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Improving screening recall services for women with false-positive mammograms: a comparison of qualitative evidence with UK guidelines

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3 **Improving screening recall services for women with false-positive**
4 **mammograms: a comparison of qualitative evidence with UK guidelines**
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Improving screening recall services for women with false-positive mammograms: a comparison of qualitative evidence with UK guidelines

Abstract

Objectives: To gain an understanding of the views of women with false-positive screening mammograms of screening recall services, their ideas for service improvements and how these compare with current UK guidelines.

Methods: Inductive qualitative content analysis of semi-structured interviews of 21 women who had false-positive screening mammograms. These were then compared with UK NHS guidelines.

Results: Participants' concerns about mammography screening recall services focused on issues of communication and choice. Many of the issues raised indicated that the 1998 National Health Service Breast Screening Programme guidelines on improving the quality of written information sent to women who are recalled, had not been fully implemented. This included being told a clear reason for recall, who may attend with them, the length of appointment, who they will see and what tests will be carried out. Additionally women voiced a need for: reassurance that a swift appointment did not imply they had cancer; choice about invasive assessment or watchful waiting; the offer of a follow-up mammogram for those uncertain about the validity of their all-clear and an extension of the role of the clinical nurse specialist, outlined in the 2012 NHSBSP guidelines, to include availability at the clinic after the all-clear for women with false-positive mammograms.

Conclusions: It is time the NHSBSP 1998 recall information guidelines were fully implemented. Additionally, the further suggestions from this research, including extending the role of the clinical nurses from the 2012 NHSBSP guidelines, should be considered. These actions have the potential to reduce the anxiety of being recalled.

Strengths and limitations of this study

- This research has been rigorously conducted by an independent, academic research team
- The suggestions for service improvements are based on empirical research
- The evidence provides current insights into women's view of mammography screening services for recalled women
- The study is limited by the small sample size
- The limited geographical location may reduce the generalizability of the findings

Introduction

Screening for breast cancer by mammography has been part of many women's routine healthcare for more than 25 years. Much research has been carried out into the anxiety produced by having a false-positive mammogram (FPM).¹⁻⁶ However, the quality of mammography screening services for women who have been recalled has been less thoroughly investigated. Internationally, questionnaire studies have found that overall women are satisfied with the service they receive.⁷⁻¹⁰ Additionally, some studies found that the attitude of clinic staff as well as the quality of information and the physical environment affected satisfaction.^{7,9-12} Furthermore, a Finnish observational study that investigated the information needs of women assessed by biopsy, found that women wanted information and reassurance throughout and after their assessment.¹¹ However, a Canadian RCT failed to find an impact on satisfaction from additional information.¹³ The above research gives an opaque picture of the information and support needs of women recalled following screening.

The situation in the UK is particularly unclear as our searches found only one UK study of service satisfaction of women with a FPM. This was by Smith et al. who found that clinic staffs' attitudes, quality of information and the physical environment had an impact on satisfaction.¹⁴ However, this survey is more than 20 years old and it is 16 years since the NHS Breast

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2 Screening Programme (NHSBSP) produced guidelines about the information needs of women
3 recalled following mammography screening.¹⁵ More recently NHSBSP Guidelines (2012)
4 highlight the important role of the clinical nurse specialist (CNS) in supporting women who have
5 been recalled.¹⁶ As FPM affects more than 50,000 women a year in England alone, we were
6 interested in women's views of the service they received, their thoughts on how they might be
7 improved and how these compared with NHSBSP guidelines.
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14 It is hypothesised that the role that adequate information and personal support play in
15 increasing service satisfaction, is due to their ability to reduce uncertainty and thus anxiety. For
16 people with acute and chronic illness, uncertainty is acknowledged to be the greatest cause of
17 stress.^{17,18} It is likely that this is also the case with recall following screening. As Warren says, 'a
18 woman who receives a recall letter experiences temporarily the diagnosis of cancer'.¹⁹
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24 The research question is: What are the views of women with false-positive screening
25 mammograms of the recall service they received, their ideas for service improvements and how
26 do these compare with existing UK guidelines?
27

28 29 30 **Method**

31
32 We chose to use semi-structured interviews because they employ open-ended questions within
33 the framework of an interview guide, facilitating a discourse where the interviewee is free to
34 respond to the questions in a self-directed way. This approach produces responses that are rich
35 in content and may contain interesting and relevant material beyond the scope of the initial
36 question.
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38 39 40 **Participants and recruitment**

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Fifty two women with FPM were invited to participate and 21 were recruited (40%). Recruitment
was through the National Institute for Health Research Primary Care Research Network, from
three local General Practices or through the University of Exeter staff e-newsletter. Participants
were purposively sampled for diversity of age, time from the false-positive experience and type
of assessment procedure. Due to the specific focus of the research it was believed that about

1
2 20 interviews would be sufficient for data saturation. If saturation did not occur further
3 participants would be recruited.²⁰ Participants gave informed consent. This study received
4 ethical approval from the UK National Research Ethics Service Committee South West,
5 approval no. 11/SW/0263.
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10 **Data collection**

11 Participants were interviewed by MB in quiet locations of their choosing, usually at home. The
12 interview guide (available from the authors) was used to gather key pieces of information. It
13 covered the experiences of being invited for screening, being recalled, the assessment clinic
14 and reflections of that experience. The guide was based on the results of the latest UK
15 systematic review¹ and reviewed by two women with FPM. The interviews were recorded and
16 transcribed.
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24 **Data analysis**

25 The interviews were analysed with inductive qualitative content analysis.²¹ This approach was
26 chosen because we wanted to develop simple categories from the interviews to compare with
27 the items in the guidelines rather than explore the deeper meanings of what the participants
28 were saying. This process involved reading and listening to the interviews iteratively as relevant
29 content was open coded. The codes were reviewed across the manuscripts by a process of
30 constant comparison, being merged and dropped as the analysis progressed. The codes were
31 then gathered into categories of similar items.²² These primary categories were subsumed into
32 higher order generic categories and so assisted the systematic description of the phenomena,
33 thus identifying the key messages in the texts.²³
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43 The results were validated using Yardley's principles of sensitivity to context, commitment and
44 rigour, transparency and coherence and impact and importance, including an audit trail and the
45 search for disconfirming cases²⁴ and participant feedback. The analysis was supported by
46 Atlas.ti 6.2 software. The application of Yardley's principles can be seen in Table 1.
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Table 1 Yardley's principles for quality in qualitative research

Yardley's Principles for quality in qualitative research		Application to this study
Principle	Qualities	
Sensitivity to context	Theoretical; relevant literature; empirical data; socio-cultural setting; participant's perspective; ethical issues	Grounding the study in the context of what is already known from the systematic review. Then gathering the new interview data to refine that knowledge, searching for examples that confirm and refute what is already known. Being aware of and sensitive to the socio-cultural place of the participants and how this might influence the meanings they give to their experiences. Also understanding those experiences from their perspective; what they meant to them, but acknowledging the influence of the researcher and their role in the interview to what is said through their demeanour, verbal and non-verbal cues and an awareness of the potentially more powerful position of the researcher. Ethical approval was gained.
Commitment & rigour	In-depth engagement with topic; methodological competence; skill; thorough data collection; depth/breadth of analysis	This is achieved through becoming committed to the process of the research, the integrity of the interviews, being immersed in the data and taking a systematic, rigorous approach to the depth of analysis and interpretation of the interviews. Accounting for the variety and complexity of the data, including the search for disconfirming cases. The trustworthiness of the analysis was further established by respondent validation of the findings. The first eight interviews were coded independently by two researchers.
Transparency & coherence	Clarity and power of description/argument; transparent methods and data presentation; fit between theory and method; reflexivity	Providing a clear audit trail of the process of the study including data analysis. Telling a clear coherent story that encompasses the range of experience of the participants, illustrated by their own words and offering a reflective interpretation of the meaning of their accounts that acknowledges the role and influences of the researcher.
Impact & importance	Theoretical (enriching understanding); socio-cultural; practical (for community, policy makers, health workers)	Clearly describing the originality and importance of the findings and how they relate to previous research. Demonstrating their importance for policy makers, in this case the NHSBSP. Offering recommendations to improve services to reduce the psychological impact of false-positive mammograms.
Source: Yardley (2000)		

Results

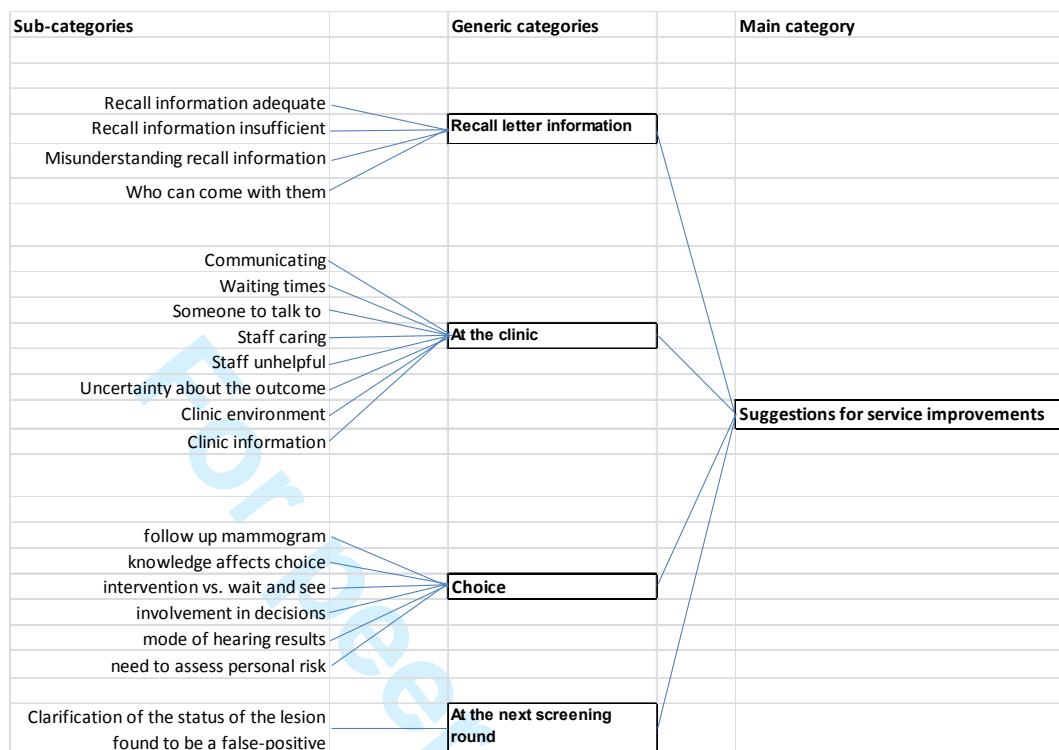
Participants' characteristics were found to fulfil the criteria of diversity, see table 2.

Table 2 Summary of participants' characteristics

Characteristics	No (%) women
Age (years)	
40-49	2 (10)
50-59	11 (52)
60-69	8 (38)
Marital status	
Married or cohabiting	19 (90)
Single, separated or widowed	2 (10)
Ethnicity	
White	21 (100)
Time since false-positive (years)	
≤ 1 year	4 (19)
2-4	7 (33)
5-7	8 (38)
8-10	1 (5)
11-13	1 (5)
Type of assessment procedure*	
Mammogram	16 (76)
Ultra-sound	12 (57)
Fine needle aspiration	1 (5)
Biopsy	4 (19)
Index of multiple deprivation %	
Unknown	4 (19)
0-9	1 (5)
10-19	0 (0)
20-29	2 (9)
30-39	3 (14)
40-49	2 (9)
50-59	4 (19)
60-69	4 (19)
70-79	1 (5)
* Many women had more than one assessment procedure	

The interview study showed that overall; almost all participants were satisfied with the mammography recall service they received. However, as they presented their stories a number of issues were raised for service improvement. These issues concerned the recall letter, the assessment clinic, choice and subsequent screening. Participants' quotes are identified by a pseudonym. A diagram of the relationship between the categories can be found in figure 1.

Figure 1



Recall letter information

Most women were satisfied with the quality of the recall information they were sent. The information was repeatedly described as reassuring. Many participants latched onto the positive messages of the letter and remembered they had been told that most recalled women were clear of breast cancer and they should not worry about being called back.

Anne: "The letter itself I think said something reassuring like... 'as a precaution we're calling you back because, there's some anomaly, or something like that, on the screen...' and then it says ... a large proportion of women who are called for second screening don't actually have anything, but it's just a precautionary thing, so I mean all the time they're kind of trying to put forward the, sort of, positive angle on it."

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2 However, there was considerable variation in what women were told to expect; some were
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4 simply told they would have another mammogram and others were given an explanation about
5
6 the reason for their recall.
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8 *Clare: "In the letter, yeah, when I was recalled, they actually said ...*
9
10 *'we'd like you to come again, so we can take some further x-rays,' and*
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12 *they've also said 'at this visit we may also carry out an ultrasound*
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14 *examination', so I was aware of what was going to happen."*

15
16 *Moira: "Only curious about what was going to happen, because you don't*
17
18 *get told beforehand. You know you're going to have a mammogram, but*
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20 *you don't know what else is going to happen... so you're not actually*
21
22 *prepared."*

23
24 Most of the women found the short time between the recall letter and their assessment
25
26 a positive thing as the time of anxiety was curtailed:
27

28 *Vicky: "When I got the letter, to be recalled was only a few days later, it*
29
30 *wasn't very long, which I'm really glad about. I couldn't have hung on two*
31
32 *or three, four weeks, it was a matter of days, it was very, very good, very*
33
34 *good."*

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36 Conversely, others interpreted the quick appointment as possibly indicating they had breast
37
38 cancer. This understanding was rooted in a belief that the NHS only responds quickly to serious
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40 health problems:
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42 *Grace: "There wasn't a lot of time, um, also between the letter - I think it*
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44 *was about a week - between me getting the letter and actually going for*
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46 *the, the next mammogram, which tends to sort of go 'oops,' anything that*
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48 *comes you don't have much time in between means that it could be*
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50 *serious."*

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2 Others who went alone found the waiting hardest as they lacked the support of a friend or
3 relative, but not everyone knew they could bring someone with them.

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6 *Wendy: "The only thing that I would have liked the letter to have said*
7
8 *was, 'if you want to bring a friend or relative, please do so.'"*

9
10 These accounts indicate a variation in the amount and content of the information that
11 participants were given. They also show that the information needs of these women differed;
12 some were able to focus on the positive messages of the recall letter and were quite happy with
13 simply being told that although they were being recalled everything was probably alright. Others
14 reacted more strongly to the uncertainty that was introduced into their lives and wanted as much
15 detail as possible about the reasons for their recall; the implications of this and what was going
16 to happen at the assessment clinic.
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23 **At the clinic**

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25 Waiting generally provoked anxiety; one participant said this could have been reduced by
26 information about how long the clinic appointment was likely to take:
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30 *Karen: "The waiting was the worst... the whole thing was bad, but the*
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32 *worst bit was having to wait and not knowing how long I was waiting for."*

33
34 Many participants reported that the clinic staff were the best thing about their experience. They
35 were repeatedly described as Rachel: lovely, Moira: friendly, Ella: supportive, Zoe: kind, Anne:
36 professional and Vicky: very, very nice:
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40 *Zoe: "They were just very kind and I think, in a way, nurturing, because*
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42 *they knew there was a possibility that you might have bad news. They*
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44 *were just very protective of you; you just felt that they were handling it*
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46 *really well, that they cared about you."*

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48 Clear explanations of the nature of the lesion were valued and helped to bring peace amid the
49 uncertainty.
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Laura: "He was ever so...really thorough, I've got to say, really put my mind at rest ... explained everything to me from start to finish, ... and did it in a way...not condescending way, he explained it in a real clear and concise manner, yeah, absolutely brilliant. I came out cock-a-hoop! "

10 Although the majority had positive encounters, not all staff were sensitive and caring.

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Chloe: "Um...yes, it didn't feel quite friendly, the staff in the unit sometimes... it was a case of, 'oh, yeah,' it's just...like the queue... 'oh, right, yeah, next."

18 There was evidence of an unmet need for information and reassurance that could have been
19 given by a CNS being available, and known to be available, after as well as before assessment.
20 This unavailability resulted in some women leaving the clinic with uncertainty and unanswered
21 questions.
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Laura: "Don't think so [someone to talk to]. Didn't see... there was a nurse, yes, there was a nurse on duty, but she was very busy and I could see she was very busy."

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Grace: "I can't recall there being anybody around."

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Fran: "Well, I suppose somebody to talk...you know, perhaps if I'd gone and talked to somebody, you know, about it all, perhaps I...it would have eased me."

40 During their assessment the amount of information that participants wanted about their lesion
41 varied. A number of them would have had more confidence in their all-clear result if they had
42 been given a clearer explanation of what their lesion meant, including the risk of it becoming
43 malignant so they could make an informed choice about how to proceed.
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Liz: "I would like the doctors to present me with the facts and say 'right, you know...if it's 20 women out of...out of 100 with hyperplasia who, you know, before they die, so they could be really old, get breast cancer,'

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2 *then I know that fact. If it's, um, you know, one in 10,000 up to the age of*
3
4 *80, then I probably would opt not to have any invasive surgery again."*
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6 One participant's experience highlighted the need for consistency between the messages from
7 the clinical staff and the literature they were given. The radiologist had told her that her cysts
8 could not become cancerous and then gave her a leaflet that said they could; this caused
9 considerable anxiety. This inconsistency led her to request an interim mammogram for
10 reassurance from her GP but was turned down:
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16 *Moirra: "And I now wait for my next mammogram...but that's the bit I don't*
17 *like. You're told you have cysts, but you're not given a follow-up from*
18 *there and you should...I'm assuming that they're quite satisfied that they*
19 *[cysts] cannot become cancerous, even though the leaflet says they can.*
20 *So I'm assuming they either haven't read the leaflet, or they simply don't*
21 *believe the leaflet, I don't know which."*
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27 While the women waited at the clinic it was apparent that the location, layout and the waiting
28 environment played a role in moderating their experience. Some participants had their initial
29 screening in mobile units but then went to a hospital for their assessment.
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34 *Zoe: "Perhaps it seems more serious because you're aware it's a place*
35 *where there are sick people... whereas if you go to the unit that goes to*
36 *the car parks and whatever, you're in and out in ten minutes and you*
37 *move on."*
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41 For some the physical layout of the clinic meant they were aware of what was happening to
42 other women ahead of them in the queue; increasing their anxiety as they waited.
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46 *Grace: "We waited in a corridor ... we, sort of, waited in a long line, sat*
47 *down in a long line ... we all waited together and we all went in and you'd*
48 *see people go through the door, but they also came out that door and*
49 *you knew if it was good or bad news for them, because obviously if it was*
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2 *good news they were looking happy, and if it was bad news they didn't go*
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4 *straight down the corridor, they went into another room. Um, and that*
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6 *would have been, I think, pretty traumatic for anybody, because you*
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8 *knew which way...but also for us, because we knew if it was good or bad*
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10 *news for them. I remember thinking, 'well, I'm going to have to go*
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12 *through that in a minute, but I don't want to witness their distress either.'*

13
14 On other occasions the participants could not see the woman diagnosed with breast cancer but
15 they could hear her crying, which similarly increased their anxiety.

