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1. INTRODUCTION

BACKGROUND

The NHS Breast Screening Programme was introduced to Northern Ireland in 1989 and was established in all four Health and Social Services Boards by 1993. Free routine breast screening is offered to all women between the ages of 50 and 64 every three years. The rationale behind the screening programme is that early detection of breast cancer contributes to an improved outcome.

The success of any screening programme is to a great extent influenced by its level of uptake. The current target recommended for breast cancer screening is that 75% of all women aged between 50-64 years should attend. The percentage of women in the Southern Board's area within this age group who were screened for breast cancer in the 3 years up to 31 March 2000 was 75% (HPSS Performance Tables for 1999-2000). However this aggregate figure for the Southern Board area disguises the differences in the level of uptake between women living in the three Trust areas. Between April 1996 and March 1999 only 61.9% of women in the Newry area attended for breast screening.

Table 1.1 Breast screening uptake rates – April 1996-March 1999

	Lurgan	Newry	Armagh	Dungannon
No. invited	11,250	7087	3295	2279
No. attended	8363	4385	2477	1836
% uptake	74.3%	61.9%	75.2%	80.6%

Source:- Lurgan Hospital Breast Screening Unit (1999).

PREVIOUS RESEARCH

Previous research has indicated a wide range of factors which may have an impact upon breast screening uptake rates. These include organisational and administrative factors such as the lack of accurate information and the type of invitation and also characteristics of the

woman such as the sociodemographic factors, attitudes, beliefs and knowledge as well as previous screening experiences.

In terms of administrative factors, Hurley et al (1994) found that the most important predictor of attendance for screening was receipt of an invitation. However McEwan et al (1989) found that the registers used by the various screening programmes were to some extent inaccurate. Sutton et al (1994) found that almost 25% of the names and addresses could not be matched with the electoral register. Boomla et al (1995) concluded that if the accuracy of the addresses improved so would uptake rates for both breast and cervical screening.

In terms of the type of invitation, Sharp et al (1996) concluded that a personal letter from the GP was as effective at increasing the uptake of breast screening in non-attenders as a nurse making a home visit to discuss the issue of breast screening. However O'Connor et al (1998) concluded that a personal recommendation by a letter prompting attendance for mammography from the GP best known to women due to be screened did not improve uptake of breast screening in an inner city practice. Hurley et al (1994) found that the response to an invitation that included an appointment time was much higher than the response to a letter without a specific appointment time. Similarly Stead et al (1998) found a significant difference in response to a second invitation between the open invitation and fixed appointment letter. The greatest disparities were between those who had attended screening in both preceding rounds and those who failed to attend either. Fixed appointments were more effective in encouraging women who had previously been screened to attend.

Socio-demographic and economic factors have been reported to predict attendance for breast screening. Hurley et al (1994) found lower attendance rates among women who lived in less well off areas. Baker and Klein (1991) found variations in the uptake of screening services with rates as low as 50% in some deprived/inner city areas and as high as 80% in affluent suburban and rural areas. Sutton et al (1994) found that women in rented accommodation were less likely to go for

screening. Pearson and Parkinson (1994) similarly found that non-attenders were significantly more likely to live in rented accommodation

The issue of the distance from and convenience to the screening site has also been examined. Hurley et al (1994) and Haiart et al (1990) found a decrease in attendance with increasing distance from the screening site. However Sutton et al (1994) in a prospective study of predictors of attendance for breast screening in inner London found distance between home and the screening centre to have been unrelated.

The attitudes and beliefs of women who do and do not attend for breast screening has been the focus of research to explain attendance and non-attendance. Maclean et al (1984), French et al (1982) and Hobbs et al (1980) all found that some non-acceptors have been found to react to an invitation to a breast screening clinic with fear and worry that a problem will be found, whilst other women regarded screening as unnecessary because they perceived their health to be good.

Sutton et al (1994) reported that women's perceived risk of breast cancer was related to the probability of attendance, with those who felt more vulnerable being more likely to go. Similarly Cockburn et al (1997) found that a woman's perception of whether she was at any risk for breast cancer was significantly associated with attendance. However perceptions of risk were not associated with the woman's age, family history of breast cancer, previous contact with other people with breast cancer or having a breast lump. Aro et al (1999) found that seeing their risk as moderate was predictive of attendance. However Marshall (1994) found no significant difference between re-attenders and non-attenders in their perceived risk of breast cancer.

Aro et al (1999) found that being worried about illness was predictive of attendance for breast screening. Sutton et al (1994) concluded that women who reported a moderate amount of worry about breast cancer were more likely to attend than those at the two extremes.

Knowledge about the symptoms of breast cancer has also been identified as being predictive. Aro et al (1999) found that believing most lumps were malignant was predictive of attendance. Maclean et al (1984) reported that 90% of women who didn't attend for breast screening considered that a lump was the way in which breast cancer was first manifested, only 4% knew that there might be pain, and only one mentioned nipple abnormalities.

Vaile et al (1993) found that the women's perceived control over attendance strongly predicted attendance. Aro et al (1999) concluded that low self-confidence in a woman's own ability in preventing breast cancer was predictive.

Aro et al (1999) reported that perceiving mammography as a sensitive technique for detecting breast cancer was predictive of attendance. Similarly Sutton et al (1994) found perceived effectiveness of breast screening to be related to levels of attendance. Kruse and Philips (1987) and Orton et al (1991) found that those who re-attended were more likely to believe that screening could detect breast problems at an early and curable stage.

Some previous research has directly examined women's reasons for either attending or not attending for breast screening. Pearson and Parkinson (1994) identified the reasons given by non-attenders for not accepting the invitation as; the arrangements were inconvenient, they thought they were not at risk of breast cancer, they were afraid of cancer, had recently had a check-up or mammogram, and they thought it would hurt or cause embarrassment. Falshaw et al (1996) identified similar reasons for non-attendance; fear of the result, fear of the unknown, low self-esteem, a feeling of being healthy and therefore not needing to attend, and not having received or understood the invitation letter.

2. METHODOLOGY

AIM

The overall aim of the project was to identify the reasons why women in the Newry and Mourne area did and did not attend for routine breast screening.

OBJECTIVES

Specific objectives were to:

- Identify the attitudes and beliefs of attenders and non-attenders to breast screening and breast cancer.
- Explore attenders' and non-attenders' knowledge about breast screening and the symptoms of breast cancer.
- Compare and contrast the attitudes, beliefs and knowledge of attenders and non-attenders.
- Compare and contrast demographic and socioeconomic factors of attenders and non-attenders such as area of residence, educational attainment and car ownership.
- Identify the factors prevalent in women's decisions to either attend or not to attend for breast screening.
- Identify ways in which the level of uptake of screening in the Newry and Mourne area could be increased.

