to the difficulties of presenting population derived information for personal decision-making. Also current controversy regarding overdiagnosis and current concerns about women's knowledge/awareness of overdiagnosis is well presented.</p> <p>Difficulties associated with the apparent paradox between women's expressed desire for more precise information regarding the risks of screening against their concerns that the information will affect participation are well structured; as are the overarching aim of the study.</p> <p>The paper identifies that there is a much needed area of research - apologies but had difficulty with the final paragraph; potentially alter the final para to better identify the main aim of the study (e.g. women's reactions to overdiagnosis), rather than the lead in that the study used similar methodology to the Australian study (would it not be suffice to say the aim of the study was to determine UK women's reactions to overdiagnosis and the effect on decision-making using</p>
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qualitative methods?). I also think the final para could be strengthened by changing the second sentence to reflect the fact it is both media attention (as you already know, few possible academic references, although a quick search of Nexis UK would yield several recent national newspaper articles) and continued publications which are highly critical of the UK information leaflets abundance of recent papers in UK-based journals).

Methods

Potentially include more information regarding the utility of FG methodology for this field of research (in comparison with face-to-face interviewing for example) if word limit allows.

The recruitment method employed is effective for this topic area. (The discussion could also address the difficulty of generalisability using this recruitment method in slightly more detail). The conduct of the study and information provided is reasonably discussed in detail - there would be expected to be criticisms regarding the use of "slow growing cancer" as opposed to overdiagnosis (the word is currently used in the mass media). This should also be addressed in the discussion section (the difficulties encountered by ref 16 could potentially be included in the methodology to reinforce the problematic use of this term).

Results

The results are presented in accordance with current guidance on qualitative methods. The authors have strived to add informative details concerning the two main themes in a novel and well constructed manner (actually an extremely useful way to present such a complex interpretation of the information of overdiagnosis by women).

Discussion

Whilst it is difficult to include all the points raised by the women in the FGs in the discussion, but potentially could include in the first para a more concise statement regarding the emotional impact and subsequent rationalisation (e.g. cynicism about statistics, therefore further difficulties when presenting population information; doctors treating an uncertain cancer 'to be on the safe side', etc).

The limitation of the recruitment method is slightly glossed over; this may cause difficulties for some readers. Potentially include a more straight-forward statement, as I would think your mitigating factor is justified to demonstrate the recruitment methods were justified and did not overtly impact on the quality of the results.

The authors have tied-in previous (almost non-existent) research in this field and applied the previous results to the current findings in a well structured and understandable way - my only concern is that this is the first time 'Fuzzy Trace Theory' has been introduced into the paper, and may benefit from this also being briefly included in the Introduction (just seems slightly out-of-place' to put such a vital piece of theoretical framework into the paper). The authors have highlighted the primary implications for their work and how this research would most definitely advance our understanding of information provision and decision-making for women invited to breast screening.

REVIEWER	Marit Solbjør, Senior researcher (PhD), Trøndelag R&D institute, Norway I declare that I have no competing interests.
REVIEW RETURNED	20-Feb-2013