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18 *Wendy: "while I was waiting somebody else had...who had been recalled,*
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20 *um, had been told that they, you know, they did have something and*
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22 *obviously they were distressed and, you know, people waiting, that was*
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24 *distressing as well...I could hear, I couldn't see her, but I could hear her*
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26 *and that was distressing, yes."*

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28 Although the staff received much praise, there was still a clear need for an opportunity to talk to
29 the CNS after the all-clear if questions remained about the reliability of the diagnosis and the
30 probability of it becoming malignant. The status of their lesion remained a concern at the next
31 screening round for some women and information about if or how it had changed would have
32 been valued. The responses also showed that a sensitivity to the clinical environment is
33 necessary with due regard for privacy.

34 35 36 37 38 39 **Choice**

40 Following their assessment a number of women were uncertain about the validity of their all-
41 clear diagnosis. They would have liked the option of a follow-up mammogram for reassurance.

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46 *Ella: "I thought 'can you just see me in a year's time, just tell me that in a*
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48 *year's time, it's all OK in a year's time?"*

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50 *Zoe: "I think the fact that you've been faced with the possibility that*
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52 *something didn't look quite right, you're not quite sure what it was that*

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2 *didn't look quite right, um, and maybe a screening a year down the line*
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4 *would have been, um, something to...to, you know, relieve any nerves."*
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6 There was also a request for mammograms as an alternative to the invasive investigation of
7 lesions by biopsy that were thought to be almost certainly benign.
8

9
10 *Liz: "Because they said, 'we're pretty sure it isn't anything, but we need*
11 *to check if it is anything.' ...and so I suppose what I'm saying is that had*
12 *there been a little bit more, um, wait and see... I wouldn't have had more*
13 *anxiety if they'd say, 'well, we'll do a mammogram again in three months*
14 *or six months."*
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20 This plea for choice was part of a desire to be more involved in the decision making process
21 about how to proceed once a lesion was detected. Many of the women felt disempowered by
22 the assessment process. They perceived themselves to be Ella: 'in the system' and passive
23 partakers of assessment procedures.
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28 *Liz: "I think when you're in the middle of it, you just go along with*
29 *whatever's being told... there could have been, uh, more consultation*
30 *maybe at the beginning of things... so...and I'd have probably still have*
31 *gone along with it, [surgery] 'cause I don't think I felt empowered not to."*
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36 Another woman would have appreciated the choice of receiving her biopsy results by post or
37 over the phone, as this further wait prolonged anxiety.
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40 *Fran: "It was just waiting for those results... every day you look for the*
41 *post... and when it's there you're frightened to open it up... it [phone call]*
42 *probably would have been better, really, 'cause you're looking every day,*
43 *aren't you, at the post and thinking, 'oh, my gosh."*
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48 It was clear that some women would have valued more choice in the assessment process.
49 Choice was requested for follow-up mammograms to reduce uncertainty and anxiety about the
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outcome of assessment, 'watchful waiting' as an alternative to biopsy and test results over the phone rather than through the post.

At the next screening round

At their next routine screening, some participants' anxieties would have been dispelled if they were told about the status of the lesions previously discovered:

Jane: "I just got the all-clear letter, sort of thing, [after subsequent screening] and when I saw the doctor [GP] I said 'when I...you got the results of me mammogram did it say anything about the cyst?' And he looked it back and he said, 'no, it hasn't said anything.' And it would have been just nice to know whether I've still got it or not."

Comparison of these results with NHSBSP guidelines

Many of our findings echo those of the research used to produce the NHSBSP 1998 guidelines and indicate that these have not been universally implemented.²⁵⁻²⁷ A comparison of the NHSBSP guidelines with our service improvement suggestions can be found in Table 3.

Table 3 Comparison of our suggestions with those of the 1998 and 2012 NHSBSP Guidelines

	NHSBSP Recall Guidelines (38) 1998	Bond et al. Service Suggestions 2014
Recall letter information	A clear reason for recall	A clear reason for recall
	Who can come with them	Who can come with them
	How long the appointment will take	How long the appointment will take
	Who they will see	Who they will see
	What tests will be carried out	What tests will be carried out
	Where they can get further information	Reassurance that a swift appointment does not imply the presence of cancer
	How to get to the assessment centre	
	How to change their appointment	
	When the results will be available	
At the clinic	NHSBSP CSN Guidelines (29) 2012	
	Availability of a CSN before assessment	Availability of a CSN before and after assessment

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	Clear explanation of why the lesion is benign with any risk of change to malignancy
	Literature about the type of lesion
	One-way layout through the clinic
Choice	The offer of a follow-up mammogram in a year for those needing reassurance of their 'all clear'
	Choice between invasive assessment and 'watchful waiting' for lesions almost certainly benign
	Choice of hearing biopsy results by post or over the phone
At the next screening round	Clarification of the status of the lesion found to be a false-positive

The following suggestions are offered to improve services.

Recall letter

Recall letters issued should be consistent and include the following items. The first five items remain unaddressed from the 1998 guidelines.

This should include:

1. The reason for recall
2. Who can come with them
3. How long the appointment is likely to take
4. Who they will see
5. What tests will be carried out
6. Where to get further information
7. The availability of a CNS to answer questions before and after assessment
8. Reassurance that a swift appointment is normal and does not indicate there is anything wrong

At the clinic

9. A pre-assessment conversation with the CNS covering, the reason for recall, the assessment process including possible harms, and the availability of the CNS for a debrief after the assessment whatever the outcome
10. From the Radiologist at diagnosis; sufficient time for a clear explanation of the type of lesion, risk of it becoming malignant, with clarity about uncertainty. If a biopsy is advised then discussion about pros and cons including the reliability of biopsy results and the choice of watchful waiting if the lesion is almost certainly benign
11. The availability of CNS post-assessment to clarify the diagnosis and provide reassurance, as a woman may not feel able to question the outcome with her GP. If the woman remains unsure of the validity of her all-clear a follow-up mammogram should be considered
12. Literature about the type of lesion found should be offered. This should agree with that from the Radiologist and give a phone number for further information
13. The choice of receiving biopsy results by phone or post
14. A one-way system through the clinic so that women do not have to have the outcome of their assessment witnessed or witness other's outcomes

At the next screening round

15. Women should be given an update about their lesion, whether it has gone, stayed the same or grown larger, with an explanation of the implications

Discussion

While overall participants were satisfied with the service they received, they raised a number of areas where it could be improved. Many of the items in the 1998 NHSBSP guidelines remained outstanding. Some women were still asking for more information in the recall letter about: the reason for their recall; who could come with them; how long the appointment might take; who they would see and what would happen to them. Some participants were also concerned that a swift appointment implied that they had cancer. At the assessment clinic a more explicit

1
2 explanation of why their lesion was benign and the risk of it becoming malignant would have
3 reduced anxiety, together with literature about their type of lesion. The women also expressed
4 requests for more choice as some were left with doubt about the validity of the outcome of the
5 assessment and would have appreciated an offer to have a follow-up mammogram in a year's
6 time for reassurance and an update on the status of their lesion at their next screening round.
7 Others felt powerless and in 'the system' when faced with a biopsy; an alternative of 'watchful
8 waiting' for lesions that were almost certainly benign, would have been valued and empowering.
9 A choice of having biopsy results by post or over the phone was also requested. Additionally
10 some participants would have valued an opportunity to see the CNS after assessment as well
11 as before. Finally, the layout of the clinic precipitated anxiety for some women while they were
12 waiting, as they were able to see and hear the distress of women who had been diagnosed with
13 cancer. There was no apparent link between participants' demographic characteristics and the
14 issues they raised.

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27 The strengths of this study are that it was rigorously conducted and provides current, in-depth
28 insights into the views of women, with false-positive mammograms of the assessment service
29 they received. Thus it provides valuable evidence of how these services may be improved so
30 that the anxiety associated with having false-positive mammograms may be reduced. The
31 influence of the researcher (MB) is acknowledged, both from her manner, verbal and non-verbal
32 cues during the interview; there is also the potential for social desirability effects²⁸. The analysis
33 has been through the filter of the researcher's particular understanding of the issues, including
34 being someone who has not had mammography. This will have influenced the way the
35 interviews were interpreted, due to the lack of first hand experience. Qualitative research is
36 notably subjective and is open to the charge that the results lack generalisability. However, we
37 believe these results are robust, transferable and relevant to policy development as the
38 interview findings were validated using Yardley's principles²⁴ and by participant feedback on a
39 lay summary of the results. The study is limited by the small sample, the limited geographical
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2 area (Devon) and the possible unreliability of the participants' memories as these events
3
4 occurred between six months and 12 years previously.

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6 Internationally, questionnaire studies have also found that overall women are satisfied with
7
8 mammography screening recall services.⁷⁻¹⁰ However, some studies found, in agreement with
9
10 ours, that the attitude of clinic staff as well as the quality of information and the physical
11
12 environment affected satisfaction.^{7;9;10;14} Our findings also agree with the results from the US
13
14 qualitative study (2001), that some participants thought the information they received was
15
16 inadequate.¹²

17
18 Although our research comes from a limited geographical area, and other regions of the UK
19
20 may have better service provision, it implies that there is still some way to go to provide women
21
22 who are recalled after breast cancer screening with a satisfactory service. There is a need for
23
24 consistency in the implementation of recommendations and a mechanism for ensuring this
25
26 occurs.

27 28 **Service implications**

29
30 These suggestions will require additional resources; increased hours for the CNS and additional
31
32 mammography for those needing reassurance or choosing 'watchful waiting'. However, most of
33
34 the suggestions can be implemented at the lower cost of revising literature and giving clearer
35
36 explanations, which may mean that fewer women are left with uncertainty and request on-going
37
38 care.

39 40 **Conclusion**

41
42 It is time the NHSBSP 1998 recall information guidelines were fully implemented. Additionally,
43
44 the further suggestions from this research, including extending the role of the CNS from the
45
46 2012 NHSBSP guidelines, should be considered.

47
48 Further research is needed to establish whether the 1998 NHSBSP recommendations are in
49
50 place nationally and if the additional measures outlined in these service recommendations are
51
52 sought by women throughout the UK.

1
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3

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6
7

8 Contribution of authors: MB obtained ethical approval, obtained NIHR adoption, recruited
9 participants with the support of the SW Primary Care Research Network, conducted and
10 analysed the interviews, obtained respondent feedback, undertook the comparison with UK
11 guidelines and formulated service improvement suggestions, wrote and edited the research
12 paper. RG contributed to the design of the study, advised on the qualitative aspects and
13 commented on the draft paper. CH contributed to the design of the study, advised on the health
14 services aspects and commented on the draft paper.
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22
23

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Improving screening recall services for women with false-positive mammograms: a comparison of qualitative evidence with UK guidelines

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4 **mammograms: a comparison of qualitative evidence with UK guidelines**
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Improving screening recall services for women with false-positive mammograms: a comparison of qualitative evidence with UK guidelines

Abstract

Objectives: To gain an understanding of the views of women with false-positive screening mammograms of screening recall services, their ideas for service improvements and how these compare with current UK guidelines.

Methods: Inductive qualitative content analysis of semi-structured interviews of 21 women who had false-positive screening mammograms. These were then compared with UK NHS guidelines.

Results: Participants' concerns about mammography screening recall services focused on issues of communication and choice. Many of the issues raised indicated that the 1998 National Health Service Breast Screening Programme guidelines on improving the quality of written information sent to women who are recalled, had not been fully implemented. This included being told a clear reason for recall, who may attend with them, the length of appointment, who they will see and what tests will be carried out. Additionally women voiced a need for: reassurance that a swift appointment did not imply they had cancer; choice about invasive assessment or watchful waiting; the offer of a follow-up mammogram for those uncertain about the validity of their all-clear and an extension of the role of the clinical nurse specialist, outlined in the 2012 NHSBSP guidelines, to include availability at the clinic after the all-clear for women with false-positive mammograms.

Conclusions: It is time the NHSBSP 1998 recall information guidelines were fully implemented. Additionally, the further suggestions from this research, including extending the role of the clinical nurses from the 2012 NHSBSP guidelines, should be considered. These actions have the potential to reduce the anxiety of being recalled.

Strengths and limitations of this study

- This research has been rigorously conducted by an independent, academic research team
- The suggestions for service improvements are based on empirical research
- The evidence provides current insights into women's view of mammography screening services for recalled women
- The study may be limited by the ability of some participants to recall distant experiences
- More detailed information about the demographic characteristics of participants would aid interpretation of the results

Introduction

Screening for breast cancer by mammography has been part of many women's routine healthcare for more than 25 years. Much research has been carried out into the anxiety produced by having a false-positive mammogram (FPM).¹⁻⁶ However, the quality of mammography screening services for women who have been recalled has been less thoroughly investigated. Internationally, questionnaire studies have found that overall women are satisfied with the service they receive.⁷⁻¹⁰ Additionally, some studies found that the attitude of clinic staff as well as the quality of information and the physical environment affected satisfaction.^{7,9-12} Furthermore, a Finnish observational study that investigated the information needs of women assessed by biopsy, found that women wanted information and reassurance throughout and after their assessment.¹¹ However, a Canadian RCT failed to find an impact on satisfaction from additional information.¹³ The above research gives an opaque picture of the information and support needs of women recalled following screening.

The situation in the UK is particularly unclear as our searches found only one UK study of service satisfaction of women with a FPM. This was by Smith et al. who found that clinic staffs' attitudes, quality of information and the physical environment had an impact on satisfaction.¹⁴

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However, this survey is more than 20 years old and it is 16 years since the NHS Breast Screening Programme (NHSBSP) produced guidelines about the information needs of women recalled following mammography screening.¹⁵ More recently NHSBSP Guidelines (2012) highlight the important role of the clinical nurse specialist (CNS) in supporting women who have been recalled.¹⁶ As FPM affects more than 50,000 women a year in England alone, we were interested in women's views of the service they received, their thoughts on how they might be improved and how these compared with NHSBSP guidelines.

The research question is: What are the views of women with false-positive screening mammograms of the recall service they received, their ideas for service improvements and how do these compare with existing UK guidelines?

Method

We chose to use semi-structured interviews because they employ open-ended questions within the framework of an interview guide, facilitating a discourse where the interviewee is free to respond to the questions in a self-directed way. This approach produces responses that are rich in content and may contain interesting and relevant material beyond the scope of the initial question.

Participants and recruitment

Fifty two women with FPM were invited to participate and 21 were recruited (40%). Recruitment was through the National Institute for Health Research Primary Care Research Network, from three local General Practices or through the University of Exeter staff e-newsletter. Participants were purposively sampled for diversity of age, time from the false-positive experience and type of assessment procedure. We were also interested in the social mix of participants and used the UK Index of Multiple Deprivation (IMD), relating to their post code, as a means of assessing this. The IMD is derived from a national survey of income, employment, health, education, housing, crime and living environment. The scores are ranked from the least to the most deprived.¹⁷ Due to the specific focus of the research it was believed that about 20 interviews would be sufficient

1
2 for data saturation. If saturation did not occur further participants would be recruited.¹⁸

3
4 Participants gave informed consent. This study received ethical approval from the UK National
5
6 Research Ethics Service Committee South West, approval no. 11/SW/0263.

7 8 **Data collection**

9
10 Participants were interviewed by MB in quiet locations of their choosing, usually at home. The
11
12 interview guide (available from the authors) was used to gather key pieces of information. It
13
14 covered the experiences of being invited for screening, being recalled, the assessment clinic
15
16 and reflections of that experience. The guide was based on the results of the latest UK
17
18 systematic review¹ and reviewed by two women with FPM. The interviews were recorded and
19
20 transcribed.

21 22 **Data analysis**

23
24 The interviews were analysed with inductive qualitative content analysis.¹⁹ This approach was
25
26 chosen because we wanted to develop simple categories from the interviews to compare with
27
28 the items in the guidelines rather than explore the deeper meanings of what the participants
29
30 were saying. This process involved reading and listening to the interviews iteratively as relevant
31
32 content was open coded. The codes were reviewed across the manuscripts by a process of
33
34 constant comparison, being merged and dropped as the analysis progressed. The codes were
35
36 then gathered into categories of similar items.²⁰ These primary categories were subsumed into
37
38 higher order generic categories and so assisted the systematic description of the phenomena,
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40 thus identifying the key messages in the texts.²¹

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42 The results were validated using Yardley's principles of sensitivity to context, commitment and
43
44 rigour, transparency and coherence and impact and importance, including an audit trail and the
45
46 search for disconfirming cases²² and participant feedback. The analysis was supported by
47
48 Atlas.ti 6.2 software. The application of Yardley's principles can be seen in Table 1.