PARTICIPANTS

The target population included all women who had been invited to attend Daisy Hill Hospital for routine breast screening under the NHS Breast Screening Programme between January and April 2000. The NHS Breast Screening Programme invites women between the ages of 50 and 64 years to attend for routine breast screening every three years.

Overall 800 women were randomly selected from the Prior Notification Lists¹ produced by the Central Services Agency of all women in the Newry and Mourne area who were invited to attend for screening between January 2000 and April 2000.

Within this timeframe, women who attended GP practices in either Newry or Warrenpoint were invited for breast screening. These are two distinct areas in Newry and Mourne therefore it was decided to take this consideration into account when selecting the sample. Before the 800 women were randomly selected the sample was split into two groups – women whose GP was based in Newry and women whose GP was based in Warrenpoint. Four hundred women from each group were randomly selected. The researchers were blind as to which women attended for screening and which did not when the sample was selected and questionnaires distributed.

PROCEDURE

A questionnaire was developed to address the aim and objectives of the research. These were distributed to the 800 women with a pre-paid envelope. The questionnaires were coded with an identity number so that reminder letters could be sent to non-respondents. All responses to the questionnaires were anonymous and treated confidentially.

Previous research indicated that a low response rate from women who did not attend for screening was likely (Aro et al 1999; Sharp et al 1996). In an attempt to encourage women to respond a number of steps were taken. Firstly all completed questionnaires returned before the closing date were entered into a draw for a meal for two at a local hotel. This information was included in the letter distributed with the questionnaire. Secondly two press releases were included in the local press at the time of the survey. The first was released at the time of the distribution of the

¹ These lists are produced by the Central Services Agency. They include women between the ages of 50 –64 years who are eligible for breast screening under the NHS Breast Screening Programme. They are circulated to GP practices in advance of the invitation being issued to check for accuracy.

questionnaire and encouraged all women to complete and return their questionnaire. The second article was released at a later date and particularly targeted women who had not attended for screening to complete and return their questionnaire.

3. FINDINGS

CHARACTERISTICS OF RESPONDENTS

In total 480 women (60%) responded to the survey. The majority (92%) said they had attended Daisy Hill Hospital for breast screening when they were invited. A small proportion (n=39, 8%) had not.²

The vast majority of women were aged between 50 and 64 years, 34% were aged between 50-54 years, 33% between 55-59 years and 29% between 60-64 years. Respondents who didn't attend for breast screening were similar in age to those who did.

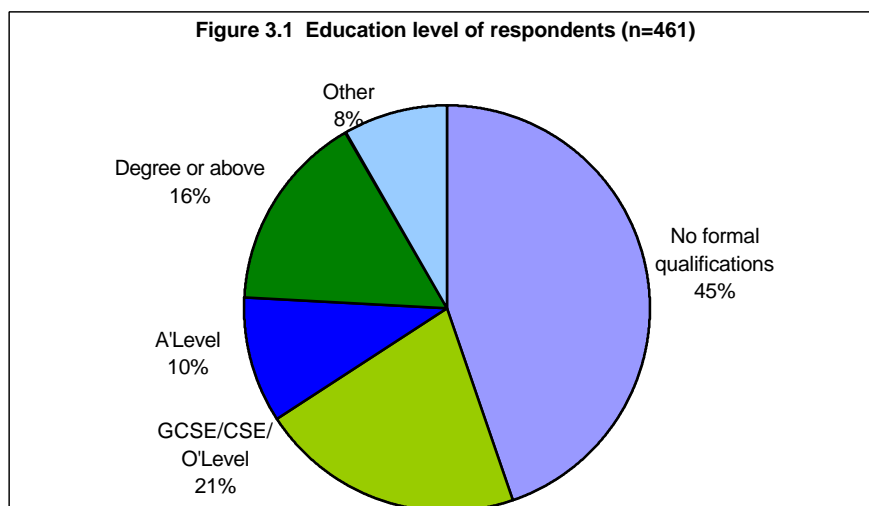
Table 3.1 Age of respondents

	Attenders (n=441)	Non-attenders (n=39)	Total
50-54 years	34%	31%	34%
55-59 years	32%	36%	33%
60-64 years	30%	28%	29%
65+ years	3%	3%	3%

[2 attenders and 1 non-attender were aged under 50 years]

Respondents' highest level of formal qualifications varied. Nearly half (45%) had no formal qualifications. One in five (21%) were educated to GCSE/CSE/O'Level, 10% to A'Level and 16% were educated to degree level or above.

² 38% of women in Newry and Mourne did not attend for breast screening (1996-99) but only 8% of respondents to the survey were non-attenders. This suggests that a higher proportion of attenders responded to the survey than did non-attenders



Most women (82%) had access to a car from within their own household. However there was a trend for more women who attended for screening to have had access (83%) than women who did not attend (69%).

Table 3.2 Car ownership

	Attenders (n=441)	Non-attenders (n=39)	Total
Car in household	83%	69%	82%
No car in household	15%	28%	16%

Attenders and non-attenders differed in their description of their health status within the previous 12 months. Women who didn't attend for breast screening were more likely than those who did to have been in poor or very poor health (23%, 10%). Subsequently attenders were more likely than non-attenders to have said their health was very good, good or average (90%, 77%).

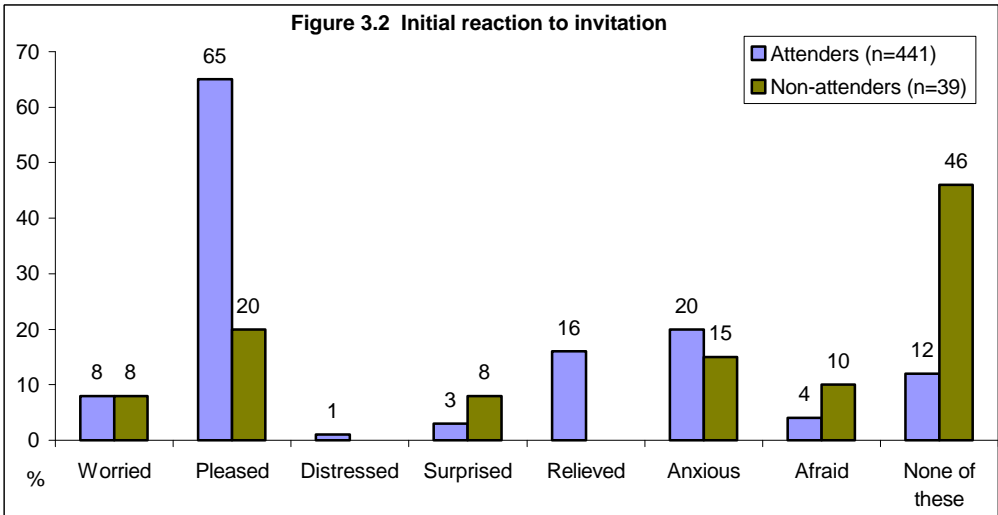
Table 3.3 Health status

	Attenders (n=441)	Non-attenders (n=39)	Total
Very good, good or average	90%	77%	88%
Poor or very poor	10%	23%	12%

REACTION TO THE INVITATION

Women who didn't attend for breast screening were significantly less likely to have expected the invitation. Half the non-attenders (50%) expected it compared to 86% of women who did attend.