GENERAL COMMENTS	<p>The context of the study and participants should be better described. Were all interviews conducted in London?</p> <p>The focus group methodology should be better described, both in general terms and why this method was considered more suitable than for instance individual interviews.</p> <p>References are mostly up to date, but more references should be added, particularly references discussing how lay people interpret statistics, as this is a main point in the article.</p> <p>First part of the results section appears somewhat immature and needs to be rewritten.</p> <p>Results should be discussed more in light of previous evidence.</p> <p>Thank you for the chance to review this interesting article. The article raises very important questions about how women understand information about overdiagnosis in mammography screening, and how such information might influence their decision making on the subject. These questions are most pertinent and this study is warranted. The article is generally well written but the authors need to address some issues that are described below.</p> <p>Abstract: Clarify setting of study/data collection/ participants.</p> <p>Introduction:</p> <p>The introduction is well written but could include more references to previous research, for instance - Barker KK, Galardi TR. Dead by 50: lay expertise and breast cancer screening. Soc Sci Med. 2011 Apr;72(8):1351-8. doi: 10.1016/j.socscimed.2011.02.024 (see lines 28-32 in the present manuscript).</p> <p>- Gummersbach, E. et al (2010) Are women getting relevant information about mammography screening... European Journal of Public Health, 20 (4):409-414</p> <p>- Jørgensen, K.J. and Götzsche, P.C. (2006) Content of invitations for publicly funded screening mammography. BMJ 332: 538-541</p> <p>Rewrite line 36 on page 1, since use of >10.000 is difficult for readers to interpret. Last four lines of second paragraph need to be rephrased. In the third paragraph the authors must make it clearer whether they refer to mammography screening or to other screenings, and make it clear if there are any differences between them.</p> <p>Page 2, lines 29-33: Argument about media coverage of overdiagnosis needs to be addressed throughout the article.</p> <p>Methods:</p> <p>The methodological approach needs to be extended. Why were focus groups the best method, why not for instance individual interviews? This paragraph needs more references and a short description of what a focus group entails.</p> <p>Participants: did all participants live in London? Were all data collection done in London? If so, include in discussion whether Londoners might represent all UK women (or not).</p> <p>P.5, line 10: "suitable community venue" - was this in London?</p> <p>Footnote 1 is confusing since having the same layout as references.</p>
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Omit or move to a box?

Line 24: explain how information was provided (oral, written?).

Line 28: Sentence about recording and transcription seems out of place. Move to end of "data collection"?

P. 6: either ref to NVivo AND SPSS, or exclude ref 21.

How were demographic data collected? Add one sentence about this.

Results:

The findings are very important to publish! They do, however, in their present state appear somewhat immature with too many repetitions of subjects throughout the subthemes. I would like the authors to look into their classifications and see whether some of the themes could be joined together, and whether these are the main themes. As presented now, each subject is more of a "teaser" than a final analysis, and I am curious to know more about each theme. It is particularly the first part of the results ("making sense...") which needs more attention. For me the subheadings overlap, and I do not understand the issue of "cynicism". Also, I do not understand that worries about NHS costs could be classified as emotional. I would urge the authors to rewrite this analysis and let us know more about the contents of the pertinent issue of how women make sense of the concept of overdiagnosis. It is of particular interest to see how these women have difficulties separating statistics and models from treatment of individual women.

Could one main category be about statistics for instance? Also, trust might perhaps be a main theme? For discussions on mammography screening and trust, see Solbjør (2008) in Brownlie, Greene and Howson (eds) *Researching Trust and Health*, Routledge, and Griffiths F, Bendelow G, Green E, Palmer J. *Screening for breast cancer: medicalization, visualization and the embodied experience*. *Health (London)*. 2010 Nov;14(6):653-68.

Could you clarify throughout the article whether it is question 6 from the interview guide that is the context for these answers, or the whole discussion within the focus groups? *

P.6, lines 37-41: is this necessary here? (as mentioned above*)

Why did the range of minutes for each focus group have such large variance?

p.7, line 28-29: please rephrase sentences as "known-about" and "off-putting" seems too colloquial (though I am not a native English speaker, authors should look into these phrasings).

Table 1: Are data available on whether some of the women had mammography more frequent than every 3rd year? As the recommended frequency in Norway is every second year, and some women tend to have mammograms even more frequent, it could be interesting to know what is hidden behind the wide category of "3 years or less".

Discussion:

Discussion should be rewritten in light of new results chapter. More discussion of previous research should be included. P.13,line 32: discuss focus groups vs individual interviews rather than survey methodology.

Line 42-46: unclear what is referred to, findings in this article or other findings? Rewrite.

Line 47: "common in qualitative research" needs references.

P.14, line 5: "Fuzzy trace theory" must be described more if used.