Table 1 Yardley's principles for quality in qualitative research

Principle	Qualities	Application to this study
Sensitivity to context	Theoretical; relevant literature; empirical data; socio-cultural setting; participant's perspective; ethical issues	Grounding the study in the context of what is already known from the systematic review. Then gathering the new interview data to refine that knowledge, searching for examples that confirm and refute what is already known. Being aware of and sensitive to the socio-cultural place of the participants and how this might influence the meanings they give to their experiences. Also understanding those experiences from their perspective; what they meant to them, but acknowledging the influence of the researcher and their role in the interview to what is said through their demeanour, verbal and non-verbal cues and an awareness of the potentially more powerful position of the researcher. Ethical approval was gained.
Commitment & rigour	In-depth engagement with topic; methodological competence; skill; thorough data collection; depth/breadth of analysis	This is achieved through becoming committed to the process of the research, the integrity of the interviews, being immersed in the data and taking a systematic, rigorous approach to the depth of analysis and interpretation of the interviews. Accounting for the variety and complexity of the data, including the search for disconfirming cases. The trustworthiness of the analysis was further established by respondent validation of the findings. The first eight interviews were coded independently by two researchers.
Transparency & coherence	Clarity and power of description/argument; transparent methods and data presentation; fit between theory and method; reflexivity	Providing a clear audit trail of the process of the study including data analysis. Telling a clear coherent story that encompasses the range of experience of the participants, illustrated by their own words and offering a reflective interpretation of the meaning of their accounts that acknowledges the role and influences of the researcher.
Impact & importance	Theoretical (enriching understanding); socio-cultural; practical (for community, policy makers, health workers)	Clearly describing the originality and importance of the findings and how they relate to previous research. Demonstrating their importance for policy makers, in this case the NHSBSP. Offering recommendations to improve services to reduce the psychological impact of false-positive mammograms.

Source: Yardley (2000)

Results

Participants' characteristics were found to fulfil the criteria of diversity. However, more detailed information about educational level, income and social group would aid interpretation of the results, see table 2. Table 2 Summary of participants' characteristics

Characteristics	No (%) women
Age (years)	
40-49	2 (10)
50-59	11 (52)
60-69	8 (38)
Marital status	
Married or cohabiting	19 (90)
Single, separated or widowed	2 (10)
Ethnicity	
White	21 (100)
Time since false-positive (years)	
≤ 1 year	4 (19)
2-4	7 (33)
5-7	8 (38)
8-10	1 (5)
11-13	1 (5)
Type of assessment procedure *	
Mammogram	16 (76)
Ultra-sound	12 (57)
Fine needle aspiration	1 (5)
Biopsy	4 (19)
Index of multiple deprivation %	
Unknown	4 (19)
0-9	1 (5)
10-19	0 (0)
20-29	2 (9)
30-39	3 (14)
40-49	2 (9)
50-59	4 (19)
60-69	4 (19)
70-79	1 (5)
* Many women had more than one assessment procedure	

The interview study showed that overall; almost all participants were satisfied with the mammography recall service they received. However, as they presented their stories a number

1
2 of issues were raised for service improvement. These issues concerned the recall letter, the
3 assessment clinic, choice and subsequent screening. Participants' quotes are identified by a
4 pseudonym. A diagram of the relationship between the categories can be found in figure 1.
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8 *Figure 1*
9

10 11 12 **Recall letter information**

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14 Most women were satisfied with the quality of the recall information they were sent. The
15 information was repeatedly described as reassuring. Many participants latched onto the positive
16 messages of the letter and remembered they had been told that most recalled women were
17 clear of breast cancer and they should not worry about being called back.
18
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20
21 *Anne: "The letter itself I think said something reassuring like... 'as a*
22 *precaution we're calling you back because, there's some anomaly, or*
23 *something like that, on the screen...' and then it says ... a large*
24 *proportion of women who are called for second screening don't actually*
25 *have anything, but it's just a precautionary thing, so I mean all the time*
26 *they're kind of trying to put forward the, sort of, positive angle on it."*
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34 However, there was considerable variation in what women were told to expect; some were
35 simply told they would have another mammogram and others were given an explanation about
36 the reason for their recall.
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40 *Clare: "In the letter, yeah, when I was recalled, they actually said ...*
41 *'we'd like you to come again, so we can take some further x-rays,' and*
42 *they've also said 'at this visit we may also carry out an ultrasound*
43 *examination', so I was aware of what was going to happen."*
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48 *Moira: "Only curious about what was going to happen, because you don't*
49 *get told beforehand. You know you're going to have a mammogram, but*
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1
2 *you don't know what else is going to happen... so you're not actually*
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4 *prepared."*

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6 Most of the women found the short time between the recall letter and their assessment
7
8 a positive thing as the time of anxiety was curtailed:
9

10 *Vicky: "When I got the letter, to be recalled was only a few days later, it*
11 *wasn't very long, which I'm really glad about. I couldn't have hung on two*
12 *or three, four weeks, it was a matter of days, it was very, very good, very*
13 *good."*

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18 Conversely, others interpreted the quick appointment as possibly indicating they had breast
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20 cancer. This understanding was rooted in a belief that the NHS only responds quickly to serious
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22 health problems:
23

24 *Grace: "There wasn't a lot of time, um, also between the letter - I think it*
25 *was about a week - between me getting the letter and actually going for*
26 *the, the next mammogram, which tends to sort of go 'oops,' anything that*
27 *comes you don't have much time in between means that it could be*
28 *serious."*

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34 Others who went alone found the waiting hardest as they lacked the support of a friend or
35
36 relative, but not everyone knew they could bring someone with them.
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38 *Wendy: "The only thing that I would have liked the letter to have said*
39 *was, 'if you want to bring a friend or relative, please do so.'"*

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41
42 These accounts indicate a variation in the amount and content of the information that
43
44 participants were given. They also show that the information needs of these women differed;
45
46 some were able to focus on the positive messages of the recall letter and were quite happy with
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48 simply being told that although they were being recalled everything was probably alright. Others
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50 reacted more strongly to the uncertainty that was introduced into their lives and wanted as much
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1
2 detail as possible about the reasons for their recall; the implications of this and what was going
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4 to happen at the assessment clinic.

6 **At the clinic**

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8 Waiting generally provoked anxiety; one participant said this could have been reduced by
9
10 information about how long the clinic appointment was likely to take:

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12 *Karen: "The waiting was the worst... the whole thing was bad, but the*
13 *worst bit was having to wait and not knowing how long I was waiting for."*

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17 Many participants reported that the clinic staff were the best thing about their experience. They
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19 were repeatedly described as Rachel: lovely, Moira: friendly, Ella: supportive, Zoe: kind, Anne:
20
21 professional and Vicky: very, very nice:

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23 *Zoe: "They were just very kind and I think, in a way, nurturing, because*
24 *they knew there was a possibility that you might have bad news. They*
25 *were just very protective of you; you just felt that they were handling it*
26 *really well, that they cared about you."*

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30 Clear explanations of the nature of the lesion were valued and helped to bring peace amid the
31
32 uncertainty.

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35 *Laura: "He was ever so...really thorough, I've got to say, really put my*
36 *mind at rest ... explained everything to me from start to finish, ... and did*
37 *it in a way...not condescending way, he explained it in a real clear and*
38 *concise manner, yeah, absolutely brilliant. I came out cock-a-hoop! "*

39
40
41
42 Although the majority had positive encounters, not all staff were sensitive and caring.

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45 *Chloe: "Um...yes, it didn't feel quite friendly, the staff in the unit*
46 *sometimes... it was a case of, 'oh, yeah,' it's just...like the queue... 'oh,*
47 *right, yeah, next."*

1
2 There was evidence of an unmet need for information and reassurance that could have been
3 given by a CNS being available, and known to be available, after as well as before assessment.
4
5 This unavailability resulted in some women leaving the clinic with uncertainty and unanswered
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7 questions.
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10 *Laura: "Don't think so [someone to talk to]. Didn't see... there was a*
11 *nurse, yes, there was a nurse on duty, but she was very busy and I could*
12 *see she was very busy."*
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16 *Grace: "I can't recall there being anybody around."*
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19 *Fran: "Well, I suppose somebody to talk...you know, perhaps if I'd gone*
20 *and talked to somebody, you know, about it all, perhaps I...it would have*
21 *eased me."*
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24 During their assessment the amount of information that participants wanted about their lesion
25 varied. A number of them would have had more confidence in their all-clear result if they had
26 been given a clearer explanation of what their lesion meant, including the risk of it becoming
27 malignant so they could make an informed choice about how to proceed.
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32 *Liz: "I would like the doctors to present me with the facts and say 'right,*
33 *you know...if it's 20 women out of...out of 100 with hyperplasia who, you*
34 *know, before they die, so they could be really old, get breast cancer,'*
35 *then I know that fact. If it's, um, you know, one in 10,000 up to the age of*
36 *80, then I probably would opt not to have any invasive surgery again."*
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42 One participant's experience highlighted the need for consistency between the messages from
43 the clinical staff and the literature they were given. The radiologist had told her that her cysts
44 could not become cancerous and then gave her a leaflet that said they could; this caused
45 considerable anxiety. This inconsistency led her to request an interim mammogram for
46 reassurance from her GP but was turned down:
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Moira: "And I now wait for my next mammogram...but that's the bit I don't like. You're told you have cysts, but you're not given a follow-up from there and you should...I'm assuming that they're quite satisfied that they [cysts] cannot become cancerous, even though the leaflet says they can. So I'm assuming they either haven't read the leaflet, or they simply don't believe the leaflet, I don't know which."

While the women waited at the clinic it was apparent that the location, layout and the waiting environment played a role in moderating their experience. Some participants had their initial screening in mobile units but then went to a hospital for their assessment.

Zoe: "Perhaps it seems more serious because you're aware it's a place where there are sick people... whereas if you go to the unit that goes to the car parks and whatever, you're in and out in ten minutes and you move on."

For some the physical layout of the clinic meant they were aware of what was happening to other women ahead of them in the queue; increasing their anxiety as they waited.

Grace: "We waited in a corridor ... we, sort of, waited in a long line, sat down in a long line ... we all waited together and we all went in and you'd see people go through the door, but they also came out that door and you knew if it was good or bad news for them, because obviously if it was good news they were looking happy, and if it was bad news they didn't go straight down the corridor, they went into another room. Um, and that would have been, I think, pretty traumatic for anybody, because you knew which way...but also for us, because we knew if it was good or bad news for them. I remember thinking, 'well, I'm going to have to go through that in a minute, but I don't want to witness their distress either.'"

1
2 On other occasions the participants could not see the woman diagnosed with breast cancer but
3
4 they could hear her crying, which similarly increased their anxiety.

5
6 *Wendy: "while I was waiting somebody else had...who had been recalled,*
7
8 *um, had been told that they, you know, they did have something and*
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10 *obviously they were distressed and, you know, people waiting, that was*
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12 *distressing as well...I could hear, I couldn't see her, but I could hear her*
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14 *and that was distressing, yes."*

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16 Although the staff received much praise, there was still a clear need for an opportunity to talk to
17
18 the CNS after the all-clear if questions remained about the reliability of the diagnosis and the
19
20 probability of it becoming malignant. The status of their lesion remained a concern at the next
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22 screening round for some women and information about if or how it had changed would have
23
24 been valued. The responses also showed that a sensitivity to the clinical environment is
25
26 necessary with due regard for privacy.

27 28 **Choice**

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30 Following their assessment a number of women were uncertain about the validity of their all-
31
32 clear diagnosis. They would have liked the option of a follow-up mammogram for reassurance.

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34 *Ella: "I thought 'can you just see me in a year's time, just tell me that in a*
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36 *year's time, it's all OK in a year's time?"*

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38 *Zoe: "I think the fact that you've been faced with the possibility that*
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40 *something didn't look quite right, you're not quite sure what it was that*
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42 *didn't look quite right, um, and maybe a screening a year down the line*
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44 *would have been, um, something to...to, you know, relieve any nerves."*

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46 There was also a request for mammograms as an alternative to the invasive investigation of
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48 lesions by biopsy that were thought to be almost certainly benign.

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50 *Liz: "Because they said, 'we're pretty sure it isn't anything, but we need*
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52 *to check if it is anything.' ...and so I suppose what I'm saying is that had*
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there been a little bit more, um, wait and see... I wouldn't have had more anxiety if they'd say, 'well, we'll do a mammogram again in three months or six months.'

This plea for choice was part of a desire to be more involved in the decision making process about how to proceed once a lesion was detected. Many of the women felt disempowered by the assessment process. They perceived themselves to be Ella: 'in the system' and passive partakers of assessment procedures.

Liz: "I think when you're in the middle of it, you just go along with whatever's being told... there could have been, uh, more consultation maybe at the beginning of things... so...and I'd have probably still have gone along with it, [surgery] 'cause I don't think I felt empowered not to."

Another woman would have appreciated the choice of receiving her biopsy results by post or over the phone, as this further wait prolonged anxiety.

Fran: "It was just waiting for those results... every day you look for the post... and when it's there you're frightened to open it up... it [phone call] probably would have been better, really, 'cause you're looking every day, aren't you, at the post and thinking, 'oh, my gosh.'"

It was clear that some women would have valued more choice in the assessment process. Choice was requested for follow-up mammograms to reduce uncertainty and anxiety about the outcome of assessment, 'watchful waiting' as an alternative to biopsy and test results over the phone rather than through the post.

At the next screening round

At their next routine screening, some participants' anxieties would have been dispelled if they were told about the status of the lesions previously discovered:

Jane: "I just got the all-clear letter, sort of thing, [after subsequent screening] and when I saw the doctor [GP] I said 'when I...you got the

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results of me mammogram did it say anything about the cyst?’ And he looked it back and he said, ‘no, it hasn’t said anything.’ And it would have been just nice to know whether I’ve still got it or not.”

Comparison of these results with NHSBSP guidelines

Many of our findings echo those of the research used to produce the NHSBSP 1998 guidelines and indicate that these have not been universally implemented.²³⁻²⁵ A comparison of the NHSBSP guidelines with our service improvement suggestions can be found in Table 3.

Table 3 Comparison of our suggestions with those of the 1998 and 2012 NHSBSP Guidelines

	NHSBSP Recall Guidelines (38) 1998	Bond et al. Service Suggestions 2014
Recall letter information	A clear reason for recall	A clear reason for recall
	Who can come with them	Who can come with them
	How long the appointment will take	How long the appointment will take
	Who they will see	Who they will see
	What tests will be carried out	What tests will be carried out
	Where they can get further information	Reassurance that a swift appointment does not imply the presence of cancer
	How to get to the assessment centre	
	How to change their appointment	
	When the results will be available	
	At the clinic	NHSBSP CSN Guidelines (29) 2012
Clear explanation of why the lesion is benign with any risk of change to malignancy		
Literature about the type of lesion		
One-way layout through the clinic		
Choice		The offer of a follow-up mammogram in a year for those needing reassurance of their ‘all clear’
		Choice between invasive assessment and ‘watchful waiting’ for lesions almost certainly benign

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**At the next
screening
round**

Choice of hearing biopsy results by post
or over the phone
Clarification of the status of the lesion
found to be a false-positive

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The following suggestions are offered to improve services.

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Recall letter

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Recall letters issued should be consistent and include the following items. The first five items remain unaddressed from the 1998 guidelines.

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This should include:

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1. The reason for recall
 2. Who can come with them
 3. How long the appointment is likely to take
 4. Who they will see
 5. What tests will be carried out
 6. Where to get further information
 7. The availability of a CNS to answer questions before and after assessment
 8. Reassurance that a swift appointment is normal and does not indicate there is anything wrong

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At the clinic

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9. A pre-assessment conversation with the CNS covering, the reason for recall, the assessment process including possible harms, and the availability of the CNS for a debrief after the assessment whatever the outcome
 10. From the Radiologist at diagnosis; sufficient time for a clear explanation of the type of lesion, risk of it becoming malignant, with clarity about uncertainty. If a biopsy is advised then discussion about pros and cons including the reliability of biopsy results and the choice of watchful waiting if the lesion is almost certainly benign

11. The availability of CNS post-assessment to clarify the diagnosis and provide reassurance, as a woman may not feel able to question the outcome with her GP. If the woman remains unsure of the validity of her all-clear a follow-up mammogram should be considered
12. Literature about the type of lesion found should be offered. This should agree with that from the Radiologist and give a phone number for further information
13. The choice of receiving biopsy results by phone or post
14. A one-way system through the clinic so that women do not have to have the outcome of their assessment witnessed or witness other's outcomes

At the next screening round

15. Women should be given an update about their lesion, whether it has gone, stayed the same or grown larger, with an explanation of the implications

Discussion

While overall participants were satisfied with the service they received, they raised a number of areas where it could be improved. Many of the items in the 1998 NHSBSP guidelines remained outstanding. Some women were still asking for more information in the recall letter about: the reason for their recall; who could come with them; how long the appointment might take; who they would see and what would happen to them. Some participants were also concerned that a swift appointment implied that they had cancer. At the assessment clinic a more explicit explanation of why their lesion was benign and the risk of it becoming malignant would have reduced anxiety, together with literature about their type of lesion. The women also expressed requests for more choice as some were left with doubt about the validity of the outcome of the assessment and would have appreciated an offer to have a follow-up mammogram in a year's time for reassurance and an update on the status of their lesion at their next screening round. Others felt powerless and in 'the system' when faced with a biopsy; an alternative of 'watchful waiting' for lesions that were almost certainly benign, would have been valued and empowering. A choice of having biopsy results by post or over the phone was also requested. Additionally

1
2 some participants would have valued an opportunity to see the CNS after assessment as well
3 as before. Finally, the layout of the clinic precipitated anxiety for some women while they were
4 waiting, as they were able to see and hear the distress of women who had been diagnosed with
5 cancer. There was no apparent link between participants' demographic characteristics and the
6 issues they raised.
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11 The strengths of this study are that it was rigorously conducted and provides current, in-depth
12 insights into the views of women, with false-positive mammograms of the assessment service
13 they received. Thus it provides valuable evidence of how these services may be improved so
14 that the anxiety associated with having false-positive mammograms may be reduced. The
15 influence of the researcher (MB) is acknowledged, both from her manner, verbal and non-verbal
16 cues during the interview; there is also the potential for social desirability effects²⁶. The analysis
17 has been through the filter of the researcher's particular understanding of the issues, including
18 being someone who has not had mammography. This will have influenced the way the
19 interviews were interpreted, due to the lack of first-hand experience. Qualitative research is
20 notably subjective and is open to the charge that the results lack generalisability. However,
21 although the study has a number of limitations and further research is needed to establish the
22 UK national picture, we believe these results are reasonably robust, transferable and relevant
23 for consideration in policy development. This is because the interview findings were validated
24 using Yardley's principles²² and by participant feedback of a lay summary of the results. The
25 study is limited by lack of demographic detail, the limited geographical area (Devon) and the
26 possible unreliability of the participants' memories as these events occurred between six
27 months and 12 years previously.
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43 Internationally, questionnaire studies have also found that overall women are satisfied with
44 mammography screening recall services.⁷⁻¹⁰ In the case of false-positive mammograms there is
45 a certain irony about this response as the women are satisfied with a service that has made a
46 mistake in recalling them and may have caused them unnecessary anxiety. Further evidence
47 comes from the Danish interview study by Lindberg et al. which found women with false-positive
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2 mammograms were grateful for the service which had brought their health into question and
3 caused them psychological distress.²⁷ Some studies found, in agreement with ours, that the
4 attitude of clinic staff as well as the quality of information and the physical environment affected
5 satisfaction.^{7,9,10,14} Our findings also agree with the results from the US qualitative study (2001),
6 that some participants thought the information they received was inadequate.¹²
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11 Although our research comes from a limited geographical area, and other regions of the UK
12 may have better service provision, it implies that there is still some way to go to provide women
13 who are recalled after breast cancer screening with a satisfactory service. There is a need for
14 consistency in the implementation of recommendations and a mechanism for ensuring this
15 occurs.
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20 21 **Service implications**

22 These suggestions will require additional resources; increased hours for the CNS and additional
23 mammography for those needing reassurance or choosing 'watchful waiting'. However, most of
24 the suggestions can be implemented at the lower cost of revising literature and giving clearer
25 explanations, which may mean that fewer women are left with uncertainty and request on-going
26 care.
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33 34 **Conclusion**

35 It is time the NHSBSP 1998 recall information guidelines were fully implemented. Additionally,
36 the further suggestions from this research, including extending the role of the CNS from the
37 2012 NHSBSP guidelines, should be considered.
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41 Further research is needed to establish whether the 1998 NHSBSP recommendations are in
42 place nationally and if the additional measures outlined in these service recommendations are
43 sought by women throughout the UK.
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50 not-for-profit sectors.
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Contribution of authors: MB obtained ethical approval, obtained NIHR adoption, recruited participants with the support of the SW Primary Care Research Network, conducted and analysed the interviews, obtained respondent feedback, undertook the comparison with UK guidelines and formulated service improvement suggestions, wrote and edited the research paper. RG contributed to the design of the study, advised on the qualitative aspects and commented on the draft paper. CH contributed to the design of the study, advised on the health services aspects and commented on the draft paper.