Women who attended for breast screening and those who didn't had different initial reactions to receiving their invitations. Attenders were significantly more likely to have been pleased (65%) and relieved (16%) than non-attenders. Non-attenders were more likely to have said that they felt none of the feelings outlined In Figure 3.2.

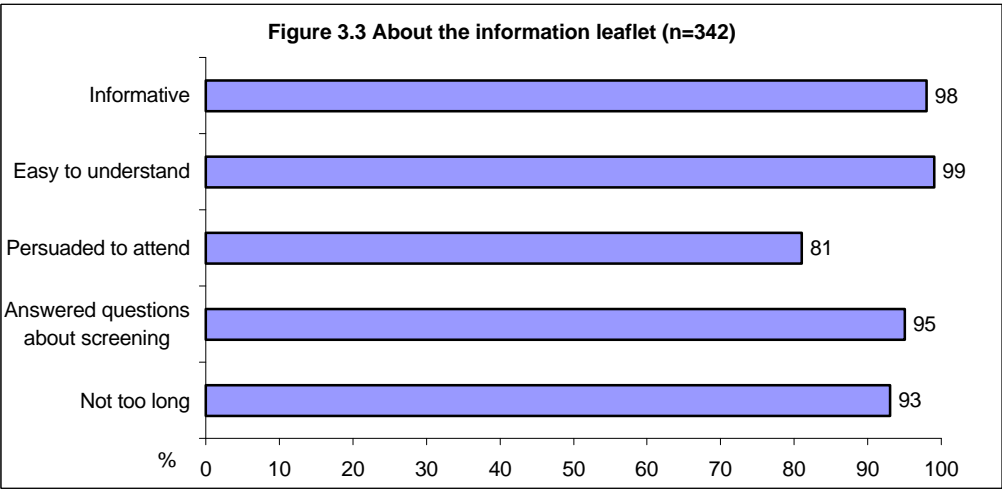


Women whose GP practice was based in Newry were more likely than women whose GP practice was in Warrenpoint to have felt worried and afraid whenever they initially received the invitation to attend for breast screening at Daisy Hill Hospital.

	Newry (n=217)	Warrenpoint (n=263)
Worried	11%	5%
Afraid	8%	3%

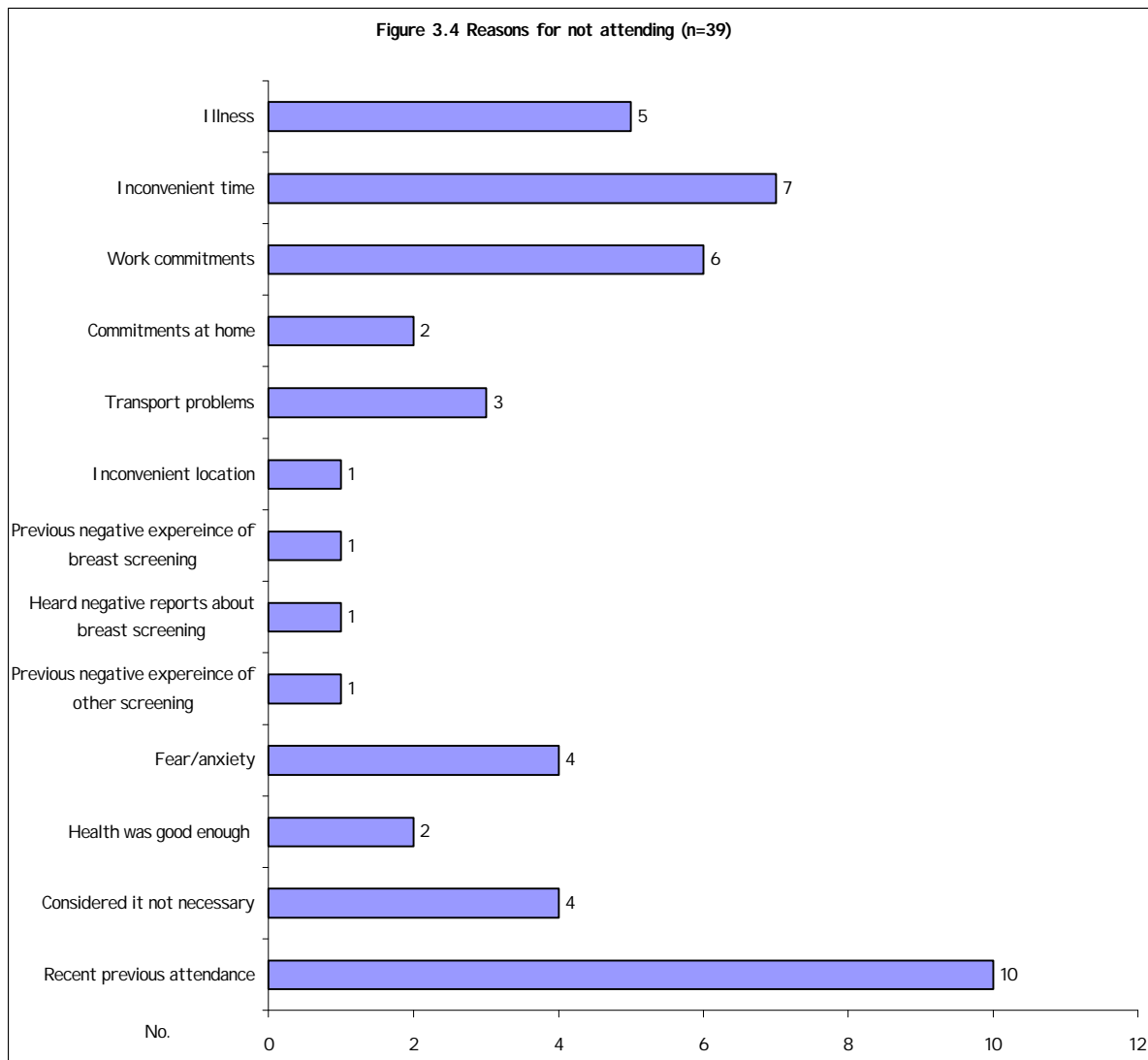
Overall, 71% of respondents said they received an information leaflet about breast screening with their invitation. The proportion that said they had was higher among attenders (76%) than non-attenders (51%).