Overall comments:

There should be more discussion of the context of the study and of the subject. How did these women relate to media debates and medical debates mentioned in introduction? Relate article to debate

	<p>on informed decision making in screening? Interpretation of statistics could be discussed with reference to the following articles or other relevant research: Adelswärd V, Sachs L. The meaning of 6.8: numeracy and normality in health information talks. Soc Sci Med. 1996 Oct;43(8):1179-87. Skolbekken JA, Østerlie W, Forsmo S. Brittle bones, pain and fractures--lay constructions of osteoporosis among Norwegian women attending the Nord-Trøndelag Health Study (HUNT). Soc Sci Med. 2008 Jun;66(12):2562-72. doi: 10.1016/j.socscimed.2008.02.022. Epub 2008 Apr 1.</p>
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REVIEWER	<p>Vikki Entwistle Professor of Health Services Research and Ethics University of Aberdeen Scotland</p> <p>I have no competing interests of which I am aware. I have recently had the pleasure to meet some of the authors at a workshop exploring what health psychology can contribute to (communication about) cancer screening programmes.</p>
REVIEW RETURNED	23-Feb-2013

GENERAL COMMENTS	<p>In my opinion, this manuscript reports on a well-conducted, small-but-useful study that used focus groups to explore women's responses to information about the 'overdiagnosis' that can occur with breast cancer screening. The manuscript is generally well structured and the writing is clear.</p> <p>I had no major concerns, but a few observations and suggestions that the authors might consider when refining their manuscript.</p> <p>Abstract: two points could perhaps be made more specific: "Few felt that they would make a different screening decision" and "It may not influence their attitudes towards screening".</p> <p>P3: Would it be helpful to explain / reference the point that it's possible that more considered responses would be different?</p> <p>P3: "In a recent UK study.... although qualitative research has shown" and p4: "The one study to date... The present study used similar qualitative methods". I think the introduction would benefit from a minor edit to make clear what kinds of methods were used in the various studies that are reported. I'm particularly keen to get a sense of how 'open' response options were and what respondents were told that might have shaped their responses.</p> <p>P4: 'sceptical' or 'suspicious'?</p> <p>P5 and associated material: Could you (a) explain what alternatives you considered and rejected before deciding to explain overdiagnosis in terms of 'slow growing' cancers; and (b) provide a bit of critical reflection on the possible implications of the particular description you gave? (I was struck by the thought that the wording would encourage me to engage in the kinds of thinking that the women reported: the finding of a slow growing cancer is still the finding of a cancer, so the issue seems to be one of needing to tailor the treatment to the slowness, not one of any treatment being inappropriate)</p>
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	<p>P7-8 The quotation about 1 to 3 in 8 didn't leave me thinking the speaker had assumed that it would be better if 3/8 than 1/8 cancers found would never have caused a problem. Would extending the quotation clarify the way she's using 'great'?</p> <p>P13 The theme of viewing others as more risk averse (etc) than oneself is perhaps not just observed in qualitative research? A reference might be helpful here.</p>
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VERSION 1 – AUTHOR RESPONSE

Reviewer: Paul Hewitson

Minor point, but further information (refs) for why focus group methodology rather than interviewing for this type of research topic may be useful.

Another reviewer made a similar comment and we have now added more information about our choice of methodology. The section (on p5) now reads as follows: It is acknowledged that focus groups are well suited to exploring 'public' topics, such as public health interventions²⁸ and are a good way to identify 'group norms and cultural values'.²⁷ 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.

Introduction

Clear and concise introduction to the difficulties of presenting population derived information for personal decision-making. Also current controversy regarding overdiagnosis and current concerns about women's knowledge/awareness of overdiagnosis is well presented.

We're glad the reviewer found the Intro clear and concise.

Difficulties associated with the apparent paradox between women's expressed desire for more precise information regarding the risks of screening against their concerns that the information will affect participation are well structured; as are the overarching aim of the study.

Again, thank you for this positive comment.

The paper identifies that there is a much needed area of research - apologies but had difficulty with the final paragraph; potentially alter the final para to better identify the main aim of the study (e.g. women's reactions to overdiagnosis), rather than the lead in that the study used similar methodology to the Australian study (would it not suffice to say the aim of the study was to determine UK women's reactions to overdiagnosis and the effect on decision-making using qualitative methods?). I also think the final para could be strengthened by changing the second sentence to reflect the fact it is both media attention (as you already know, few possible academic references, although a quick search of Nexis UK would yield several recent national newspaper articles) and continued publications which are highly critical of the UK information leaflets abundance of recent papers in UK-based journals).