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Figure 1 Category development

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6 **Improving screening recall services for women with false-positive**
7 **mammograms: a comparison of qualitative evidence with UK guidelines**
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Improving screening recall services for women with false-positive mammograms: a comparison of qualitative evidence with UK guidelines

Abstract

Objectives: To gain an understanding of the views of women with false-positive screening mammograms of screening recall services, their ideas for service improvements and how these compare with current UK guidelines.

Methods: Inductive qualitative content analysis of semi-structured interviews of 21 women who had false-positive screening mammograms. These were then compared with UK NHS guidelines.

Results: Participants' concerns about mammography screening recall services focused on issues of communication and choice. Many of the issues raised indicated that the 1998 National Health Service Breast Screening Programme guidelines on improving the quality of written information sent to women who are recalled, had not been fully implemented. This included being told a clear reason for recall, who may attend with them, the length of appointment, who they will see and what tests will be carried out. Additionally women voiced a need for: reassurance that a swift appointment did not imply they had cancer; choice about invasive assessment or watchful waiting; the offer of a follow-up mammogram for those uncertain about the validity of their all-clear and an extension of the role of the clinical nurse specialist, outlined in the 2012 NHSBSP guidelines, to include availability at the clinic after the all-clear for women with false-positive mammograms.

Conclusions: It is time the NHSBSP 1998 recall information guidelines were fully implemented. Additionally, the further suggestions from this research, including extending the role of the clinical nurses from the 2012 NHSBSP guidelines, should be considered. These actions have the potential to reduce the anxiety of being recalled.

Strengths and limitations of this study

- This research has been rigorously conducted by an independent, academic research team
- The suggestions for service improvements are based on empirical research
- The evidence provides current insights into women's view of mammography screening services for recalled women
- ~~The study is limited by the small sample size~~
- The study may be limited by the ability of some participants to recall distant experiences
- More detailed information about the demographic characteristics of participants would aid interpretation of the results
- ~~The limited geographical location may reduce the generalizability of the findings~~

Introduction

Screening for breast cancer by mammography has been part of many women's routine healthcare for more than 25 years. Much research has been carried out into the anxiety produced by having a false-positive mammogram (FPM).¹⁻⁶ However, the quality of mammography screening services for women who have been recalled has been less thoroughly investigated. Internationally, questionnaire studies have found that overall women are satisfied with the service they receive.⁷⁻¹⁰ Additionally, some studies found that the attitude of clinic staff as well as the quality of information and the physical environment affected satisfaction.^{7,9-12} Furthermore, a Finnish observational study that investigated the information needs of women assessed by biopsy, found that women wanted information and reassurance throughout and after their assessment.¹¹ However, a Canadian RCT failed to find an impact on satisfaction from additional information.¹³ The above research gives an opaque picture of the information and support needs of women recalled following screening.

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5 The situation in the UK is particularly unclear as our searches found only one UK study of
6 service satisfaction of women with a FPM. This was by Smith et al. who found that clinic staffs'
7 attitudes, quality of information and the physical environment had an impact on satisfaction.¹⁴
8
9 However, this survey is more than 20 years old and it is 16 years since the NHS Breast
10 Screening Programme (NHSBSP) produced guidelines about the information needs of women
11 recalled following mammography screening.¹⁵ More recently NHSBSP Guidelines (2012)
12 highlight the important role of the clinical nurse specialist (CNS) in supporting women who have
13 been recalled.¹⁶ As FPM affects more than 50,000 women a year in England alone, we were
14 interested in women's views of the service they received, their thoughts on how they might be
15 improved and how these compared with NHSBSP guidelines.
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22 ~~It is hypothesised that the role that adequate information and personal support play in~~
23 ~~increasing service satisfaction, is due to their ability to reduce uncertainty and thus anxiety. For~~
24 ~~people with acute and chronic illness, uncertainty is acknowledged to be the greatest cause of~~
25 ~~stress.^{17,18} It is likely that this is also the case with recall following screening. As Warren says, 'a~~
26 ~~woman who receives a recall letter experiences temporarily the diagnosis of cancer'.¹⁹~~
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31 The research question is: What are the views of women with false-positive screening
32 mammograms of the recall service they received, their ideas for service improvements and how
33 do these compare with existing UK guidelines?
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36 Method

37 We chose to use semi-structured interviews because they employ open-ended questions within
38 the framework of an interview guide, facilitating a discourse where the interviewee is free to
39 respond to the questions in a self-directed way. This approach produces responses that are rich
40 in content and may contain interesting and relevant material beyond the scope of the initial
41 question.
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Participants and recruitment

Fifty two women with FPM were invited to participate and 21 were recruited (40%). Recruitment was through the National Institute for Health Research Primary Care Research Network, from three local General Practices or through the University of Exeter staff e-newsletter. Participants were purposively sampled for diversity of age, time from the false-positive experience and type of assessment procedure. We were also interested in the social mix of participants and used the UK Index of Multiple Deprivation (IMD), relating to their post code, as a means of assessing this. The IMD is derived from a national survey of income, employment, health, education, housing, crime and living environment. The scores are ranked from the least to the most deprived.¹⁷ Due to the specific focus of the research it was believed that about 20 interviews would be sufficient for data saturation. If saturation did not occur further participants would be recruited.^{18²⁰} Participants gave informed consent. This study received ethical approval from the UK National Research Ethics Service Committee South West, approval no. 11/SW/0263.

Data collection

Participants were interviewed by MB in quiet locations of their choosing, usually at home. The interview guide (available from the authors) was used to gather key pieces of information. It covered the experiences of being invited for screening, being recalled, the assessment clinic and reflections of that experience. The guide was based on the results of the latest UK systematic review¹ and reviewed by two women with FPM. The interviews were recorded and transcribed.

Data analysis

The interviews were analysed with inductive qualitative content analysis.^{19²⁴} This approach was chosen because we wanted to develop simple categories from the interviews to compare with the items in the guidelines rather than explore the deeper meanings of what the participants were saying. This process involved reading and listening to the interviews iteratively as relevant content was open coded. The codes were reviewed across the manuscripts by a process of constant comparison, being merged and dropped as the analysis progressed. The codes were

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then gathered into categories of similar items.²⁰²² These primary categories were subsumed into higher order generic categories and so assisted the systematic description of the phenomena,

thus identifying the key messages in the texts.²¹²³

The results were validated using Yardley's principles of sensitivity to context, commitment and rigour, transparency and coherence and impact and importance, including an audit trail and the search for disconfirming cases.²²²⁴ and participant feedback. The analysis was supported by Atlas.ti 6.2 software. The application of Yardley's principles can be seen in Table 1.

Table 1 Yardley's principles for quality in qualitative research

Yardley's Principles for quality in qualitative research		Application to this study
Principle	Qualities	
Sensitivity to context	Theoretical; relevant literature; empirical data; socio-cultural setting; participant's perspective; ethical issues	Grounding the study in the context of what is already known from the systematic review. Then gathering the new interview data to refine that knowledge, searching for examples that confirm and refute what is already known. Being aware of and sensitive to the socio-cultural place of the participants and how this might influence the meanings they give to their experiences. Also understanding those experiences from their perspective; what they meant to them, but acknowledging the influence of the researcher and their role in the interview to what is said through their demeanour, verbal and non-verbal cues and an awareness of the potentially more powerful position of the researcher. Ethical approval was gained.
Commitment & rigour	In-depth engagement with topic; methodological competence; skill; thorough data collection; depth/breadth of analysis	This is achieved through becoming committed to the process of the research, the integrity of the interviews, being emersed in the data and taking a systematic, rigorous approach to the depth of analysis and interpretation of the interviews. Accounting for the variety and complexity of the data, including the search for disconfirming cases. The trustworthiness of the analysis was further established by respondent validation of the findings. The first eight interviews were coded independently by two researchers.
Transparency & coherence	Clarity and power of description/argument; transparent methods and data presentation; fit between theory and method; reflexivity	Providing a clear audit trail of the process of the study including data analysis. Telling a clear coherent story that encompasses the range of experience of the participants, illustrated by their own words and offering a reflective interpretation of the meaning of their accounts that acknowledges the role and influences of the researcher.
Impact & importance	Theoretical (enriching understanding); socio-cultural; practical (for community, policy makers, health workers)	Clearly describing the originality and importance of the findings and how they relate to previous research. Demonstrating their importance for policy makers, in this case the NHSBSP. Offering recommendations to improve services to reduce the psychological impact of false-positive mammograms.
Source: Yardley (2000)		

Results

Participants' characteristics were found to fulfil the criteria of diversity. However, more detailed information about educational level, income and social group would aid interpretation of the results, see table 2.

Table 2 Summary of participants' characteristics

Characteristics	No (%) women
Age (years)	
40-49	2 (10)
50-59	11 (52)
60-69	8 (38)
Marital status	
Married or cohabiting	19 (90)
Single, separated or widowed	2 (10)
Ethnicity	
White	21 (100)
Time since false-positive (years)	
≤ 1 year	4 (19)
2-4	7 (33)
5-7	8 (38)
8-10	1 (5)
11-13	1 (5)
Type of assessment procedure*	
Mammogram	16 (76)
Ultra-sound	12 (57)
Fine needle aspiration	1 (5)
Biopsy	4 (19)
Index of multiple deprivation %	
Unknown	4 (19)
0-9	1 (5)
10-19	0 (0)
20-29	2 (9)
30-39	3 (14)
40-49	2 (9)
50-59	4 (19)
60-69	4 (19)
70-79	1 (5)

* Many women had more than one assessment procedure

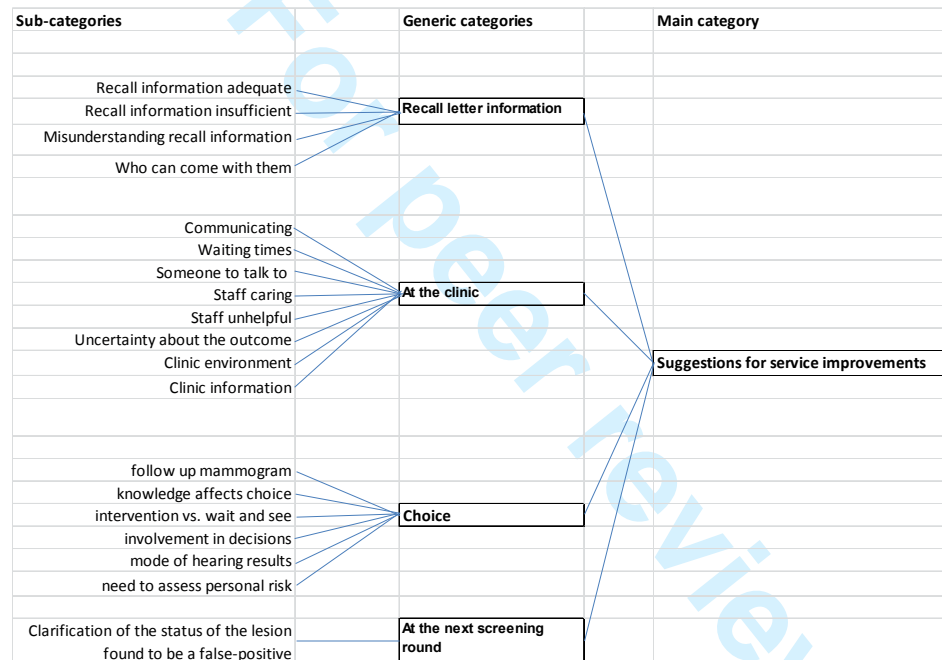
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The interview study showed that overall; almost all participants were satisfied with the mammography recall service they received. However, as they presented their stories a number of issues were raised for service improvement. These issues concerned the recall letter, the assessment clinic, choice and subsequent screening. Participants' quotes are identified by a pseudonym. A diagram of the relationship between the categories can be found in figure 1.

Figure 1



Recall letter information

Most women were satisfied with the quality of the recall information they were sent. The information was repeatedly described as reassuring. Many participants latched onto the positive messages of the letter and remembered they had been told that most recalled women were clear of breast cancer and they should not worry about being called back.

Anne: "The letter itself I think said something reassuring like... 'as a precaution we're calling you back because, there's some anomaly, or

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6 *something like that, on the screen...’ and then it says ... a large*
7 *proportion of women who are called for second screening don’t actually*
8 *have anything, but it’s just a precautionary thing, so I mean all the time*
9 *they’re kind of trying to put forward the, sort of, positive angle on it.”*
10
11

12 However, there was considerable variation in what women were told to expect; some were
13 simply told they would have another mammogram and others were given an explanation about
14 the reason for their recall.
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18 *Clare: “In the letter, yeah, when I was recalled, they actually said ...*
19 *‘we’d like you to come again, so we can take some further x-rays,’ and*
20 *they’ve also said ‘at this visit we may also carry out an ultrasound*
21 *examination’, so I was aware of what was going to happen.”*
22
23

24 *Moira: “Only curious about what was going to happen, because you don’t*
25 *get told beforehand. You know you’re going to have a mammogram, but*
26 *you don’t know what else is going to happen... so you’re not actually*
27 *prepared.”*
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31 Most of the women found the short time between the recall letter and their assessment
32 a positive thing as the time of anxiety was curtailed:
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35 *Vicky: “When I got the letter, to be recalled was only a few days later, it*
36 *wasn’t very long, which I’m really glad about. I couldn’t have hung on two*
37 *or three, four weeks, it was a matter of days, it was very, very good, very*
38 *good.”*
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42 Conversely, others interpreted the quick appointment as possibly indicating they had breast
43 cancer. This understanding was rooted in a belief that the NHS only responds quickly to serious
44 health problems:
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47 *Grace: “There wasn’t a lot of time, um, also between the letter - I think it*
48 *was about a week - between me getting the letter and actually going for*
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5 *the, the next mammogram, which tends to sort of go 'oops,' anything that*
6 *comes you don't have much time in between means that it could be*
7 *serious."*
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11 Others who went alone found the waiting hardest as they lacked the support of a friend or
12 relative, but not everyone knew they could bring someone with them.
13

14 *Wendy: "The only thing that I would have liked the letter to have said*
15 *was, 'if you want to bring a friend or relative, please do so."*
16
17

18 These accounts indicate a variation in the amount and content of the information that
19 participants were given. They also show that the information needs of these women differed;
20 some were able to focus on the positive messages of the recall letter and were quite happy with
21 simply being told that although they were being recalled everything was probably alright. Others
22 reacted more strongly to the uncertainty that was introduced into their lives and wanted as much
23 detail as possible about the reasons for their recall; the implications of this and what was going
24 to happen at the assessment clinic.
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30 **At the clinic**

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32 Waiting generally provoked anxiety; one participant said this could have been reduced by
33 information about how long the clinic appointment was likely to take:
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35 *Karen: "The waiting was the worst... the whole thing was bad, but the*
36 *worst bit was having to wait and not knowing how long I was waiting for."*
37
38

39 Many participants reported that the clinic staff were the best thing about their experience. They
40 were repeatedly described as Rachel: lovely, Moira: friendly, Ella: supportive, Zoe: kind, Anne:
41 professional and Vicky: very, very nice:
42
43

44 *Zoe: "They were just very kind and I think, in a way, nurturing, because*
45 *they knew there was a possibility that you might have bad news. They*
46 *were just very protective of you; you just felt that they were handling it*
47 *really well, that they cared about you."*
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Clear explanations of the nature of the lesion were valued and helped to bring peace amid the uncertainty.

Laura: "He was ever so...really thorough, I've got to say, really put my mind at rest ... explained everything to me from start to finish, ... and did it in a way...not condescending way, he explained it in a real clear and concise manner, yeah, absolutely brilliant. I came out cock-a-hoop! "

Although the majority had positive encounters, not all staff were sensitive and caring.

Chloe: "Um...yes, it didn't feel quite friendly, the staff in the unit sometimes... it was a case of, 'oh, yeah,' it's just...like the queue... 'oh, right, yeah, next."