The vast majority of respondents, who recalled receiving a copy of the information leaflet, rated it positively. Most (99%) found it easy to understand, 98% said it was informative, 95% said it answered any questions they had about screening, 93% disagreed that it was too long and 81% said it persuaded them to attend for breast screening.



REASONS FOR NOT ATTENDING

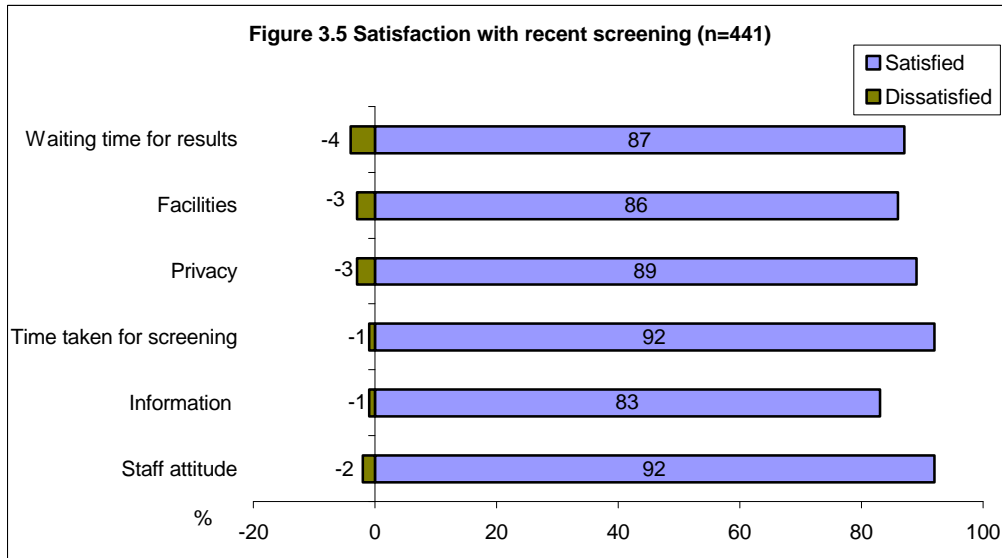
The most common reason why women who responded to the survey gave for not attending was because they had recently had a mammogram (n=10). The next most common reason was due to the inconvenience of the appointment time. Six women did not attend because of work commitments, 4 of whom had previously attended for breast screening (1995 - 1997). Five women did not attend because of illness, 4 because of fear or anxiety about the screening process and 4 women did not consider it necessary to attend. Other reasons why women did not attend included transport problems (3), commitments at home (2) and 2 women considered they were in good enough health.



EXPERIENCES OF BREAST SCREENING

- **Recent screening**

The vast majority of women who attended were satisfied with their most recent experience of breast screening, 92% were satisfied with the attitude of staff and the length of time taken. Most (83%-89%) were also satisfied with the information provided, the facilities, the time taken to receive the results and the privacy while being screened. Overall 7% of women indicated that they were dissatisfied with some aspect of the screening process. The most commonly mentioned aspects which caused dissatisfaction were; the time taken to get the results (4%), privacy and facilities for screening (3%) and staff attitude (2%).



Women were dissatisfied with the waiting time to get the results because they were anxious or worried about getting them.

“Waiting time for results too long. This led to great anxiety for me.”

“...Friend had screening same day, same time approx. She had results within one week. My results took up to 2 weeks – worried as to delay.”

Privacy caused dissatisfaction because of the lack of gowns, having to move to a different room while undressed and the presence of other staff during the screening process. Women were dissatisfied with the actual screening process because they found it painful.

“Felt lack of privacy from change room to x-ray room. You have to put a loose blouse or jacket around you from change room to x-ray as doorway opposite x-ray room you are entering is in use and you have to dodge the people from outside seeing you enter the x-ray room and returning to change room.”

“There were no gowns available due to cutbacks – also had to walk across a corridor stripped to the waist with only your own jacket etc held close.”

“...Other members of staff came into the room while I was being screened, or just had been screened and it was embarrassing.”

“There seemed to be a problem with the machine and one side had to be done twice.”

“My only gripe would be the actual design of the screening equipment – it can prove very painful.”

“...The machine itself terrified me. I was afraid its jaws would not be manually stopped in time and would hurt. This happened.”

Others were unhappy with staff attitude because they felt they were insensitive or did not put the individual at ease.

“When staff were collecting my letter they didn’t take time to speak to me closely, or make me feel at ease. P.S. a smile.”

“I was not happy with some of the staff’s attitude towards me regarding tenderness in my left breast on the same day, and actually felt like a piece of meat for the slaughter. I thought they were very insensitive with my breasts and it was quite uncomfortable as well.”

In addition a small proportion of women (4%) found the process embarrassing. There was a degree of overlap in what caused dissatisfaction and what caused embarrassment. Lack of privacy and feeling exposed were commonly mentioned.

“Although I was dealt with by one member of staff satisfactorily, other staff were moving in and out and generally moving in the confined screening area.”

“...Would have liked some sort of screen or curtain between me and the door. Felt someone might walk in – some other patient or general public, that made me anxious.”

“There were four female medical staff in the room with me – maybe five. I found this a bit less intimate than expected and a bit embarrassing standing around waiting for the machine to be prepared.”