Thank you for this comment. As suggested, we have revised the final paragraph of the Introduction and added references to some additional media coverage. The paragraph now reads as follows: The

present study aimed to use qualitative methods to elicit British women's reactions to the notion of overdiagnosis and examine the effect they felt it might have on their decision-making about mammography participation. The UK context is important firstly because of the media attention there had already been to the overdiagnosis issue at the time of this study,^{1;21-23} and secondly because of the on-going and high-profile criticism of the information provided to women in the UK about the breast screening programme.²⁴⁻²⁶ We focused on the impact of relatively brief information on overdiagnosis, to reflect the kind that might be provided in a screening information leaflet.

Methods

Potentially include more information regarding the utility of FG methodology for this field of research (in comparison with face-to-face interviewing for example) if word limit allows.

We have amended to Methodology paragraph to include more detail about the advantages of focus groups over individual interviews (see above).

The recruitment method employed is effective for this topic area. (The discussion could also address the difficulty of generalisability using this recruitment method in slightly more detail).

We have added a line to the Discussion (on p14) to acknowledge the limited generalizability of our sample.

The conduct of the study and information provided is reasonably discussed in detail - there would be expected to be criticisms regarding the use of "slow growing cancer" as opposed to overdiagnosis (the word is currently used in the mass media). This should also be addressed in the discussion section (the difficulties encountered by ref 16 could potentially be included in the methodology to reinforce the problematic use of this term).

We agree that our use of the term 'slow growing cancer' could be problematic, and Vikki Entwistle has made a similar point. Both Ref 16 and the citizen's jury carried out as part of the review of NHS screening materials have identified problems with the term overdiagnosis. We have now addressed this in greater detail in the Discussion section (pp14-15), and have added more information about our decision to use to term 'slow-growing' in the Methods section (p6).

Results

The results are presented in accordance with current guidance on qualitative methods. The authors have strived to add informative details concerning the two main themes in a novel and well-constructed manner (actually an extremely useful way to present such a complex interpretation of the information of overdiagnosis by women).

Thank you for these positive comments on the analysis and presentation of Results.

Discussion

Whilst it is difficult to include all the points raised by the women in the FGs in the discussion, but potentially could include in the first para a more concise statement regarding the emotional impact and subsequent rationalisation (e.g. cynicism about statistics, therefore further difficulties when presenting population information; doctors treating an uncertain cancer 'to be on the safe side', etc).

We have expanded the first paragraph of the Discussion (pp13-14) slightly to give a more comprehensive summary of the results while trying not to go too far over the word limit.

The limitation of the recruitment method is slightly glossed over; this may cause difficulties for some readers. Potentially include a more straight-forward statement, as I would think your mitigating factor

is justified to demonstrate the recruitment methods were justified and did not overtly impact on the quality of the results.

We have added a straightforward statement about the limitations of our sample (p14): In common with most qualitative research, we used non-random sampling, recruiting women using a range of methods. This, and the fact that women were recruited in and around London, may also limit the generalizability of our findings.

The authors have tied-in previous (almost non-existent) research in this field and applied the previous results to the current findings in a well-structured and understandable way - my only concern is that this is the first time 'Fuzzy Trace Theory' has been introduced into the paper, and may benefit from this also being briefly included in the Introduction (just seems slightly out-of-place' to put such a vital piece of theoretical framework into the paper). The authors have highlighted the primary implications for their work and how this research would most definitely advance our understanding of information provision and decision-making for women invited to breast screening.

On reflection, and in response to the comments made by Marit Solbjør, we have decided to remove this reference to Fuzzy Trace Theory. We did not use the theory to guide the development of the study (hence not mentioning it in the Intro) but we agree that the very brief mention in the Discussion is out of place, and a considerable amount of explanation would be needed to explain more clearly how our findings might fit into the model. Given the space constraints, we feel that it is better to remove this point.

Reviewer: Marit Solbjør

We had difficulty responding to some of these comments as we were unable to generate a version of the manuscript with line numbers matching those used by the reviewer. We have tried our best to understand the points being made but were sometimes unsure which sections of text she was referring to.

The context of the study and participants should be better described. Were all interviews conducted in London?

The reviewer is right in thinking that all the discussion groups took place in London. We have now clarified this in the Methods section (p5) as well as the Abstract (p2).