There was evidence of an unmet need for information and reassurance that could have been given by a CNS being available, and known to be available, after as well as before assessment.

This unavailability resulted in some women leaving the clinic with uncertainty and unanswered questions.

Laura: "Don't think so [someone to talk to]. Didn't see... there was a nurse, yes, there was a nurse on duty, but she was very busy and I could see she was very busy."

Grace: "I can't recall there being anybody around."

Fran: "Well, I suppose somebody to talk...you know, perhaps if I'd gone and talked to somebody, you know, about it all, perhaps I...it would have eased me."

During their assessment the amount of information that participants wanted about their lesion varied. A number of them would have had more confidence in their all-clear result if they had been given a clearer explanation of what their lesion meant, including the risk of it becoming malignant so they could make an informed choice about how to proceed.

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5 *Liz: "I would like the doctors to present me with the facts and say 'right,*
6 *you know...if it's 20 women out of...out of 100 with hyperplasia who, you*
7 *know, before they die, so they could be really old, get breast cancer,'*
8 *then I know that fact. If it's, um, you know, one in 10,000 up to the age of*
9 *80, then I probably would opt not to have any invasive surgery again."*

14 One participant's experience highlighted the need for consistency between the messages from
15 the clinical staff and the literature they were given. The radiologist had told her that her cysts
16 could not become cancerous and then gave her a leaflet that said they could; this caused
17 considerable anxiety. This inconsistency led her to request an interim mammogram for
18 reassurance from her GP but was turned down:
19

22 *Moira: "And I now wait for my next mammogram...but that's the bit I don't*
23 *like. You're told you have cysts, but you're not given a follow-up from*
24 *there and you should...I'm assuming that they're quite satisfied that they*
25 *[cysts] cannot become cancerous, even though the leaflet says they can.*
26 *So I'm assuming they either haven't read the leaflet, or they simply don't*
27 *believe the leaflet, I don't know which."*

33 While the women waited at the clinic it was apparent that the location, layout and the waiting
34 environment played a role in moderating their experience. Some participants had their initial
35 screening in mobile units but then went to a hospital for their assessment.
36

38 *Zoe: "Perhaps it seems more serious because you're aware it's a place*
39 *where there are sick people... whereas if you go to the unit that goes to*
40 *the car parks and whatever, you're in and out in ten minutes and you*
41 *move on."*

45 For some the physical layout of the clinic meant they were aware of what was happening to
46 other women ahead of them in the queue; increasing their anxiety as they waited.
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5 Grace: "We waited in a corridor ... we, sort of, waited in a long line, sat
6 down in a long line ... we all waited together and we all went in and you'd
7 see people go through the door, but they also came out that door and
8 you knew if it was good or bad news for them, because obviously if it was
9 good news they were looking happy, and if it was bad news they didn't go
10 straight down the corridor, they went into another room. Um, and that
11 would have been, I think, pretty traumatic for anybody, because you
12 knew which way...but also for us, because we knew if it was good or bad
13 news for them. I remember thinking, 'well, I'm going to have to go
14 through that in a minute, but I don't want to witness their distress either.'"
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22 On other occasions the participants could not see the woman diagnosed with breast cancer but
23 they could hear her crying, which similarly increased their anxiety.
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26 Wendy: "while I was waiting somebody else had...who had been recalled,
27 um, had been told that they, you know, they did have something and
28 obviously they were distressed and, you know, people waiting, that was
29 distressing as well...I could hear, I couldn't see her, but I could hear her
30 and that was distressing, yes."
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34 Although the staff received much praise, there was still a clear need for an opportunity to talk to
35 the CNS after the all-clear if questions remained about the reliability of the diagnosis and the
36 probability of it becoming malignant. The status of their lesion remained a concern at the next
37 screening round for some women and information about if or how it had changed would have
38 been valued. The responses also showed that a sensitivity to the clinical environment is
39 necessary with due regard for privacy.
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45 Choice

46 Following their assessment a number of women were uncertain about the validity of their all-
47 clear diagnosis. They would have liked the option of a follow-up mammogram for reassurance.
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5 Ella: "I thought 'can you just see me in a year's time, just tell me that in a
6 year's time, it's all OK in a year's time?"
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9 Zoe: "I think the fact that you've been faced with the possibility that
10 something didn't look quite right, you're not quite sure what it was that
11 didn't look quite right, um, and maybe a screening a year down the line
12 would have been, um, something to...to, you know, relieve any nerves."
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16 There was also a request for mammograms as an alternative to the invasive investigation of
17 lesions by biopsy that were thought to be almost certainly benign.
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20 Liz: "Because they said, 'we're pretty sure it isn't anything, but we need
21 to check if it is anything.' ...and so I suppose what I'm saying is that had
22 there been a little bit more, um, wait and see... I wouldn't have had more
23 anxiety if they'd say, 'well, we'll do a mammogram again in three months
24 or six months.'
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28 This plea for choice was part of a desire to be more involved in the decision making process
29 about how to proceed once a lesion was detected. Many of the women felt disempowered by
30 the assessment process. They perceived themselves to be Ella: 'in the system' and passive
31 partakers of assessment procedures.
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35 Liz: "I think when you're in the middle of it, you just go along with
36 whatever's being told... there could have been, uh, more consultation
37 maybe at the beginning of things... so...and I'd have probably still have
38 gone along with it, [surgery] 'cause I don't think I felt empowered not to."
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42 Another woman would have appreciated the choice of receiving her biopsy results by post or
43 over the phone, as this further wait prolonged anxiety.
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46 Fran: "It was just waiting for those results... every day you look for the
47 post... and when it's there you're frightened to open it up... it [phone call]
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probably would have been better, really, 'cause you're looking every day, aren't you, at the post and thinking, 'oh, my gosh.'"

It was clear that some women would have valued more choice in the assessment process. Choice was requested for follow-up mammograms to reduce uncertainty and anxiety about the outcome of assessment, 'watchful waiting' as an alternative to biopsy and test results over the phone rather than through the post.

At the next screening round

At their next routine screening, some participants' anxieties would have been dispelled if they were told about the status of the lesions previously discovered:

Jane: "I just got the all-clear letter, sort of thing, [after subsequent screening] and when I saw the doctor [GP] I said 'when I...you got the results of me mammogram did it say anything about the cyst?' And he looked it back and he said, 'no, it hasn't said anything.' And it would have been just nice to know whether I've still got it or not."

Comparison of these results with NHSBSP guidelines

Many of our findings echo those of the research used to produce the NHSBSP 1998 guidelines and indicate that these have not been universally implemented. ^{23-25,26-27} A comparison of the NHSBSP guidelines with our service improvement suggestions can be found in Table 3.

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Table 3 Comparison of our suggestions with those of the 1998 and 2012 NHSBSP Guidelines

	NHSBSP Recall Guidelines (38) 1998	Bond et al. Service Suggestions 2014
Recall letter information	A clear reason for recall	A clear reason for recall
	Who can come with them	Who can come with them
	How long the appointment will take	How long the appointment will take
	Who they will see	Who they will see
	What tests will be carried out	What tests will be carried out
	Where they can get further information	Reassurance that a swift appointment does not imply the presence of cancer
	How to get to the assessment centre	

	How to change their appointment	
	When the results will be available	
At the clinic	NHSBSP CSN Guidelines (29) 2012	
	Availability of a CSN before assessment	Availability of a CSN before and after assessment
		Clear explanation of why the lesion is benign with any risk of change to malignancy
		Literature about the type of lesion
		One-way layout through the clinic
Choice		The offer of a follow-up mammogram in a year for those needing reassurance of their 'all clear'
		Choice between invasive assessment and 'watchful waiting' for lesions almost certainly benign
		Choice of hearing biopsy results by post or over the phone
At the next screening round		Clarification of the status of the lesion found to be a false-positive

The following suggestions are offered to improve services.

Recall letter

Recall letters issued should be consistent and include the following items. The first five items remain unaddressed from the 1998 guidelines.

This should include:

1. The reason for recall
2. Who can come with them
3. How long the appointment is likely to take
4. Who they will see
5. What tests will be carried out
6. Where to get further information

7. The availability of a CNS to answer questions before and after assessment
8. Reassurance that a swift appointment is normal and does not indicate there is anything wrong

At the clinic

9. A pre-assessment conversation with the CNS covering, the reason for recall, the assessment process including possible harms, and the availability of the CNS for a debrief after the assessment whatever the outcome
10. From the Radiologist at diagnosis; sufficient time for a clear explanation of the type of lesion, risk of it becoming malignant, with clarity about uncertainty. If a biopsy is advised then discussion about pros and cons including the reliability of biopsy results and the choice of watchful waiting if the lesion is almost certainly benign
11. The availability of CNS post-assessment to clarify the diagnosis and provide reassurance, as a woman may not feel able to question the outcome with her GP. If the woman remains unsure of the validity of her all-clear a follow-up mammogram should be considered
12. Literature about the type of lesion found should be offered. This should agree with that from the Radiologist and give a phone number for further information
13. The choice of receiving biopsy results by phone or post
14. A one-way system through the clinic so that women do not have to have the outcome of their assessment witnessed or witness other's outcomes

At the next screening round

15. Women should be given an update about their lesion, whether it has gone, stayed the same or grown larger, with an explanation of the implications

Discussion

While overall participants were satisfied with the service they received, they raised a number of areas where it could be improved. Many of the items in the 1998 NHSBSP guidelines remained

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5 outstanding. Some women were still asking for more information in the recall letter about: the
6 reason for their recall; who could come with them; how long the appointment might take; who
7 they would see and what would happen to them. Some participants were also concerned that a
8 swift appointment implied that they had cancer. At the assessment clinic a more explicit
9 explanation of why their lesion was benign and the risk of it becoming malignant would have
10 reduced anxiety, together with literature about their type of lesion. The women also expressed
11 requests for more choice as some were left with doubt about the validity of the outcome of the
12 assessment and would have appreciated an offer to have a follow-up mammogram in a year's
13 time for reassurance and an update on the status of their lesion at their next screening round.
14 Others felt powerless and in 'the system' when faced with a biopsy; an alternative of 'watchful
15 waiting' for lesions that were almost certainly benign, would have been valued and empowering.
16 A choice of having biopsy results by post or over the phone was also requested. Additionally
17 some participants would have valued an opportunity to see the CNS after assessment as well
18 as before. Finally, the layout of the clinic precipitated anxiety for some women while they were
19 waiting, as they were able to see and hear the distress of women who had been diagnosed with
20 cancer. There was no apparent link between participants' demographic characteristics and the
21 issues they raised.
22

23
24 The strengths of this study are that it was rigorously conducted and provides current, in-depth
25 insights into the views of women, with false-positive mammograms of the assessment service
26 they received. Thus it provides valuable evidence of how these services may be improved so
27 that the anxiety associated with having false-positive mammograms may be reduced. The
28 influence of the researcher (MB) is acknowledged, both from her manner, verbal and non-verbal
29 cues during the interview; there is also the potential for social desirability effects²⁶²⁸. The
30 analysis has been through the filter of the researcher's particular understanding of the issues,
31 including being someone who has not had mammography. This will have influenced the way the
32 interviews were interpreted, due to the lack of first-hand experience. Qualitative research is
33 notably subjective and is open to the charge that the results lack generalisability. However,
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6 although the study has a number of limitations and further research is needed to establish the
7 UK national picture, we believe these results are reasonably robust, transferable and relevant ~~to~~
8 for consideration in policy development. This is because ~~as~~ the interview findings were validated
9 using Yardley's principles^{22,24} and by participant feedback ~~on~~ of a lay summary of the results.
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11 The study is limited by ~~the small sample~~ lack of demographic detail, the limited geographical
12 area (Devon) and the possible unreliability of the participants' memories as these events
13 occurred between six months and 12 years previously.
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17 Internationally, questionnaire studies have also found that overall women are satisfied with
18 mammography screening recall services.⁷⁻¹⁰ In the case of false-positive mammograms there is
19 a certain irony about this response as the women are satisfied with a service that has made a
20 mistake in recalling them and may have caused them unnecessary anxiety. Further evidence
21 comes from the Danish interview study by Lindberg et al. which found women with false-positive
22 mammograms were grateful for the service which had brought their health into question and
23 caused them psychological distress.²⁷ ~~However, s~~Some studies found, in agreement with ours,
24 that the attitude of clinic staff as well as the quality of information and the physical environment
25 affected satisfaction.^{7,9;10;14} Our findings also agree with the results from the US qualitative study
26 (2001), that some participants thought the information they received was inadequate.¹²
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29 Although our research comes from a limited geographical area, and other regions of the UK
30 may have better service provision, it implies that there is still some way to go to provide women
31 who are recalled after breast cancer screening with a satisfactory service. There is a need for
32 consistency in the implementation of recommendations and a mechanism for ensuring this
33 occurs.
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35 Service implications

36 These suggestions will require additional resources; increased hours for the CNS and additional
37 mammography for those needing reassurance or choosing 'watchful waiting'. However, most of
38 the suggestions can be implemented at the lower cost of revising literature and giving clearer
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5 explanations, which may mean that fewer women are left with uncertainty and request on-going
6 care.
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8 9 **Conclusion**

10 It is time the NHSBSP 1998 recall information guidelines were fully implemented. Additionally,
11 the further suggestions from this research, including extending the role of the CNS from the
12 2012 NHSBSP guidelines, should be considered.
13

14 Further research is needed to establish whether the 1998 NHSBSP recommendations are in
15 place nationally and if the additional measures outlined in these service recommendations are
16 sought by women throughout the UK.
17

18 Competing interests: None declared
19

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25 analysed the interviews, obtained respondent feedback, undertook the comparison with UK
26 guidelines and formulated service improvement suggestions, wrote and edited the research
27 paper. RG contributed to the design of the study, advised on the qualitative aspects and
28 commented on the draft paper. CH contributed to the design of the study, advised on the health
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30

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5 publication. The views expressed in this publication are those of the authors and not necessarily
6 those of the NHS, the NIHR or the Department of Health in England.
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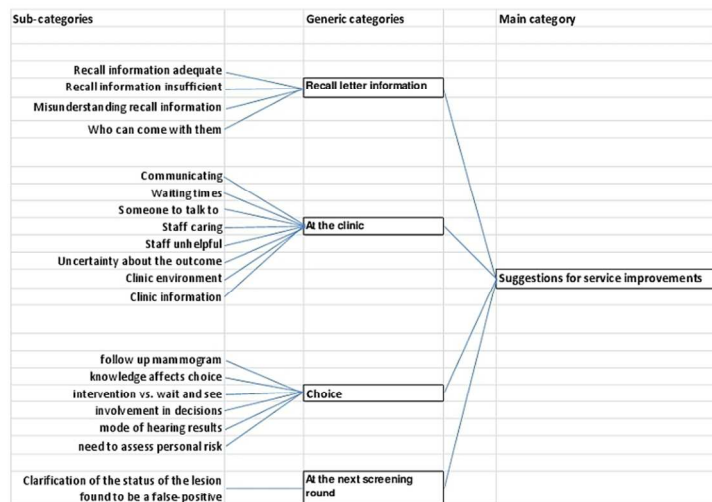
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Figure 1 Category development



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Improving screening recall services for women with false-positive mammograms: a comparison of qualitative evidence with UK guidelines

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3 **Improving screening recall services for women with false-positive**
4 **mammograms: a comparison of qualitative evidence with UK guidelines**
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Improving screening recall services for women with false-positive mammograms: a comparison of qualitative evidence with UK guidelines

Abstract

Objectives: To gain an understanding of the views of women with false-positive screening mammograms of screening recall services, their ideas for service improvements and how these compare with current UK guidelines.

Methods: Inductive qualitative content analysis of semi-structured interviews of 21 women who had false-positive screening mammograms. These were then compared with UK NHS guidelines.

Results: Participants' concerns about mammography screening recall services focused on issues of communication and choice. Many of the issues raised indicated that the 1998 National Health Service Breast Screening Programme guidelines on improving the quality of written information sent to women who are recalled, had not been fully implemented. This included being told a clear reason for recall, who may attend with them, the length of appointment, who they will see and what tests will be carried out. Additionally women voiced a need for: reassurance that a swift appointment did not imply they had cancer; choice about invasive assessment or watchful waiting; the offer of a follow-up mammogram for those uncertain about the validity of their all-clear and an extension of the role of the clinical nurse specialist, outlined in the 2012 NHSBSP guidelines, to include availability at the clinic after the all-clear for women with false-positive mammograms.

Conclusions: It is time the NHSBSP 1998 recall information guidelines were fully implemented. Additionally, the further suggestions from this research, including extending the role of the clinical nurses from the 2012 NHSBSP guidelines, should be considered. These actions have the potential to reduce the anxiety of being recalled.

Strengths and limitations of this study

- This research has been rigorously conducted by an independent, academic research team
- The suggestions for service improvements are based on empirical research
- The evidence provides current insights into women's view of mammography screening services for recalled women
- The study may be limited by the ability of some participants to recall distant experiences
- More detailed information about the demographic characteristics of participants would aid interpretation of the results

Introduction

Screening for breast cancer by mammography has been part of many women's routine healthcare for more than 25 years. Much research has been carried out into the anxiety produced by having a false-positive mammogram (FPM).¹⁻⁶ However, the quality of mammography screening services for women who have been recalled has been less thoroughly investigated. Internationally, questionnaire studies have found that overall women are satisfied with the service they receive.⁷⁻¹⁰ Additionally, some studies found that the attitude of clinic staff as well as the quality of information and the physical environment affected satisfaction.^{7,9-12} Furthermore, a Finnish observational study that investigated the information needs of women assessed by biopsy, found that women wanted information and reassurance throughout and after their assessment.¹¹ However, a Canadian RCT failed to find an impact on satisfaction from additional information.¹³ The above research gives an opaque picture of the information and support needs of women recalled following screening.

The situation in the UK is particularly unclear as our searches found only one UK study of service satisfaction of women with a FPM. This was by Smith et al. who found that clinic staffs' attitudes, quality of information and the physical environment had an impact on satisfaction.¹⁴

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However, this survey is more than 20 years old and it is 16 years since the NHS Breast Screening Programme (NHSBSP) produced guidelines about the information needs of women recalled following mammography screening.¹⁵ More recently NHSBSP Guidelines (2012) highlight the important role of the clinical nurse specialist (CNS) in supporting women who have been recalled.¹⁶ As FPM affects more than 50,000 women a year in England alone, we were interested in women's views of the service they received, their thoughts on how they might be improved and how these compared with NHSBSP guidelines.