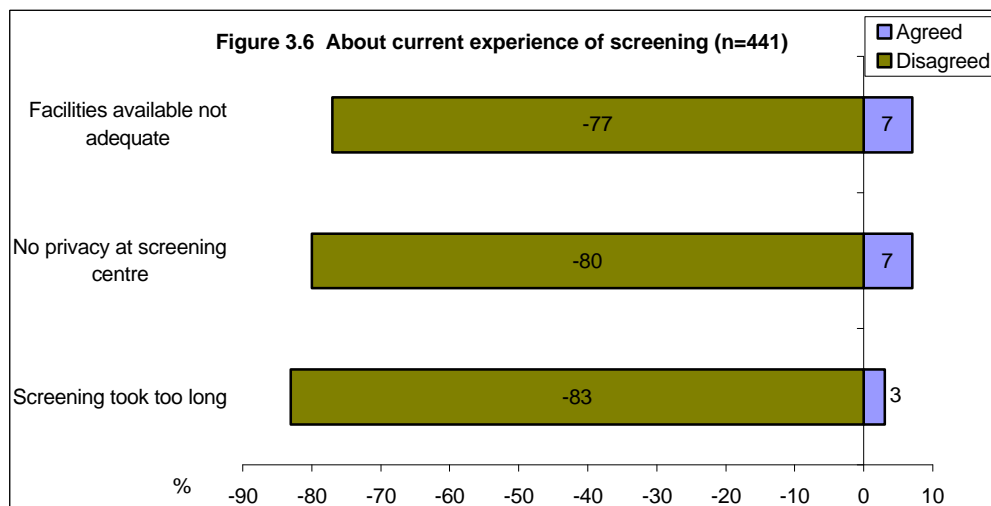
“Going from the changing room to the x-ray room. I feel some sort of a gown should have been provided.”

Some women felt embarrassed about their size.

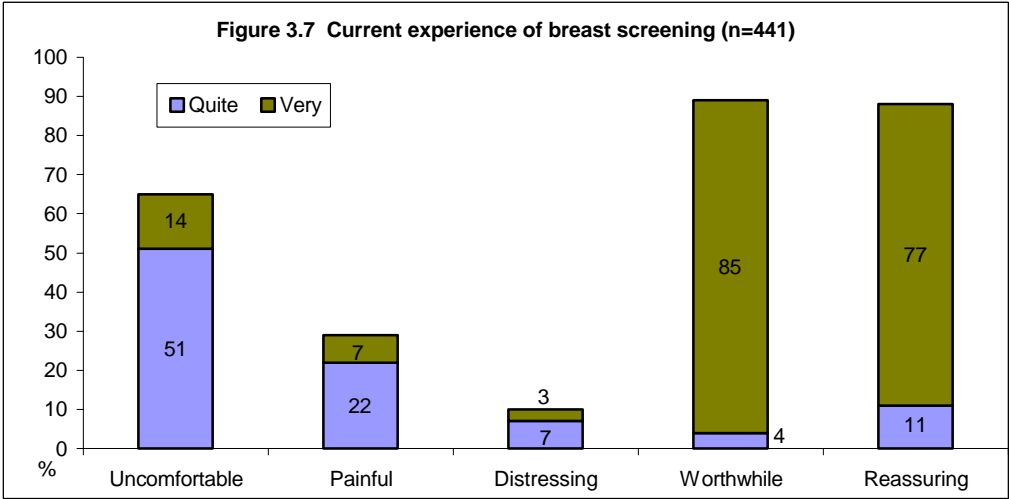
“I felt embarrassed when other staff entered the room during my screening/or just after I was screened. It is embarrassing if you are quite big in the bust!”

“As my breasts are rather large the radiographer suggested I ask to be screened in Craigavon next time where they have better facilities to cater for ‘larger ladies!’”

The vast majority of women disagreed that; the screening process took too long (83%), there was no privacy at the screening centre (80%) and the facilities available were inadequate (77%). However a small proportion (7%) did find the facilities and the level of privacy inadequate.



The vast majority of women considered their experience of breast screening to have been worthwhile (89%) and reassuring (88%). Most rated it as ‘very’ worthwhile and ‘very’ reassuring. However just under two thirds (65%) considered it uncomfortable, nearly one in three (29%) found it painful and 10% said it was distressing.



- Previous screening**

Women who attended for breast screening were more likely to have had previously attended than were women who did not attend, 82% of attenders had previously attended compared to 59% of non-attenders.

Most women who had been screened had done so three years before – 40% said their last attendance for breast screening was in 1997. Just less than a quarter (23%) said their most recent screening occurred in either 1998 or 1999.

Table 3.5 Previous attendance for screening (n=383)

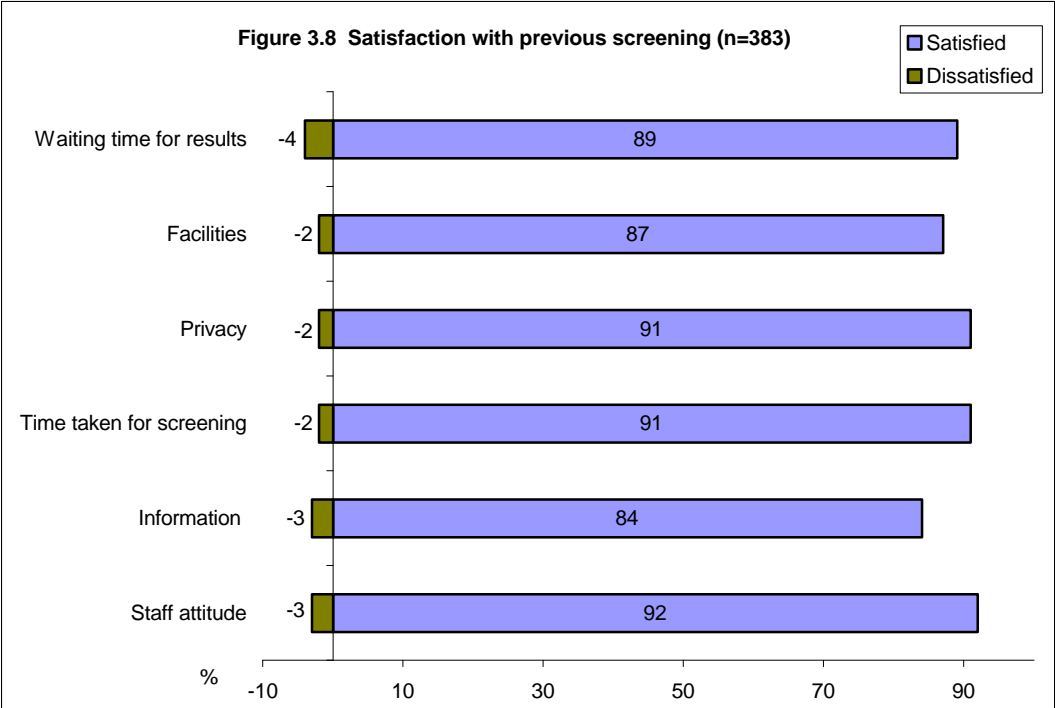
1996 or earlier	13%
1997	40%
1998	12%
1999	11%
2000	5%

Nearly a fifth (18%-n=7) of all non-attenders had attended for screening within the previous year. Six non-attenders had attended for mammography during the previous round in 1997.