The focus group methodology should be better described, both in general terms and why this method was considered more suitable than for instance individual interviews.

Paul Hewiston made a similar comment and we have expanded the Methodology paragraph to make this clearer (see above).

References are mostly up to date, but more references should be added, particularly references discussing how lay people interpret statistics, as this is a main point in the article.

Thank you for this comment. Please see our response to specific suggestions about references below.

First part of the results section appear somewhat immature and need to be rewritten

Please see response to specific suggestions on the Results section below.

Results should be discussed more in light of previous evidence.

Please see response to specific suggestions about the Discussion section below.

Thank you for the chance to review this interesting article. The article raises very important questions about how women understand information about overdiagnosis in mammography screening, and how such information might influence their decision making on the subject. These questions are most pertinent and this study is warranted. The article is generally well written but the authors need to address some issues that are described below.

Thank you for these positive comments.

Abstract: Clarify setting of study/data collection/ participants.

I'm afraid we were not quite sure how to further clarify these points in the Abstract but we have added some clarification of the sampling methods. If the editors feel that aspects of the Abstract need further information, we would of course be happy to add this.

Introduction:

The introduction is well written but could include more references to previous research, for instance – Barker KK, Galardi TR. Dead by 50: lay expertise and breast cancer screening. *Soc Sci Med.* 2011 Apr;72(8):1351-8. doi: 10.1016/j.socscimed.2011.02.024 (see lines 28-32 in the present manuscript).
- Gummersbach, E. et al (2010) Are women getting relevant information about mammography screening... *European Journal of Public Health*, 20 (4):409-414
- Jørgensen, K.J. and Götzsche, P.C. (2006) Content of invitations for publicly funded screening mammography. *BMJ* 332: 538-541

Thank you for these suggestions. We have added references to the Gummersbach and Jørgensen papers. We read the Barker & Galardi paper with interest but as the focus was online discussion forums of women with breast cancer, we did not feel that it fitted with our focus on public communication.

Rewrite line 36 on page 1, since use of >10.000 is difficult for readers to interpret.

We have rephrased this and hope it is now clearer: 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 (p3)

Last four lines of second paragraph need to be rephrased.

We have re-written this sentence so it now reads: In order to take forward new approaches to the provision of breast screening information, it is crucial to gain an understanding of women's perspective on the idea of 'overdiagnosis'. Information must be provided in a manner that is understandable and not likely to undermine equality of access. (p4)

In the third paragraph the authors must make it clearer whether they refer to mammography screening or to other screenings, and make it clear if there are any differences between them.

Thank you for pointing out this omission – we have clarified that some of these studies focus on colorectal rather than breast screening.

Page 2, lines 29-33: Argument about media coverage of overdiagnosis needs to be addressed throughout the article.

We have added some extra references to newspaper articles as suggested by Paul Hewitson.

Methods:

The methodological approach needs to be extended. Why were focus groups the best method, why not for instance individual interviews? This paragraph needs more references and a short description of what a focus group entails.

We have amended the Methodology paragraph to include more information (p5).

Participants: did all participants live in London? Were all data collection done in London? If so, include in discussion whether Londoners might represent all UK women (or not).

Women were recruited in and around London, and all the groups took place in London. We have clarified this point (p5) and have acknowledged the possible impact on generalizability in the Discussion (p14).

P.5, line 10: "suitable community venue" - was this in London?

Yes, we have added this information.

Footnote 1 is confusing since having the same lay out as references. Omit or move to a box?

Thank you for noting this confusion. We have removed the footnote and added the bullet point from the leaflet into the main text, in brackets.

Line 24: explain how information was provided (oral, written?).

The information in Box 1 was read to women – we have now clarified this point in the text as well as in the title of the box (p6).

Line 28: Sentence about recording and transcription seems out of place. Move to end of "data collection"?

Thank you – we have moved it to the end of the section as suggested.

P. 6: either ref to NVivo AND SPSS, or exclude ref 21.

Thanks for pointing out this inconsistency. We have removed reference 21.

How were demographic data collected? Add one sentence about this.

Women completed a short demographic questionnaire. We have added a sentence to the 'Data collection' section (p6).