The research question is: What are the views of women with false-positive screening mammograms of the recall service they received, their ideas for service improvements and how do these compare with existing UK guidelines?

Method

We chose to use semi-structured interviews because they employ open-ended questions within the framework of an interview guide, facilitating a discourse where the interviewee is free to respond to the questions in a self-directed way. This approach produces responses that are rich in content and may contain interesting and relevant material beyond the scope of the initial question.

Participants and recruitment

Fifty two women with FPM were invited to participate and 21 were recruited (40%). Recruitment was through the National Institute for Health Research Primary Care Research Network, from three local General Practices or through the University of Exeter staff e-newsletter. Participants were purposively sampled for diversity of age, time from the false-positive experience and type of assessment procedure. We were also interested in the social mix of participants and used the UK Index of Multiple Deprivation (IMD), relating to their post code, as a means of assessing this. The IMD is derived from a national survey of income, employment, health, education, housing, crime and living environment. The scores are ranked from the least to the most deprived.¹⁷ Due to the specific focus of the research it was believed that about 20 interviews would be sufficient

1
2 for data saturation. If saturation did not occur further participants would be recruited.¹⁸

3
4 Participants gave informed consent. This study received ethical approval from the UK National
5
6 Research Ethics Service Committee South West, approval no. 11/SW/0263.

7 8 **Data collection**

9
10 Participants were interviewed by MB in quiet locations of their choosing, usually at home. The
11
12 interview guide (available from the authors) was used to gather key pieces of information. It
13
14 covered the experiences of being invited for screening, being recalled, the assessment clinic
15
16 and reflections of that experience. The guide was based on the results of the latest UK
17
18 systematic review¹ and reviewed by two women with FPM. The interviews were recorded and
19
20 transcribed.

21 22 **Data analysis**

23
24 The interviews were analysed with inductive qualitative content analysis.¹⁹ This approach was
25
26 chosen because we wanted to develop simple categories from the interviews to compare with
27
28 the items in the guidelines rather than explore the deeper meanings of what the participants
29
30 were saying. This process involved reading and listening to the interviews iteratively as relevant
31
32 content was open coded. The codes were reviewed across the manuscripts by a process of
33
34 constant comparison, being merged and dropped as the analysis progressed. The codes were
35
36 then gathered into categories of similar items.²⁰ These primary categories were subsumed into
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38 higher order generic categories and so assisted the systematic description of the phenomena,
39
40 thus identifying the key messages in the texts.²¹

41
42 The results were validated using Yardley's principles of sensitivity to context, commitment and
43
44 rigour, transparency and coherence and impact and importance, including an audit trail and the
45
46 search for disconfirming cases²² and participant feedback. The analysis was supported by
47
48 Atlas.ti 6.2 software. The application of Yardley's principles can be seen in Table 1.

Table 1 Yardley's principles for quality in qualitative research

Principle	Qualities	Application to this study
Sensitivity to context	Theoretical; relevant literature; empirical data; socio-cultural setting; participant's perspective; ethical issues	Grounding the study in the context of what is already known from the systematic review. Then gathering the new interview data to refine that knowledge, searching for examples that confirm and refute what is already known. Being aware of and sensitive to the socio-cultural place of the participants and how this might influence the meanings they give to their experiences. Also understanding those experiences from their perspective; what they meant to them, but acknowledging the influence of the researcher and their role in the interview to what is said through their demeanour, verbal and non-verbal cues and an awareness of the potentially more powerful position of the researcher. Ethical approval was gained.
Commitment & rigour	In-depth engagement with topic; methodological competence; skill; thorough data collection; depth/breadth of analysis	This is achieved through becoming committed to the process of the research, the integrity of the interviews, being immersed in the data and taking a systematic, rigorous approach to the depth of analysis and interpretation of the interviews. Accounting for the variety and complexity of the data, including the search for disconfirming cases. The trustworthiness of the analysis was further established by respondent validation of the findings. The first eight interviews were coded independently by two researchers.
Transparency & coherence	Clarity and power of description/argument; transparent methods and data presentation; fit between theory and method; reflexivity	Providing a clear audit trail of the process of the study including data analysis. Telling a clear coherent story that encompasses the range of experience of the participants, illustrated by their own words and offering a reflective interpretation of the meaning of their accounts that acknowledges the role and influences of the researcher.
Impact & importance	Theoretical (enriching understanding); socio-cultural; practical (for community, policy makers, health workers)	Clearly describing the originality and importance of the findings and how they relate to previous research. Demonstrating their importance for policy makers, in this case the NHSBSP. Offering recommendations to improve services to reduce the psychological impact of false-positive mammograms.

Source: Yardley (2000)

Results

Participants' characteristics were found to fulfil the criteria of diversity. However, more detailed information about educational level, income and social group would aid interpretation of the results, see table 2. Table 2 Summary of participants' characteristics

Table 2 Summary of Participants' Characteristics

Characteristics	No (%) women
Age (years)	
40-49	2 (10)
50-59	11 (52)
60-69	8 (38)
Marital status	
Married or cohabiting	19 (90)
Single, separated or widowed	2 (10)
Ethnicity	
White	21 (100)
Time since false-positive (years)	
≤1 year	4 (19)
2-4	7 (33)
5-7	8 (38)
8-10	1 (5)
11-13	1 (5)
Type of Assessment procedure*	
Mammogram	16 (76)
Ultra-sound	12 (57)
Fine needle aspiration	1 (5)
Biopsy	4 (19)
Index of multiple deprivation %	
Unknown	4 (19)
0-9	1 (5)
10-19	0 (0)
20-29	2 (9)
30-39	3 (14)
40-49	2 (9)
50-59	4 (19)
60-69	4 (19)
70-79	1 (5)

*Many women had more than one assessment procedure

The interview study showed that overall; almost all participants were satisfied with the mammography recall service they received. However, as they presented their stories a number

1
2 of issues were raised for service improvement. These issues concerned the recall letter, the
3 assessment clinic, choice and subsequent screening. Participants' quotes are identified by a
4 pseudonym. A diagram of the relationship between the categories can be found in figure 1.
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7

8 *Figure 1*
9

10 11 12 **Recall letter information**

13
14 Most women were satisfied with the quality of the recall information they were sent. The
15 information was repeatedly described as reassuring. Many participants latched onto the positive
16 messages of the letter and remembered they had been told that most recalled women were
17 clear of breast cancer and they should not worry about being called back.
18
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20
21 *Anne: "The letter itself I think said something reassuring like... 'as a*
22 *precaution we're calling you back because, there's some anomaly, or*
23 *something like that, on the screen...' and then it says ... a large*
24 *proportion of women who are called for second screening don't actually*
25 *have anything, but it's just a precautionary thing, so I mean all the time*
26 *they're kind of trying to put forward the, sort of, positive angle on it."*
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34 However, there was considerable variation in what women were told to expect; some were
35 simply told they would have another mammogram and others were given an explanation about
36 the reason for their recall.
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40 *Clare: "In the letter, yeah, when I was recalled, they actually said ...*
41 *'we'd like you to come again, so we can take some further x-rays,' and*
42 *they've also said 'at this visit we may also carry out an ultrasound*
43 *examination', so I was aware of what was going to happen."*
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48 *Moira: "Only curious about what was going to happen, because you don't*
49 *get told beforehand. You know you're going to have a mammogram, but*
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2 *you don't know what else is going to happen... so you're not actually*
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4 *prepared."*

5
6 Most of the women found the short time between the recall letter and their assessment
7
8 a positive thing as the time of anxiety was curtailed:

9
10 *Vicky: "When I got the letter, to be recalled was only a few days later, it*
11 *wasn't very long, which I'm really glad about. I couldn't have hung on two*
12 *or three, four weeks, it was a matter of days, it was very, very good, very*
13 *good."*

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18 Conversely, others interpreted the quick appointment as possibly indicating they had breast
19
20 cancer. This understanding was rooted in a belief that the NHS only responds quickly to serious
21
22 health problems:

23
24 *Grace: "There wasn't a lot of time, um, also between the letter - I think it*
25 *was about a week - between me getting the letter and actually going for*
26 *the, the next mammogram, which tends to sort of go 'oops,' anything that*
27 *comes you don't have much time in between means that it could be*
28 *serious."*

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34 Others who went alone found the waiting hardest as they lacked the support of a friend or
35
36 relative, but not everyone knew they could bring someone with them.

37
38 *Wendy: "The only thing that I would have liked the letter to have said*
39 *was, 'if you want to bring a friend or relative, please do so.'"*

40
41
42 These accounts indicate a variation in the amount and content of the information that
43
44 participants were given. They also show that the information needs of these women differed;
45
46 some were able to focus on the positive messages of the recall letter and were quite happy with
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48 simply being told that although they were being recalled everything was probably alright. Others
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50 reacted more strongly to the uncertainty that was introduced into their lives and wanted as much
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1
2 detail as possible about the reasons for their recall; the implications of this and what was going
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4 to happen at the assessment clinic.

6 **At the clinic**

7
8 Waiting generally provoked anxiety; one participant said this could have been reduced by
9
10 information about how long the clinic appointment was likely to take:

11
12 *Karen: "The waiting was the worst... the whole thing was bad, but the*
13
14 *worst bit was having to wait and not knowing how long I was waiting for."*

15
16 Many participants reported that the clinic staff were the best thing about their experience. They
17
18 were repeatedly described as Rachel: lovely, Moira: friendly, Ella: supportive, Zoe: kind, Anne:
19
20 professional and Vicky: very, very nice:

21
22 *Zoe: "They were just very kind and I think, in a way, nurturing, because*
23
24 *they knew there was a possibility that you might have bad news. They*
25
26 *were just very protective of you; you just felt that they were handling it*
27
28 *really well, that they cared about you."*

29
30 Clear explanations of the nature of the lesion were valued and helped to bring peace amid the
31
32 uncertainty.

33
34 *Laura: "He was ever so...really thorough, I've got to say, really put my*
35
36 *mind at rest ... explained everything to me from start to finish, ... and did*
37
38 *it in a way...not condescending way, he explained it in a real clear and*
39
40 *concise manner, yeah, absolutely brilliant. I came out cock-a-hoop! "*

41
42 Although the majority had positive encounters, not all staff were sensitive and caring.

43
44 *Chloe: "Um...yes, it didn't feel quite friendly, the staff in the unit*
45
46 *sometimes... it was a case of, 'oh, yeah,' it's just...like the queue... 'oh,*
47
48 *right, yeah, next."*

1
2 There was evidence of an unmet need for information and reassurance that could have been
3 given by a CNS being available, and known to be available, after as well as before assessment.
4 This unavailability resulted in some women leaving the clinic with uncertainty and unanswered
5 questions.
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10 *Laura: "Don't think so [someone to talk to]. Didn't see... there was a*
11 *nurse, yes, there was a nurse on duty, but she was very busy and I could*
12 *see she was very busy."*
13

14 *Grace: "I can't recall there being anybody around."*
15

16 *Fran: "Well, I suppose somebody to talk...you know, perhaps if I'd gone*
17 *and talked to somebody, you know, about it all, perhaps I...it would have*
18 *eased me."*
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24 During their assessment the amount of information that participants wanted about their lesion
25 varied. A number of them would have had more confidence in their all-clear result if they had
26 been given a clearer explanation of what their lesion meant, including the risk of it becoming
27 malignant so they could make an informed choice about how to proceed.
28
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32 *Liz: "I would like the doctors to present me with the facts and say 'right,*
33 *you know...if it's 20 women out of...out of 100 with hyperplasia who, you*
34 *know, before they die, so they could be really old, get breast cancer,'*
35 *then I know that fact. If it's, um, you know, one in 10,000 up to the age of*
36 *80, then I probably would opt not to have any invasive surgery again."*
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42 One participant's experience highlighted the need for consistency between the messages from
43 the clinical staff and the literature they were given. The radiologist had told her that her cysts
44 could not become cancerous and then gave her a leaflet that said they could; this caused
45 considerable anxiety. This inconsistency led her to request an interim mammogram for
46 reassurance from her GP but was turned down:
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Moira: "And I now wait for my next mammogram...but that's the bit I don't like. You're told you have cysts, but you're not given a follow-up from there and you should...I'm assuming that they're quite satisfied that they [cysts] cannot become cancerous, even though the leaflet says they can. So I'm assuming they either haven't read the leaflet, or they simply don't believe the leaflet, I don't know which."

While the women waited at the clinic it was apparent that the location, layout and the waiting environment played a role in moderating their experience. Some participants had their initial screening in mobile units but then went to a hospital for their assessment.

Zoe: "Perhaps it seems more serious because you're aware it's a place where there are sick people... whereas if you go to the unit that goes to the car parks and whatever, you're in and out in ten minutes and you move on."

For some the physical layout of the clinic meant they were aware of what was happening to other women ahead of them in the queue; increasing their anxiety as they waited.

Grace: "We waited in a corridor ... we, sort of, waited in a long line, sat down in a long line ... we all waited together and we all went in and you'd see people go through the door, but they also came out that door and you knew if it was good or bad news for them, because obviously if it was good news they were looking happy, and if it was bad news they didn't go straight down the corridor, they went into another room. Um, and that would have been, I think, pretty traumatic for anybody, because you knew which way...but also for us, because we knew if it was good or bad news for them. I remember thinking, 'well, I'm going to have to go through that in a minute, but I don't want to witness their distress either.'"

1
2 On other occasions the participants could not see the woman diagnosed with breast cancer but
3
4 they could hear her crying, which similarly increased their anxiety.

5
6 *Wendy: "while I was waiting somebody else had...who had been recalled,*
7
8 *um, had been told that they, you know, they did have something and*
9
10 *obviously they were distressed and, you know, people waiting, that was*
11
12 *distressing as well...I could hear, I couldn't see her, but I could hear her*
13
14 *and that was distressing, yes."*

15
16 Although the staff received much praise, there was still a clear need for an opportunity to talk to
17
18 the CNS after the all-clear if questions remained about the reliability of the diagnosis and the
19
20 probability of it becoming malignant. The status of their lesion remained a concern at the next
21
22 screening round for some women and information about if or how it had changed would have
23
24 been valued. The responses also showed that a sensitivity to the clinical environment is
25
26 necessary with due regard for privacy.

27 28 **Choice**

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30 Following their assessment a number of women were uncertain about the validity of their all-
31
32 clear diagnosis. They would have liked the option of a follow-up mammogram for reassurance.

33
34 *Ella: "I thought 'can you just see me in a year's time, just tell me that in a*
35
36 *year's time, it's all OK in a year's time?"*

37
38 *Zoe: "I think the fact that you've been faced with the possibility that*
39
40 *something didn't look quite right, you're not quite sure what it was that*
41
42 *didn't look quite right, um, and maybe a screening a year down the line*
43
44 *would have been, um, something to...to, you know, relieve any nerves."*

45
46 There was also a request for mammograms as an alternative to the invasive investigation of
47
48 lesions by biopsy that were thought to be almost certainly benign.

49
50 *Liz: "Because they said, 'we're pretty sure it isn't anything, but we need*
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52 *to check if it is anything.' ...and so I suppose what I'm saying is that had*
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there been a little bit more, um, wait and see... I wouldn't have had more anxiety if they'd say, 'well, we'll do a mammogram again in three months or six months.'

This plea for choice was part of a desire to be more involved in the decision making process about how to proceed once a lesion was detected. Many of the women felt disempowered by the assessment process. They perceived themselves to be Ella: 'in the system' and passive partakers of assessment procedures.

Liz: "I think when you're in the middle of it, you just go along with whatever's being told... there could have been, uh, more consultation maybe at the beginning of things... so...and I'd have probably still have gone along with it, [surgery] 'cause I don't think I felt empowered not to."

Another woman would have appreciated the choice of receiving her biopsy results by post or over the phone, as this further wait prolonged anxiety.

Fran: "It was just waiting for those results... every day you look for the post... and when it's there you're frightened to open it up... it [phone call] probably would have been better, really, 'cause you're looking every day, aren't you, at the post and thinking, 'oh, my gosh.'"

It was clear that some women would have valued more choice in the assessment process. Choice was requested for follow-up mammograms to reduce uncertainty and anxiety about the outcome of assessment, 'watchful waiting' as an alternative to biopsy and test results over the phone rather than through the post.

At the next screening round

At their next routine screening, some participants' anxieties would have been dispelled if they were told about the status of the lesions previously discovered:

Jane: "I just got the all-clear letter, sort of thing, [after subsequent screening] and when I saw the doctor [GP] I said 'when I...you got the

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results of me mammogram did it say anything about the cyst?’ And he looked it back and he said, ‘no, it hasn’t said anything.’ And it would have been just nice to know whether I’ve still got it or not.”

Comparison of these results with NHSBSP guidelines

Many of our findings echo those of the research used to produce the NHSBSP 1998 guidelines and indicate that these have not been universally implemented.²³⁻²⁵ A comparison of the NHSBSP guidelines with our service improvement suggestions can be found in Table 3.

Table 3 Comparison of our suggestions with those of the 1998 and 2012 NHSBSP Guidelines

	NHSBSP Recall Guidelines (38) 1998	Bond et al. Service Suggestions 2014
Recall letter information	A clear reason for recall	A clear reason for recall
	Who can come with them	Who can come with them
	How long the appointment will take	How long the appointment will take
	Who they will see	Who they will see
	What tests will be carried out	What tests will be carried out
	Where they can get further information	Reassurance that a swift appointment does not imply the presence of cancer
	How to get to the assessment centre	
	How to change their appointment	
	When the results will be available	
	At the clinic	NHSBSP CSN Guidelines (29) 2012
Clear explanation of why the lesion is benign with any risk of change to malignancy		
Literature about the type of lesion		
One-way layout through the clinic		
Choice		The offer of a follow-up mammogram in a year for those needing reassurance of their ‘all clear’
		Choice between invasive assessment and ‘watchful waiting’ for lesions almost certainly benign

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**At the next
screening
round**

Choice of hearing biopsy results by post
or over the phone
Clarification of the status of the lesion
found to be a false-positive

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The following suggestions are offered to improve services.