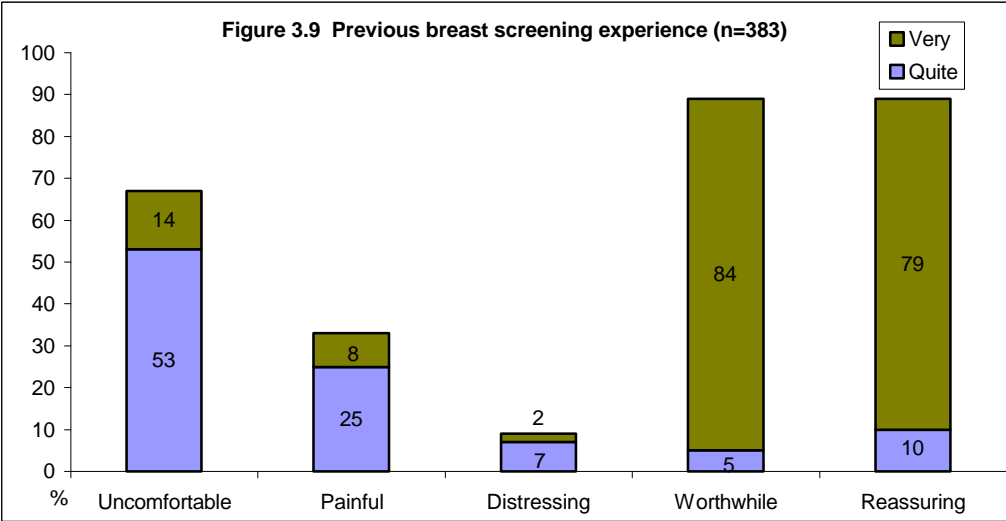
Table 3.6 Previous attendance of non-attenders (n=23)

1996 or earlier	4
1997	6
1998	2
1999	6
2000	1
* 4 missing cases	

The majority of respondents were satisfied with their previous experience of breast screening. The vast majority (92%) were satisfied with staff attitude and the time taken for the screening. Satisfaction with the other aspects ranged from 83% - 89%. Similar to the most recent experience, dissatisfaction with the previous screening ranged from 2% - 4%. The most commonly mentioned aspect which caused dissatisfaction was the waiting time to get the results (4%).



The vast majority of respondents (89%) considered their previous experience to have been worthwhile and reassuring. Most rated it as ‘very’ worthwhile and ‘very’ reassuring. Just over two thirds (67%) said it was uncomfortable, one in three (33%) found it painful and 9% said it was distressing.



Non-attenders who had previously been screened were less likely to have found the experience ‘very’ worthwhile (54%) than attenders (87%) and more likely to have found it ‘very’ or ‘quite’ distressing (23% & 8%).

Table 3.7 Differences in previous experiences

	Attenders (n=358)	Non-attenders (n=23)
Very or quite distressing	8%	23%
Very worthwhile	87%	54%

A small proportion (3%) found some aspect of their previous screening experience embarrassing. The issues highlighted were similar to those highlighted by respondents in relation to their recent experience – lack of privacy and feeling exposed.

One in five women (22%) who had attended screening previously made suggestions as to how the experience of breast screening could be improved. Some suggestions referred to improving the actual screening process so that it was less painful.

“It would be the screening, I found it painful, and I had some blood in my left nipple some weeks later.”

“The clamp used to x-ray the breast is closed very tight. A new device in which the breast could be placed and not clamped would make the procedure a lot less painful and uncomfortable.”

“I don’t quite know how, but I would have thought that modern technology could make the procedure less painful – I found it very painful!”

“I feel a scan would be more comfortable and more accurate. A lump wasn’t found on mammogram on my sister. The lump showed up on scan and it was malignant.”

“The design of equipment – why is it necessary to squash a round breast between two plates – the breast isn’t squashed to scan it.”

Other suggestions referred to shorter waiting times to get the results.

“Results quicker – It would be great if results were available on day – like Craigavon Area Hospital.”

“Get results to women out quicker as it is so distressing when you have say a mother who dies with it and a sister with it.”

“Waiting time for results if there is thought to be a problem.”

“I know it’s not always possible, but, not too long a wait – gives for time to think.”

Other women suggested that the screening should take place more frequently and that other age groups should also be eligible.

“Screen all women every two years irrespective of age.”

“I would like to see the time when women could get breast screening done on a yearly basis but fully realise this is not possible as yet. Also as I am now 64 I would like to be able to continue going as long as possible.”

“To extend screening to include age group 20-34 years. (Especially if there is a family history of breast cancer).”

“An annual screening perhaps?”

Some women made suggestions which referred to improving the privacy and dignity during the screening process.

“Privacy. One member of staff in private.”

“That no one would enter the room while you are having the procedure carried out.”

“...no other people coming and going, even though they are professional and female, while I’m sitting there half naked.”

“Private door to screening room.”

Suggestions relating to the attitude of staff were also made.

“That staff could be more pleasant and not so abrupt. It doesn’t cost anything to smile and it goes a long way in reassuring a nervous person.”

“A kinder and more friendly attitude from staff.”

“Maybe if the staff on hand could speak and reassure you while you were uncomfortable, in pain and distressed.”

Other suggestions included the need for more information, the special needs of those with disabilities and the waiting area.

“It is very tiring for me to stand and sitting would be more comfortable.”

“To make it more accessible for people with mobility problems and those who use a wheelchair.”

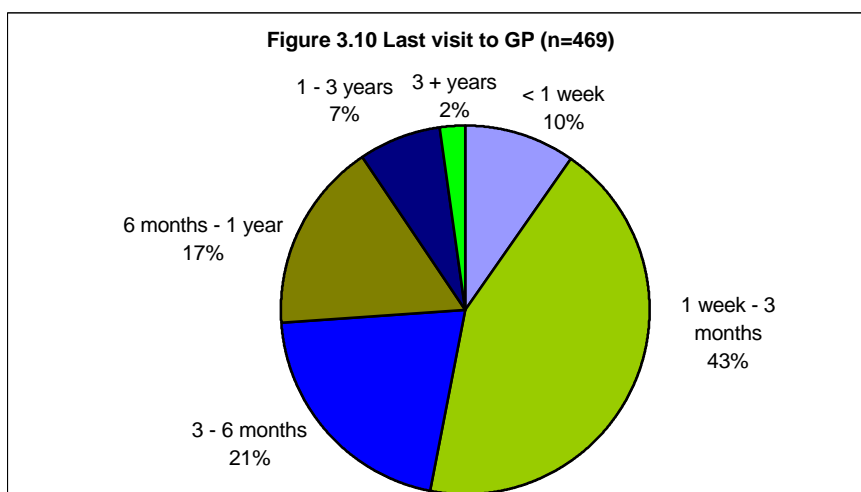
“More information on breast cancer from staff and literature on latest research on same.”