Results:

The findings are very important to publish! They do, however, in their present state appear somewhat immature with too many repetitions of subjects throughout the subthemes. I would like the authors to look into their classifications and see whether some of the themes could be joined together, and whether these are the main themes. As presented now, each subject is more of a "teaser" than a final analysis, and I am curious to know more about each theme. It is particularly the first part of the results

("making sense..."), which needs more attention. For me the subheadings overlap, and I do not understand the issue of "cynicism". Also, I do not understand that worries about NHS costs could be classified as emotional. I would urge the authors to rewrite this analysis and let us know more about the contents of the pertinent issue of how women make sense of the concept of overdiagnosis. It is of particular interest to see how these women have difficulties separating statistics and models from treatment of individual women.

We have given serious consideration to these thoughtful comments and have looked again at our analysis. The themes were developed between the four authors with input from another researcher who moderated some of the focus groups. In addition, a member of our team who had no involvement in the data collection has read all the transcripts and the analysis to provide independent validation. As neither of the other reviewers raised any significant issues with our analysis or interpretation, we contacted the journal editor for advice. Given that the editor requested 'minor revisions' within a fortnight, and suggested the reanalysis was at our discretion, we are inclined to stay with our initial themes.

Could one main category be about statistics for instance? Also, trust might perhaps be a main theme? For discussions on mammography screening and trust, see Solbjør (2008) in Brownlie, Greene and Howson (eds) *Researching Trust and Health*, Routledge, and Griffiths F, Bendelow G, Green E, Palmer J. *Screening for breast cancer: medicalization, visualization and the embodied experience*. *Health* (London). 2010 Nov;14(6):653-68.

There are extremely interesting references, but we feel that to focus on the issue of trust would detract from our main aim, which was to understand responses specifically to the issue of overdiagnosis.

Could you clarify throughout the article whether it is question 6 from the interview guide that is the context for these answers, or the whole discussion within the focus groups?

We have tried to make it clearer that the analysis focuses on responses to the overdiagnosis information in Box 1, which is Question 6 from the discussion guide. We have added a sentence in the Results section (p.7) to further clarify this.

* P.6, lines 37-41: is this necessary here? (as mentioned above*)

I'm afraid we couldn't quite work out what this comment referred to.

Why did the range of minutes for each focus group have such large variance?

We have added some text to explain why the length of the discussions varied (simply because some groups had more to say on the issues being discussed than others) (p7).

p.7, line 28-29: please rephrase sentences as "known-about" and "off-putting" seems too colloquial (though I am not a native English speaker, authors should look into these phrasings).

We have re-phrased these wordings (p8).

Table 1: Are data available on whether some of the women had mammography more frequent than every 3rd year? As the recommended frequency in Norway is every second year, and some women tend to have mammograms even more frequent, it could be interesting to know what is hidden behind the wide category of "3 years or less".

We collected information about the date of participants' last mammogram and used this to calculate time since last screen. We do not know whether women were screened more frequently than recommended, but given the 3 yearly call-recall system used in the UK, it is unlikely. We don't feel that it would be helpful to break down the '3 years of less' category as we have no way of knowing how soon women were planning to go for their next mammogram, so it would probably only tell us how far they were through their 3 year cycle.

Discussion:

Discussion should be rewritten in light of new results chapter.

As we have chosen to leave our analysis as it was, we have not undertaken a major re-write of the Discussion.

More discussion of previous research should be included.

Thank you for your helpful suggestions for additional references, some of which we have included as noted. We have also added other additional references to the Discussion section in light of other reviewer comments, as summarised in this document. We hope that these changes sufficiently address this point, within the constraints of the word limit

P.13,line 32: discuss focus groups vs. individual interviews rather than survey methodology.

We have now amended this paragraph to discuss differences between focus groups and individual interviews.

Line 42-46: unclear what is referred to, findings in this article or other findings? Rewrite.

I'm afraid we weren't sure which sentence this comment referred to but we hope our editing of the Discussion has addressed the concern.

Line 47: "common in qualitative research" needs references.

We have amended this section as suggested here, and by Vikki Entwistle (p15).

P.14, line 5: "Fuzzy trace theory" must be described more if used.