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Recall letter

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Recall letters issued should be consistent and include the following items. The first five items remain unaddressed from the 1998 guidelines.

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This should include:

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1. The reason for recall
 2. Who can come with them
 3. How long the appointment is likely to take
 4. Who they will see
 5. What tests will be carried out
 6. Where to get further information
 7. The availability of a CNS to answer questions before and after assessment
 8. Reassurance that a swift appointment is normal and does not indicate there is anything wrong

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At the clinic

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9. A pre-assessment conversation with the CNS covering, the reason for recall, the assessment process including possible harms, and the availability of the CNS for a debrief after the assessment whatever the outcome
 10. From the Radiologist at diagnosis; sufficient time for a clear explanation of the type of lesion, risk of it becoming malignant, with clarity about uncertainty. If a biopsy is advised then discussion about pros and cons including the reliability of biopsy results and the choice of watchful waiting if the lesion is almost certainly benign

11. The availability of CNS post-assessment to clarify the diagnosis and provide reassurance, as a woman may not feel able to question the outcome with her GP. If the woman remains unsure of the validity of her all-clear a follow-up mammogram should be considered
12. Literature about the type of lesion found should be offered. This should agree with that from the Radiologist and give a phone number for further information
13. The choice of receiving biopsy results by phone or post
14. A one-way system through the clinic so that women do not have to have the outcome of their assessment witnessed or witness other's outcomes

At the next screening round

15. Women should be given an update about their lesion, whether it has gone, stayed the same or grown larger, with an explanation of the implications

Discussion

While overall participants were satisfied with the service they received, they raised a number of areas where it could be improved. Many of the items in the 1998 NHSBSP guidelines remained outstanding. Some women were still asking for more information in the recall letter about: the reason for their recall; who could come with them; how long the appointment might take; who they would see and what would happen to them. Some participants were also concerned that a swift appointment implied that they had cancer. At the assessment clinic a more explicit explanation of why their lesion was benign and the risk of it becoming malignant would have reduced anxiety, together with literature about their type of lesion. The women also expressed requests for more choice as some were left with doubt about the validity of the outcome of the assessment and would have appreciated an offer to have a follow-up mammogram in a year's time for reassurance and an update on the status of their lesion at their next screening round. Others felt powerless and in 'the system' when faced with a biopsy; an alternative of 'watchful waiting' for lesions that were almost certainly benign, would have been valued and empowering. A choice of having biopsy results by post or over the phone was also requested. Additionally

1
2 some participants would have valued an opportunity to see the CNS after assessment as well
3 as before. Finally, the layout of the clinic precipitated anxiety for some women while they were
4 waiting, as they were able to see and hear the distress of women who had been diagnosed with
5 cancer. There was no apparent link between participants' demographic characteristics and the
6 issues they raised.
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11 The strengths of this study are that it was rigorously conducted and provides current, in-depth
12 insights into the views of women, with false-positive mammograms of the assessment service
13 they received. Thus it provides valuable evidence of how these services may be improved so
14 that the anxiety associated with having false-positive mammograms may be reduced. The
15 influence of the researcher (MB) is acknowledged, both from her manner, verbal and non-verbal
16 cues during the interview; there is also the potential for social desirability effects²⁶. The analysis
17 has been through the filter of the researcher's particular understanding of the issues, including
18 being someone who has not had mammography. This will have influenced the way the
19 interviews were interpreted, due to the lack of first-hand experience. Qualitative research is
20 notably subjective and is open to the charge that the results lack generalisability. However,
21 although the study has a number of limitations and further research is needed to establish the
22 UK national picture, we believe these results are reasonably robust, transferable and relevant
23 for consideration in policy development. This is because the interview findings were validated
24 using Yardley's principles²² and by participant feedback of a lay summary of the results. The
25 study is limited by lack of demographic detail, the limited geographical area (Devon) and the
26 possible unreliability of the participants' memories as these events occurred between six
27 months and 12 years previously i.e. recall bias.²⁷ However, the consistency of our findings with
28 previous research²³⁻²⁵ and other studies, which have shown a positive association between the
29 accuracy of long-term recall and the traumatic impact of an event up to 21 years^{28,29}, give us
30 confidence in the reliability of our results.
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49 Internationally, questionnaire studies have also found that overall women are satisfied with
50 mammography screening recall services.⁷⁻¹⁰ In the case of false-positive mammograms there is
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2 a certain irony about this response as the women are satisfied with a service that has made a
3 mistake in recalling them and may have caused them unnecessary anxiety. Further evidence
4 comes from the Danish interview study by Lindberg et al. which found women with false-positive
5 mammograms were grateful for the service which had brought their health into question and
6 caused them psychological distress.³⁰ Some studies found, in agreement with ours, that the
7 attitude of clinic staff as well as the quality of information and the physical environment affected
8 satisfaction.^{7,9,10,14} Our findings also agree with the results from the US qualitative study (2001),
9 that some participants thought the information they received was inadequate.¹²
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11

12 Although our research comes from a limited geographical area, and other regions of the UK
13 may have better service provision, it implies that there is still some way to go to provide women
14 who are recalled after breast cancer screening with a satisfactory service. There is a need for
15 consistency in the implementation of recommendations and a mechanism for ensuring this
16 occurs.
17

18 **Service implications**

19 These suggestions will require additional resources; increased hours for the CNS and additional
20 mammography for those needing reassurance or choosing 'watchful waiting'. However, most of
21 the suggestions can be implemented at the lower cost of revising literature and giving clearer
22 explanations, which may mean that fewer women are left with uncertainty and request on-going
23 care.
24
25

26 **Conclusion**

27 It is time the NHSBSP 1998 recall information guidelines were fully implemented. Additionally,
28 the further suggestions from this research, including extending the role of the CNS from the
29 2012 NHSBSP guidelines, should be considered.
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32 Further research is needed to establish whether the 1998 NHSBSP recommendations are in
33 place nationally and if the additional measures outlined in these service recommendations are
34 sought by women throughout the UK.
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6
7

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9 participants with the support of the SW Primary Care Research Network, conducted and
10 analysed the interviews, obtained respondent feedback, undertook the comparison with UK
11 guidelines and formulated service improvement suggestions, wrote and edited the research
12 paper. RG contributed to the design of the study, advised on the qualitative aspects and
13 commented on the draft paper. CH contributed to the design of the study, advised on the health
14 services aspects and commented on the draft paper.
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22
23

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30 those of the NHS, the NIHR or the Department of Health in England.
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37 Figure 1 Category development
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Improving screening recall services for women with false-positive mammograms: a comparison of qualitative evidence with UK guidelines

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Improving screening recall services for women with false-positive mammograms: a comparison of qualitative evidence with UK guidelines

Abstract

Objectives: To gain an understanding of the views of women with false-positive screening mammograms of screening recall services, their ideas for service improvements and how these compare with current UK guidelines.

Methods: Inductive qualitative content analysis of semi-structured interviews of 21 women who had false-positive screening mammograms. These were then compared with UK NHS guidelines.

Results: Participants' concerns about mammography screening recall services focused on issues of communication and choice. Many of the issues raised indicated that the 1998 National Health Service Breast Screening Programme guidelines on improving the quality of written information sent to women who are recalled, had not been fully implemented. This included being told a clear reason for recall, who may attend with them, the length of appointment, who they will see and what tests will be carried out. Additionally women voiced a need for: reassurance that a swift appointment did not imply they had cancer; choice about invasive assessment or watchful waiting; the offer of a follow-up mammogram for those uncertain about the validity of their all-clear and an extension of the role of the clinical nurse specialist, outlined in the 2012 NHSBSP guidelines, to include availability at the clinic after the all-clear for women with false-positive mammograms.

Conclusions: It is time the NHSBSP 1998 recall information guidelines were fully implemented. Additionally, the further suggestions from this research, including extending the role of the clinical nurses from the 2012 NHSBSP guidelines, should be considered. These actions have the potential to reduce the anxiety of being recalled.

Strengths and limitations of this study

- This research has been rigorously conducted by an independent, academic research team
- The suggestions for service improvements are based on empirical research
- The evidence provides current insights into women's view of mammography screening services for recalled women
- The study may be limited by the ability of some participants to recall distant experiences
- More detailed information about the demographic characteristics of participants would aid interpretation of the results

Introduction

Screening for breast cancer by mammography has been part of many women's routine healthcare for more than 25 years. Much research has been carried out into the anxiety produced by having a false-positive mammogram (FPM).¹⁻⁶ However, the quality of mammography screening services for women who have been recalled has been less thoroughly investigated. Internationally, questionnaire studies have found that overall women are satisfied with the service they receive.⁷⁻¹⁰ Additionally, some studies found that the attitude of clinic staff as well as the quality of information and the physical environment affected satisfaction.^{7,9-12} Furthermore, a Finnish observational study that investigated the information needs of women assessed by biopsy, found that women wanted information and reassurance throughout and after their assessment.¹¹ However, a Canadian RCT failed to find an impact on satisfaction from additional information.¹³ The above research gives an opaque picture of the information and support needs of women recalled following screening.

The situation in the UK is particularly unclear as our searches found only one UK study of service satisfaction of women with a FPM. This was by Smith et al. who found that clinic staffs' attitudes, quality of information and the physical environment had an impact on satisfaction.¹⁴

1
2 However, this survey is more than 20 years old and it is 16 years since the NHS Breast
3 Screening Programme (NHSBSP) produced guidelines about the information needs of women
4 recalled following mammography screening.¹⁵ More recently NHSBSP Guidelines (2012)
5 highlight the important role of the clinical nurse specialist (CNS) in supporting women who have
6 been recalled.¹⁶ As FPM affects more than 50,000 women a year in England alone, we were
7 interested in women's views of the service they received, their thoughts on how they might be
8 improved and how these compared with NHSBSP guidelines.
9

10
11 The research question is: What are the views of women with false-positive screening
12 mammograms of the recall service they received, their ideas for service improvements and how
13 do these compare with existing UK guidelines?
14

15 16 17 18 19 20 21 22 **Method**

23 We chose to use semi-structured interviews because they employ open-ended questions within
24 the framework of an interview guide, facilitating a discourse where the interviewee is free to
25 respond to the questions in a self-directed way. This approach produces responses that are rich
26 in content and may contain interesting and relevant material beyond the scope of the initial
27 question.
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29

30 31 32 33 34 **Participants and recruitment**

35 Fifty two women with FPM were invited to participate and 21 were recruited (40%). Recruitment
36 was through the National Institute for Health Research Primary Care Research Network, from
37 three local General Practices or through the University of Exeter staff e-newsletter. Participants
38 were purposively sampled for diversity of age, time from the false-positive experience and type
39 of assessment procedure. We were also interested in the social mix of participants and used the
40 UK Index of Multiple Deprivation (IMD), relating to their post code, as a means of assessing this.
41 The IMD is derived from a national survey of income, employment, health, education, housing,
42 crime and living environment. The scores are ranked from the least to the most deprived.¹⁷ Due
43 to the specific focus of the research it was believed that about 20 interviews would be sufficient
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2 for data saturation. If saturation did not occur further participants would be recruited.¹⁸
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4 Participants gave informed consent. This study received ethical approval from the UK National
5
6 Research Ethics Service Committee South West, approval no. 11/SW/0263.
7

8 9 **Data collection**

10 Participants were interviewed by MB in quiet locations of their choosing, usually at home. The
11
12 interview guide (available from the authors) was used to gather key pieces of information. It
13
14 covered the experiences of being invited for screening, being recalled, the assessment clinic
15
16 and reflections of that experience. The guide was based on the results of the latest UK
17
18 systematic review¹ and reviewed by two women with FPM. The interviews were recorded and
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20 transcribed.
21

22 23 **Data analysis**

24 The interviews were analysed with inductive qualitative content analysis.¹⁹ This approach was
25
26 chosen because we wanted to develop simple categories from the interviews to compare with
27
28 the items in the guidelines rather than explore the deeper meanings of what the participants
29
30 were saying. This process involved reading and listening to the interviews iteratively as relevant
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32 content was open coded. The codes were reviewed across the manuscripts by a process of
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34 constant comparison, being merged and dropped as the analysis progressed. The codes were
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36 then gathered into categories of similar items.²⁰ These primary categories were subsumed into
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38 higher order generic categories and so assisted the systematic description of the phenomena,
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40 thus identifying the key messages in the texts.²¹

41 The results were validated using Yardley's principles of sensitivity to context, commitment and
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43 rigour, transparency and coherence and impact and importance, including an audit trail and the
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45 search for disconfirming cases²² and participant feedback. The analysis was supported by
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47 Atlas.ti 6.2 software. The application of Yardley's principles can be seen in Table 1.
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Table 1 Yardley's principles for quality in qualitative research

Principle	Qualities	Application to this study
Sensitivity to context	Theoretical; relevant literature; empirical data; socio-cultural setting; participant's perspective; ethical issues	Grounding the study in the context of what is already known from the systematic review. Then gathering the new interview data to refine that knowledge, searching for examples that confirm and refute what is already known. Being aware of and sensitive to the socio-cultural place of the participants and how this might influence the meanings they give to their experiences. Also understanding those experiences from their perspective; what they meant to them, but acknowledging the influence of the researcher and their role in the interview to what is said through their demeanour, verbal and non-verbal cues and an awareness of the potentially more powerful position of the researcher. Ethical approval was gained.
Commitment & rigour	In-depth engagement with topic; methodological competence; skill; thorough data collection; depth/breadth of analysis	This is achieved through becoming committed to the process of the research, the integrity of the interviews, being immersed in the data and taking a systematic, rigorous approach to the depth of analysis and interpretation of the interviews. Accounting for the variety and complexity of the data, including the search for disconfirming cases. The trustworthiness of the analysis was further established by respondent validation of the findings. The first eight interviews were coded independently by two researchers.
Transparency & coherence	Clarity and power of description/argument; transparent methods and data presentation; fit between theory and method; reflexivity	Providing a clear audit trail of the process of the study including data analysis. Telling a clear coherent story that encompasses the range of experience of the participants, illustrated by their own words and offering a reflective interpretation of the meaning of their accounts that acknowledges the role and influences of the researcher.
Impact & importance	Theoretical (enriching understanding); socio-cultural; practical (for community, policy makers, health workers)	Clearly describing the originality and importance of the findings and how they relate to previous research. Demonstrating their importance for policy makers, in this case the NHSBSP. Offering recommendations to improve services to reduce the psychological impact of false-positive mammograms.

Source: Yardley (2000)

Results

Participants' characteristics were found to fulfil the criteria of diversity. However, more detailed information about educational level, income and social group would aid interpretation of the results, see table 2. Table 2 Summary of participants' characteristics

Characteristics	No (%) women
Age (years)	
40-49	2 (10)
50-59	11 (52)
60-69	8 (38)
Marital status	
Married or cohabiting	19 (90)
Single, separated or widowed	2 (10)
Ethnicity	
White	21 (100)
Time since false-positive (years)	
≤ 1 year	4 (19)
2-4	7 (33)
5-7	8 (38)
8-10	1 (5)
11-13	1 (5)
Type of assessment procedure *	
Mammogram	16 (76)
Ultra-sound	12 (57)
Fine needle aspiration	1 (5)
Biopsy	4 (19)
Index of multiple deprivation %	
Unknown	4 (19)
0-9	1 (5)
10-19	0 (0)
20-29	2 (9)
30-39	3 (14)
40-49	2 (9)
50-59	4 (19)
60-69	4 (19)
70-79	1 (5)
* Many women had more than one assessment procedure	

The interview study showed that overall; almost all participants were satisfied with the mammography recall service they received. However, as they presented their stories a number

1
2 of issues were raised for service improvement. These issues concerned the recall letter, the
3 assessment clinic, choice and subsequent screening. Participants' quotes are identified by a
4 pseudonym. A diagram of the relationship between the categories can be found in figure 1.
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8 *Figure 1*
9

10 11 12 **Recall letter information**

13
14 Most women were satisfied with the quality of the recall information they were sent. The
15 information was repeatedly described as reassuring. Many participants latched onto the positive
16 messages of the letter and remembered they had been told that most recalled women were
17 clear of breast cancer and they should not worry about being called back.
18
19

20
21 *Anne: "The letter itself I think said something reassuring like... 'as a*
22 *precaution we're calling you back because, there's some anomaly, or*
23 *something like that, on the screen...' and then it says ... a large*
24 *proportion of women who are called for second screening don't actually*
25 *have anything, but it's just a precautionary thing, so I mean all the time*
26 *they're kind of trying to put forward the, sort of, positive angle on it."*
27
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34 However, there was considerable variation in what women were told to expect; some were
35 simply told they would have another mammogram and others were given an explanation about
36 the reason for their recall.
37
38

39
40 *Clare: "In the letter, yeah, when I was recalled, they actually said ...*
41 *'we'd like you to come again, so we can take some further x-rays,' and*
42 *they've also said 'at this visit we may also carry out an ultrasound*
43 *examination', so I was aware of what was going to happen."*
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48 *Moira: "Only curious about what was going to happen, because you don't*
49 *get told beforehand. You know you're going to have a mammogram, but*
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you don't know what else is going to happen... so you're not actually prepared."

Most of the women found the short time between the recall letter and their assessment a positive thing as the time of anxiety was curtailed:

Vicky: "When I got the letter, to be recalled was only a few days later, it wasn't very long, which I'm really glad about. I couldn't have hung on two or three, four weeks, it was a matter of days, it was very, very good, very good."

Conversely, others interpreted the quick appointment as possibly indicating they had breast cancer. This understanding was rooted in a belief that the NHS only responds quickly to serious health problems:

Grace: "There wasn't a lot of time, um, also between the letter - I think it was about a week - between me getting the letter and actually going for the, the next mammogram, which tends to sort of go 'oops,' anything that comes you don't have much time in between means that it could be serious."

Others who went alone found the waiting hardest as they lacked the support of a friend or relative, but not everyone knew they could bring someone with them.

Wendy: "The only thing that I would have liked the letter to have said was, 'if you want to bring a friend or relative, please do so.'"