“That perhaps, there could be some-one, who could show me how to examine my breasts properly, at the time of screening.”

“Perhaps clinic area (waiting) could be more cheerful...”

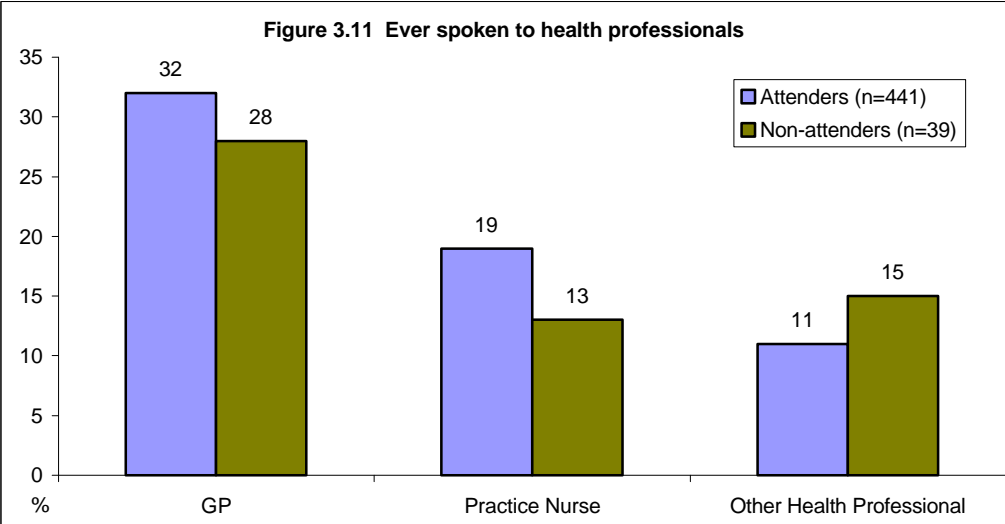
CONTACT WITH OTHER HEALTH PROFESSIONALS

Three quarters of all women who responded to the survey (74%) had visited their GP within the previous 6 months. Just over half (53%) had done so within the previous three months and 10% within the previous week.



Less than a third (31%) had spoken to their GP about breast screening although they were more likely to have spoken to their GP than any other health professional. Nineteen percent had spoken to a practice nurse and 11% said they had discussed it with some other health professional at some stage. Just under a third of women who attended for screening

(32%) and 28% of those who didn't had at some stage spoken to their GP about breast screening. Nineteen percent of attenders and 13% of non-attenders had spoken to a practice nurse and 11% of attenders and 15% of non-attenders had discussed the issue with another health professional.

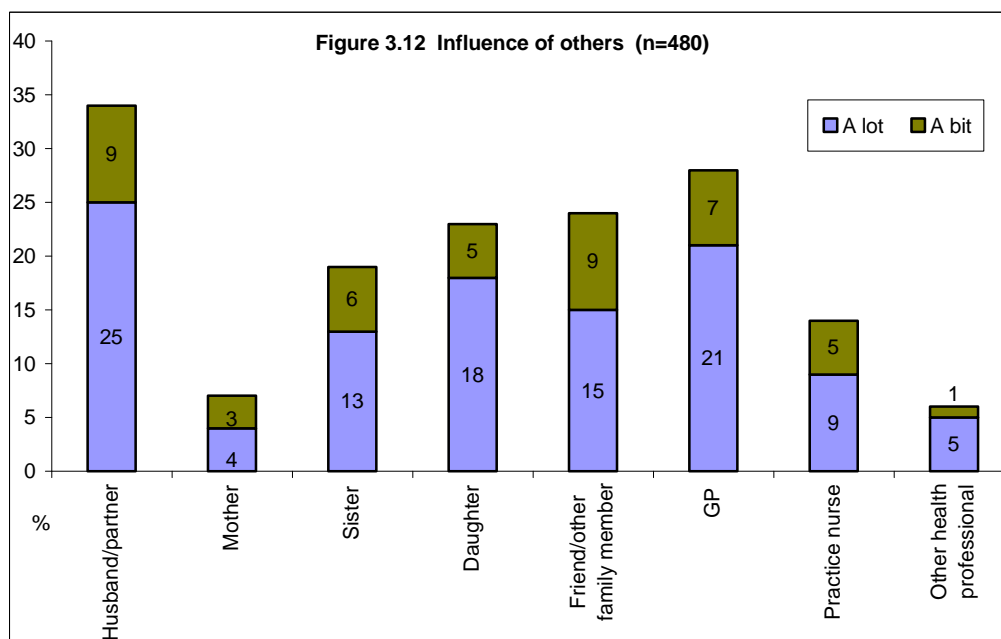


The last time respondents had spoken with the various health professionals about breast screening varied from less than 3 months to over 3 years. Over a quarter of discussions with the GP (27%) and the practice nurse (26%) took place 6 months – 1 year previously. Nearly half of discussions with other health professionals (46%) took place within the previous 6 months.

Table 3.8 Discussions about breast screening with health professional

	< 3 months	3-6 months	6 months – 1 year	1-3 years	3+ years
GP (n=150)	16%	21%	27%	14%	17%
Practice Nurse (n=90)	14%	21%	26%	22%	9%
Other Health Professional (n=53)	23%	23%	15%	19%	11%

Respondents indicated a range of individuals who had some degree of influence in their decision to attend for breast screening. The respondent's husband/partner was most frequently mentioned - 25% said their husband/partner had 'a lot' of influence in their decision and 9% said they had 'a bit'.



Just over a quarter (28%) said their GP influenced their decision. Women whose GP practice was in Warrenpoint were more likely than women whose GP practice was in Newry to have said that their GP influenced their decision. One in five (20%) respondents who attended a GP practice in the Newry area said their GP had ‘a lot’ or ‘a bit’ of influence in their decision whether or not to attend for breast screening compared to 35% of respondents whose GP was in Warrenpoint.

Table 3.9 Influence of GP by area

	GP practice in Newry (n=217)	GP practice in Warrenpoint (n=263)
GP had a lot of influence	16%	25%
GP had a bit of influence	4%	10%

In examining the impact of the influence of others Table 3.10 illustrates a trend that attenders were more likely than non-attenders to indicate that a family member influenced their decision. Differences were greatest in relation to their husband/partner (36% and 13% respectively) and their daughters (25% and 13%). While overall similar proportions of attenders and non-attenders indicated their sister influenced their decision (20%

and 16%), a larger proportion of attenders stated that their sister had ‘a lot’ of influence over their decision (15% and 3%).