We agree, and have now removed our reference to Fuzzy Trace Theory (see earlier response to Paul Hewiston).

Overall comments:

There should be more discussion of the context of the study and of the subject. How did these women relate to media debates and medical debates mentioned in introduction? Relate article to debate on informed decision making in screening? Interpretation of statistics could be discussed with reference to the following articles or other relevant research:

Adelswärd V, Sachs L. The meaning of 6.8: numeracy and normality in health information talks. *Soc Sci Med.* 1996 Oct;43(8):1179-87.

Skolbekken JA, Østerlie W, Forsmo S. Brittle bones, pain and fractures--lay constructions of osteoporosis among Norwegian women attending the Nord-Trøndelag Health Study (HUNT). *Soc Sci Med.* 2008 Jun;66(12):2562-72. doi: 10.1016/j.socscimed.2008.02.022. Epub 2008 Apr 1.

We have added a line to the final paragraph to acknowledge the shift to informed decision-making in screening and the importance of communication about overdiagnosis in this context. We have also

included a brief discussion of numeracy and have referred to the very interesting paper by Adelswärd and Sachs as suggested.

Reviewer: Vikki Entwistle

In my opinion, this manuscript reports on a well-conducted, small-but-useful study that used focus groups to explore women's responses to information about the 'overdiagnosis' that can occur with breast cancer screening. The manuscript is generally well structured and the writing is clear. I had no major concerns, but a few observations and suggestions that the authors might consider when refining their manuscript.

Thank you for these positive comments.

Abstract: two points could perhaps be made more specific: "Few felt that they would make a different screening decision" and "It may not influence their attitudes towards screening".

We have changed the first sentence as follows to make it clearer: After discussing overdiagnosis, few women felt that they would make different decisions about breast screening in the future, and the second sentence to: understanding overdiagnosis may not always influence women's attitudes towards participation in breast screening. We hope that the abstract is now clearer.

P3: Would it be helpful to explain / reference the point that it's possible that more considered responses would be different?

Yes, we have expanded this point and little and added a reference.

P3: "In a recent UK study.... although qualitative research has shown" and p4: "The one study to date... The present study used similar qualitative methods". I think the introduction would benefit from a minor edit to make clear what kinds of methods were used in the various studies that are reported. I'm particularly keen to get a sense of how 'open' response options were and what respondents were told that might have shaped their responses.

We have added more detail about the methodologies of these studies and we hope that we have shown more clearly the different responses that come from open vs. closed questioning in surveys and qualitative studies.

P4: 'sceptical' or 'suspicious'?

Hersch and colleagues use the word sceptical, but we agree that suspicious is probably more appropriate and have changed it.

P5 and associated material: Could you (a) explain what alternatives you considered and rejected before deciding to explain overdiagnosis in terms of 'slow growing' cancers

We have added more detail about the decision to use the term 'slow growing' in the Methods section.

(b) provide a bit of critical reflection on the possible implications of the particular description you gave? (I was struck by the thought that the wording would encourage me to engage in the kinds of thinking that the women reported: the finding of a slow growing cancer is still the finding of a cancer, so the issue seems to be one of needing to tailor the treatment to the slowness, not one of any treatment being inappropriate)

This is a very good point. We have added a paragraph to the Discussion to explore the issue of how best to communicate the concept of overdiagnosis, and the implications of our choice to use the term 'slow growing'. Of course once a cancer is diagnosed, there is currently no way of knowing whether it needs treatment or not, so the risk of overdiagnosis has to feed into screening decisions, not treatment decisions.

P7-8 The quotation about 1 to 3 in 8 didn't leave me thinking the speaker had assumed that it would be better if 3/8 than 1/8 cancers found would never have caused a problem. Would extending the quotation clarify the way she's using 'great'?

Thank you for this perceptive comment. Looking back at the transcript, we realise we may have misinterpreted the quote. We assumed 'great' meant 'good', but on reflection, it may have been a comment on the magnitude of the number. We have replaced the quote with one that illustrates someone explaining overdiagnosis to another participant who was confused.

P13 The theme of viewing others as more risk averse (etc.) than oneself is perhaps not just observed in qualitative research? A reference might be helpful here.

We agree, and have added a reference and expanded to point.