These accounts indicate a variation in the amount and content of the information that participants were given. They also show that the information needs of these women differed; some were able to focus on the positive messages of the recall letter and were quite happy with simply being told that although they were being recalled everything was probably alright. Others reacted more strongly to the uncertainty that was introduced into their lives and wanted as much

1
2 detail as possible about the reasons for their recall; the implications of this and what was going
3
4 to happen at the assessment clinic.

6 **At the clinic**

7
8 Waiting generally provoked anxiety; one participant said this could have been reduced by
9
10 information about how long the clinic appointment was likely to take:

11
12 *Karen: "The waiting was the worst... the whole thing was bad, but the*
13 *worst bit was having to wait and not knowing how long I was waiting for."*

14
15
16
17 Many participants reported that the clinic staff were the best thing about their experience. They
18
19 were repeatedly described as Rachel: lovely, Moira: friendly, Ella: supportive, Zoe: kind, Anne:
20
21 professional and Vicky: very, very nice:

22
23 *Zoe: "They were just very kind and I think, in a way, nurturing, because*
24 *they knew there was a possibility that you might have bad news. They*
25 *were just very protective of you; you just felt that they were handling it*
26 *really well, that they cared about you."*

27
28
29
30 Clear explanations of the nature of the lesion were valued and helped to bring peace amid the
31
32 uncertainty.

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34
35 *Laura: "He was ever so...really thorough, I've got to say, really put my*
36 *mind at rest ... explained everything to me from start to finish, ... and did*
37 *it in a way...not condescending way, he explained it in a real clear and*
38 *concise manner, yeah, absolutely brilliant. I came out cock-a-hoop! "*

39
40
41
42 Although the majority had positive encounters, not all staff were sensitive and caring.

43
44
45 *Chloe: "Um...yes, it didn't feel quite friendly, the staff in the unit*
46 *sometimes... it was a case of, 'oh, yeah,' it's just...like the queue... 'oh,*
47 *right, yeah, next."*

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There was evidence of an unmet need for information and reassurance that could have been given by a CNS being available, and known to be available, after as well as before assessment. This unavailability resulted in some women leaving the clinic with uncertainty and unanswered questions.

Laura: "Don't think so [someone to talk to]. Didn't see... there was a nurse, yes, there was a nurse on duty, but she was very busy and I could see she was very busy."

Grace: "I can't recall there being anybody around."

Fran: "Well, I suppose somebody to talk...you know, perhaps if I'd gone and talked to somebody, you know, about it all, perhaps I...it would have eased me."

During their assessment the amount of information that participants wanted about their lesion varied. A number of them would have had more confidence in their all-clear result if they had been given a clearer explanation of what their lesion meant, including the risk of it becoming malignant so they could make an informed choice about how to proceed.

Liz: "I would like the doctors to present me with the facts and say 'right, you know...if it's 20 women out of...out of 100 with hyperplasia who, you know, before they die, so they could be really old, get breast cancer,' then I know that fact. If it's, um, you know, one in 10,000 up to the age of 80, then I probably would opt not to have any invasive surgery again."

One participant's experience highlighted the need for consistency between the messages from the clinical staff and the literature they were given. The radiologist had told her that her cysts could not become cancerous and then gave her a leaflet that said they could; this caused considerable anxiety. This inconsistency led her to request an interim mammogram for reassurance from her GP but was turned down:

1
2 Maira: "And I now wait for my next mammogram...but that's the bit I don't
3
4 like. You're told you have cysts, but you're not given a follow-up from
5
6 there and you should...I'm assuming that they're quite satisfied that they
7
8 [cysts] cannot become cancerous, even though the leaflet says they can.
9
10 So I'm assuming they either haven't read the leaflet, or they simply don't
11
12 believe the leaflet, I don't know which."

13
14 While the women waited at the clinic it was apparent that the location, layout and the waiting
15
16 environment played a role in moderating their experience. Some participants had their initial
17
18 screening in mobile units but then went to a hospital for their assessment.

19
20 Zoe: "Perhaps it seems more serious because you're aware it's a place
21
22 where there are sick people... whereas if you go to the unit that goes to
23
24 the car parks and whatever, you're in and out in ten minutes and you
25
26 move on."

27
28 For some the physical layout of the clinic meant they were aware of what was happening to
29
30 other women ahead of them in the queue; increasing their anxiety as they waited.

31
32 Grace: "We waited in a corridor ... we, sort of, waited in a long line, sat
33
34 down in a long line ... we all waited together and we all went in and you'd
35
36 see people go through the door, but they also came out that door and
37
38 you knew if it was good or bad news for them, because obviously if it was
39
40 good news they were looking happy, and if it was bad news they didn't go
41
42 straight down the corridor, they went into another room. Um, and that
43
44 would have been, I think, pretty traumatic for anybody, because you
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46 knew which way...but also for us, because we knew if it was good or bad
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48 news for them. I remember thinking, 'well, I'm going to have to go
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50 through that in a minute, but I don't want to witness their distress either.'"
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2 On other occasions the participants could not see the woman diagnosed with breast cancer but
3 they could hear her crying, which similarly increased their anxiety.
4

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6 *Wendy: "while I was waiting somebody else had...who had been recalled,*
7
8 *um, had been told that they, you know, they did have something and*
9
10 *obviously they were distressed and, you know, people waiting, that was*
11
12 *distressing as well...I could hear, I couldn't see her, but I could hear her*
13
14 *and that was distressing, yes."*
15

16 Although the staff received much praise, there was still a clear need for an opportunity to talk to
17 the CNS after the all-clear if questions remained about the reliability of the diagnosis and the
18 probability of it becoming malignant. The status of their lesion remained a concern at the next
19 screening round for some women and information about if or how it had changed would have
20 been valued. The responses also showed that a sensitivity to the clinical environment is
21 necessary with due regard for privacy.
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28 **Choice**

29 Following their assessment a number of women were uncertain about the validity of their all-
30 clear diagnosis. They would have liked the option of a follow-up mammogram for reassurance.
31
32

33
34 *Ella: "I thought 'can you just see me in a year's time, just tell me that in a*
35
36 *year's time, it's all OK in a year's time?"*
37

38 *Zoe: "I think the fact that you've been faced with the possibility that*
39
40 *something didn't look quite right, you're not quite sure what it was that*
41
42 *didn't look quite right, um, and maybe a screening a year down the line*
43
44 *would have been, um, something to...to, you know, relieve any nerves."*
45

46 There was also a request for mammograms as an alternative to the invasive investigation of
47 lesions by biopsy that were thought to be almost certainly benign.
48

49
50 *Liz: "Because they said, 'we're pretty sure it isn't anything, but we need*
51
52 *to check if it is anything.' ...and so I suppose what I'm saying is that had*
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2 *there been a little bit more, um, wait and see... I wouldn't have had more*
3 *anxiety if they'd say, 'well, we'll do a mammogram again in three months*
4 *or six months.'*
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7

8 This plea for choice was part of a desire to be more involved in the decision making process
9 about how to proceed once a lesion was detected. Many of the women felt disempowered by
10 the assessment process. They perceived themselves to be Ella: 'in the system' and passive
11 partakers of assessment procedures.
12
13
14

15
16 *Liz: "I think when you're in the middle of it, you just go along with*
17 *whatever's being told... there could have been, uh, more consultation*
18 *maybe at the beginning of things... so...and I'd have probably still have*
19 *gone along with it, [surgery] 'cause I don't think I felt empowered not to."*
20
21
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23

24 Another woman would have appreciated the choice of receiving her biopsy results by post or
25 over the phone, as this further wait prolonged anxiety.
26
27

28 *Fran: "It was just waiting for those results... every day you look for the*
29 *post... and when it's there you're frightened to open it up... it [phone call]*
30 *probably would have been better, really, 'cause you're looking every day,*
31 *aren't you, at the post and thinking, 'oh, my gosh.'"*
32
33
34
35

36 It was clear that some women would have valued more choice in the assessment process.
37 Choice was requested for follow-up mammograms to reduce uncertainty and anxiety about the
38 outcome of assessment, 'watchful waiting' as an alternative to biopsy and test results over the
39 phone rather than through the post.
40
41
42
43

44 **At the next screening round**

45
46 At their next routine screening, some participants' anxieties would have been dispelled if they
47 were told about the status of the lesions previously discovered:
48
49

50 *Jane: "I just got the all-clear letter, sort of thing, [after subsequent*
51 *screening] and when I saw the doctor [GP] I said 'when I...you got the*
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results of me mammogram did it say anything about the cyst?’ And he looked it back and he said, ‘no, it hasn’t said anything.’ And it would have been just nice to know whether I’ve still got it or not.”

Comparison of these results with NHSBSP guidelines

Many of our findings echo those of the research used to produce the NHSBSP 1998 guidelines and indicate that these have not been universally implemented.²³⁻²⁵ A comparison of the NHSBSP guidelines with our service improvement suggestions can be found in Table 3.

Table 3 Comparison of our suggestions with those of the 1998 and 2012 NHSBSP Guidelines

	NHSBSP Recall Guidelines (38) 1998	Bond et al. Service Suggestions 2014
Recall letter information	A clear reason for recall	A clear reason for recall
	Who can come with them	Who can come with them
	How long the appointment will take	How long the appointment will take
	Who they will see	Who they will see
	What tests will be carried out	What tests will be carried out
	Where they can get further information	Reassurance that a swift appointment does not imply the presence of cancer
	How to get to the assessment centre	
	How to change their appointment	
	When the results will be available	
	At the clinic	NHSBSP CSN Guidelines (29) 2012
Availability of a CSN before assessment		Availability of a CSN before and after assessment
		Clear explanation of why the lesion is benign with any risk of change to malignancy
Choice		Literature about the type of lesion
		One-way layout through the clinic
		The offer of a follow-up mammogram in a year for those needing reassurance of their ‘all clear’
		Choice between invasive assessment and ‘watchful waiting’ for lesions almost certainly benign

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**At the next
screening
round**

Choice of hearing biopsy results by post
or over the phone

Clarification of the status of the lesion
found to be a false-positive

The following suggestions are offered to improve services.

Recall letter

Recall letters issued should be consistent and include the following items. The first five items remain unaddressed from the 1998 guidelines.

This should include:

1. The reason for recall
2. Who can come with them
3. How long the appointment is likely to take
4. Who they will see
5. What tests will be carried out
6. Where to get further information
7. The availability of a CNS to answer questions before and after assessment
8. Reassurance that a swift appointment is normal and does not indicate there is anything wrong

At the clinic

9. A pre-assessment conversation with the CNS covering, the reason for recall, the assessment process including possible harms, and the availability of the CNS for a debrief after the assessment whatever the outcome
10. From the Radiologist at diagnosis; sufficient time for a clear explanation of the type of lesion, risk of it becoming malignant, with clarity about uncertainty. If a biopsy is advised then discussion about pros and cons including the reliability of biopsy results and the choice of watchful waiting if the lesion is almost certainly benign

11. The availability of CNS post-assessment to clarify the diagnosis and provide reassurance, as a woman may not feel able to question the outcome with her GP. If the woman remains unsure of the validity of her all-clear a follow-up mammogram should be considered
12. Literature about the type of lesion found should be offered. This should agree with that from the Radiologist and give a phone number for further information
13. The choice of receiving biopsy results by phone or post
14. A one-way system through the clinic so that women do not have to have the outcome of their assessment witnessed or witness other's outcomes

At the next screening round

15. Women should be given an update about their lesion, whether it has gone, stayed the same or grown larger, with an explanation of the implications

Discussion

While overall participants were satisfied with the service they received, they raised a number of areas where it could be improved. Many of the items in the 1998 NHSBSP guidelines remained outstanding. Some women were still asking for more information in the recall letter about: the reason for their recall; who could come with them; how long the appointment might take; who they would see and what would happen to them. Some participants were also concerned that a swift appointment implied that they had cancer. At the assessment clinic a more explicit explanation of why their lesion was benign and the risk of it becoming malignant would have reduced anxiety, together with literature about their type of lesion. The women also expressed requests for more choice as some were left with doubt about the validity of the outcome of the assessment and would have appreciated an offer to have a follow-up mammogram in a year's time for reassurance and an update on the status of their lesion at their next screening round. Others felt powerless and in 'the system' when faced with a biopsy; an alternative of 'watchful waiting' for lesions that were almost certainly benign, would have been valued and empowering. A choice of having biopsy results by post or over the phone was also requested. Additionally

1
2 some participants would have valued an opportunity to see the CNS after assessment as well
3
4 as before. Finally, the layout of the clinic precipitated anxiety for some women while they were
5
6 waiting, as they were able to see and hear the distress of women who had been diagnosed with
7
8 cancer. There was no apparent link between participants' demographic characteristics and the
9
10 issues they raised.

11
12 The strengths of this study are that it was rigorously conducted and provides current, in-depth
13
14 insights into the views of women, with false-positive mammograms of the assessment service
15
16 they received. Thus it provides valuable evidence of how these services may be improved so
17
18 that the anxiety associated with having false-positive mammograms may be reduced. The
19
20 influence of the researcher (MB) is acknowledged, both from her manner, verbal and non-verbal
21
22 cues during the interview; there is also the potential for social desirability effects²⁶. The analysis
23
24 has been through the filter of the researcher's particular understanding of the issues, including
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26 being someone who has not had mammography. This will have influenced the way the
27
28 interviews were interpreted, due to the lack of first-hand experience. Qualitative research is
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30 notably subjective and is open to the charge that the results lack generalisability. However,
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32 although the study has a number of limitations and further research is needed to establish the
33
34 UK national picture, we believe these results are reasonably robust, transferable and relevant
35
36 for consideration in policy development. This is because the interview findings were validated
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38 using Yardley's principles²² and by participant feedback of a lay summary of the results. The
39
40 study is limited by lack of demographic detail, the limited geographical area (Devon) and the
41
42 possible unreliability of the participants' memories as these events occurred between six
43
44 months and 12 years previously i.e. recall bias.²⁷ However, the consistency of our findings with
45
46 previous research²³⁻²⁵ and other studies, which have shown a positive association between the
47
48 accuracy of long-term recall and the traumatic impact of an event up to 21 years^{28,29}, give us
49
50 confidence in the reliability of our results.

51
52 Internationally, questionnaire studies have also found that overall women are satisfied with
53
54 mammography screening recall services.⁷⁻¹⁰ In the case of false-positive mammograms there is
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a certain irony about this response as the women are satisfied with a service that has made a mistake in recalling them and may have caused them unnecessary anxiety. Further evidence comes from the Danish interview study by Lindberg et al. which found women with false-positive mammograms were grateful for the service which had brought their health into question and caused them psychological distress.³⁰ Some studies found, in agreement with ours, that the attitude of clinic staff as well as the quality of information and the physical environment affected satisfaction.^{7,9,10,14} Our findings also agree with the results from the US qualitative study (2001), that some participants thought the information they received was inadequate.¹²

Although our research comes from a limited geographical area, and other regions of the UK may have better service provision, it implies that there is still some way to go to provide women who are recalled after breast cancer screening with a satisfactory service. There is a need for consistency in the implementation of recommendations and a mechanism for ensuring this occurs.

Service implications

These suggestions will require additional resources; increased hours for the CNS and additional mammography for those needing reassurance or choosing 'watchful waiting'. However, most of the suggestions can be implemented at the lower cost of revising literature and giving clearer explanations, which may mean that fewer women are left with uncertainty and request on-going care.

Conclusion

It is time the NHSBSP 1998 recall information guidelines were fully implemented. Additionally, the further suggestions from this research, including extending the role of the CNS from the 2012 NHSBSP guidelines, should be considered.

Further research is needed to establish whether the 1998 NHSBSP recommendations are in place nationally and if the additional measures outlined in these service recommendations are sought by women throughout the UK.

1
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3

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6
7

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9 participants with the support of the SW Primary Care Research Network, conducted and
10 analysed the interviews, obtained respondent feedback, undertook the comparison with UK
11 guidelines and formulated service improvement suggestions, wrote and edited the research
12 paper. RG contributed to the design of the study, advised on the qualitative aspects and
13 commented on the draft paper. CH contributed to the design of the study, advised on the health
14 services aspects and commented on the draft paper.
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22
23

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37 Figure 1 Category development
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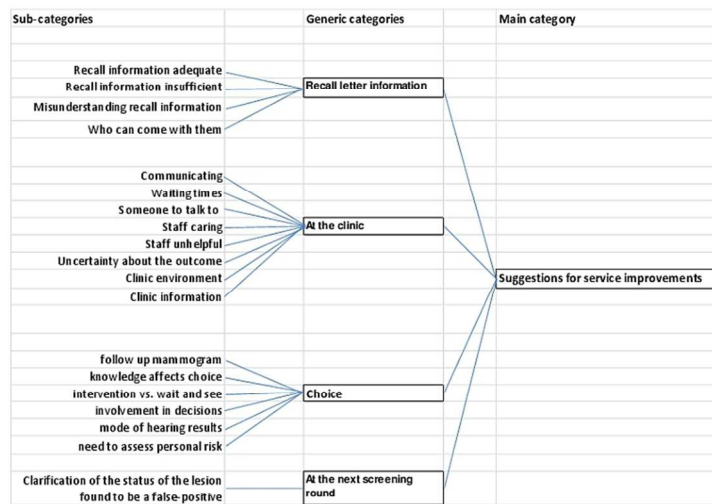
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Figure 1 Category development



90x63mm (300 x 300 DPI)

view only

Table 2 Summary of participants' characteristics

Characteristics	No (%) women
Age (years)	
40-49	2 (10)
50-59	11 (52)
60-69	8 (38)
Marital status	
Married or cohabiting	19 (90)
Single, separated or widowed	2 (10)
Ethnicity	
White	21 (100)
Time since false-positive (years)	
≤ 1 year	4 (19)
2-4	7 (33)
5-7	8 (38)
8-10	1 (5)
11-13	1 (5)
Type of assessment procedure*	
Mammogram	16 (76)
Ultra-sound	12 (57)
Fine needle aspiration	1 (5)
Biopsy	4 (19)
Index of multiple deprivation %	
Unknown	4 (19)
0-9	1 (5)
10-19	0 (0)
20-29	2 (9)
30-39	3 (14)
40-49	2 (9)
50-59	4 (19)
60-69	4 (19)
70-79	1 (5)
* Many women had more than one assessment procedure	