Table 3.10 Influence of others by attendance

	Attenders (n=441)		Non-attenders (n=39)	
	A lot	A bit	A lot	A bit
Husband/partner	27%	9%	8%	5%
Sister	15%	5%	3%	13%
Daughter	20%	5%	5%	8%

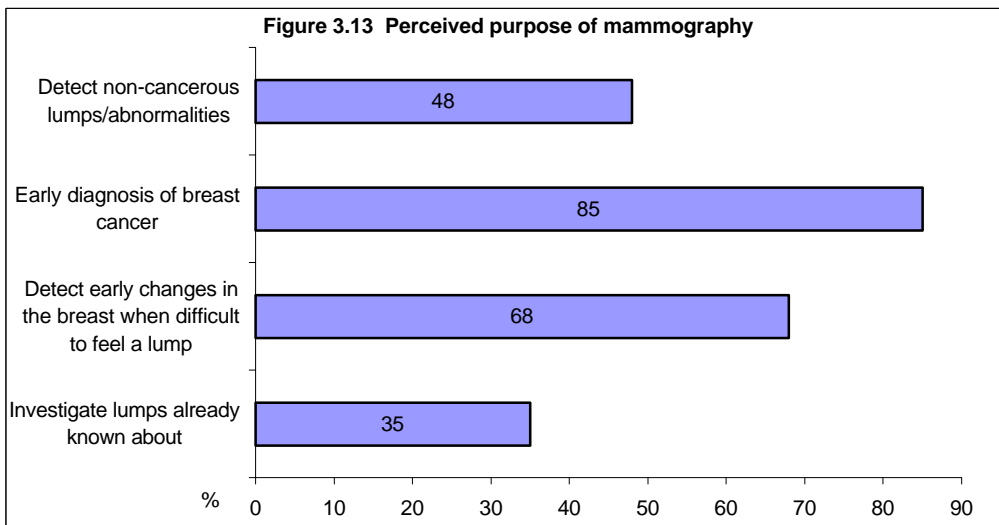
KNOWLEDGE

Overall, 38% of respondents correctly identified that women between the ages of 50-64 years should attend for breast screening and 35% were aware that this should take place every three years. Women who had attended for screening were more likely to have known this. Over a third (38%) of attenders and 28% of non-attenders knew that the target group for breast screening was 50-64 years and 36% of attenders and 18% of non-attenders knew that a woman should attend for screening every three years.

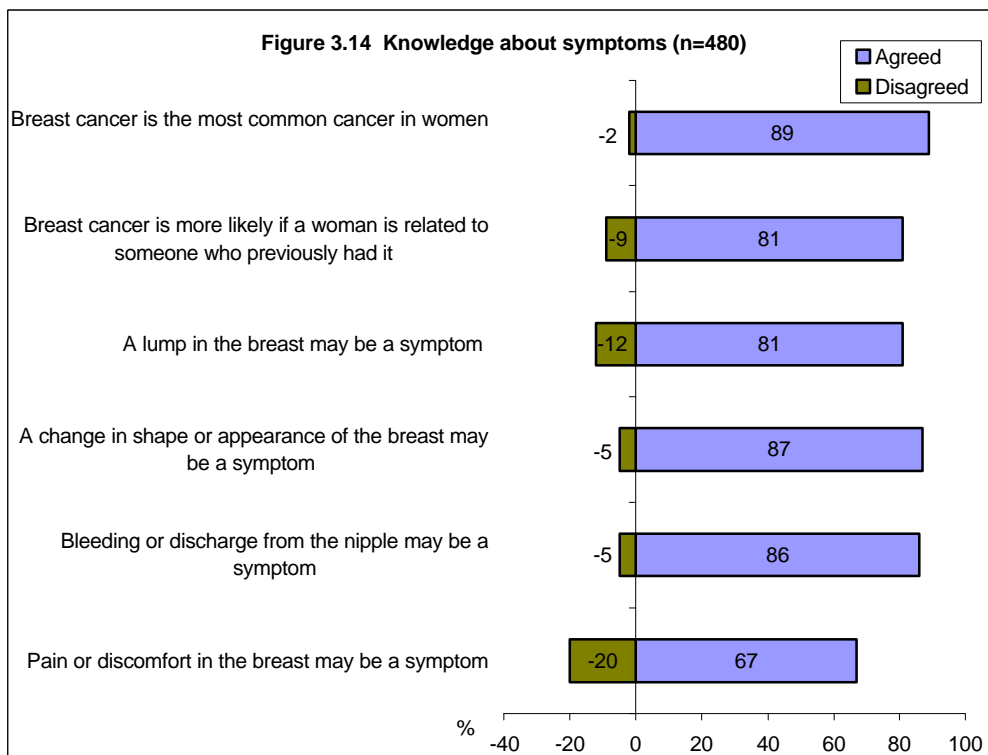
Table 3.11 Knowledge about eligible age group and frequency

	Attenders (n=441)	Non attenders (n=39)
Women between ages of 50-64 should attend for breast screening	38%	28%
Women should attend for breast screening every three years	36%	18%

The most commonly perceived purpose of mammography was for early diagnosis of breast cancer (85%). Just over two thirds (68%) thought it was to detect early changes in the breast when it is difficult to feel a lump, 48% thought it was to detect non-cancerous lumps/abnormalities and 35% perceived it was to investigate lumps already known about.



The vast majority of women (89%) agreed with the statement - breast cancer is the most common cancer in women. Most also agreed that breast cancer is more likely if a woman is related to someone who previously had it (81%) however nearly one in 10 (9%) disagreed with this.



The majority of women agreed that a change in shape or appearance of the breast (87%) or bleeding or discharge from the nipple (86%) may be

symptoms of breast cancer. Most also agreed that a lump in the breast (81%) or pain or discomfort in the breast (67%) may also be symptoms. However a substantial proportion of women rejected these statements. Over one in 10 (12%) disagreed that a lump may be a symptom and 20% disagreed that pain or discomfort in the breast may be a symptom.

Overall 86% of women said they personally knew someone who had breast cancer. Most (57%) said this person was a friend, 38% their mother, sister or other family member and 29% a neighbour.

Table 3.12 Acquaintance with someone with breast cancer
(n=414 – all who knew some-one with breast cancer)

Mother/sister	12%
Other family member	26%
Neighbour	29%
Friend	57%
Other	11%

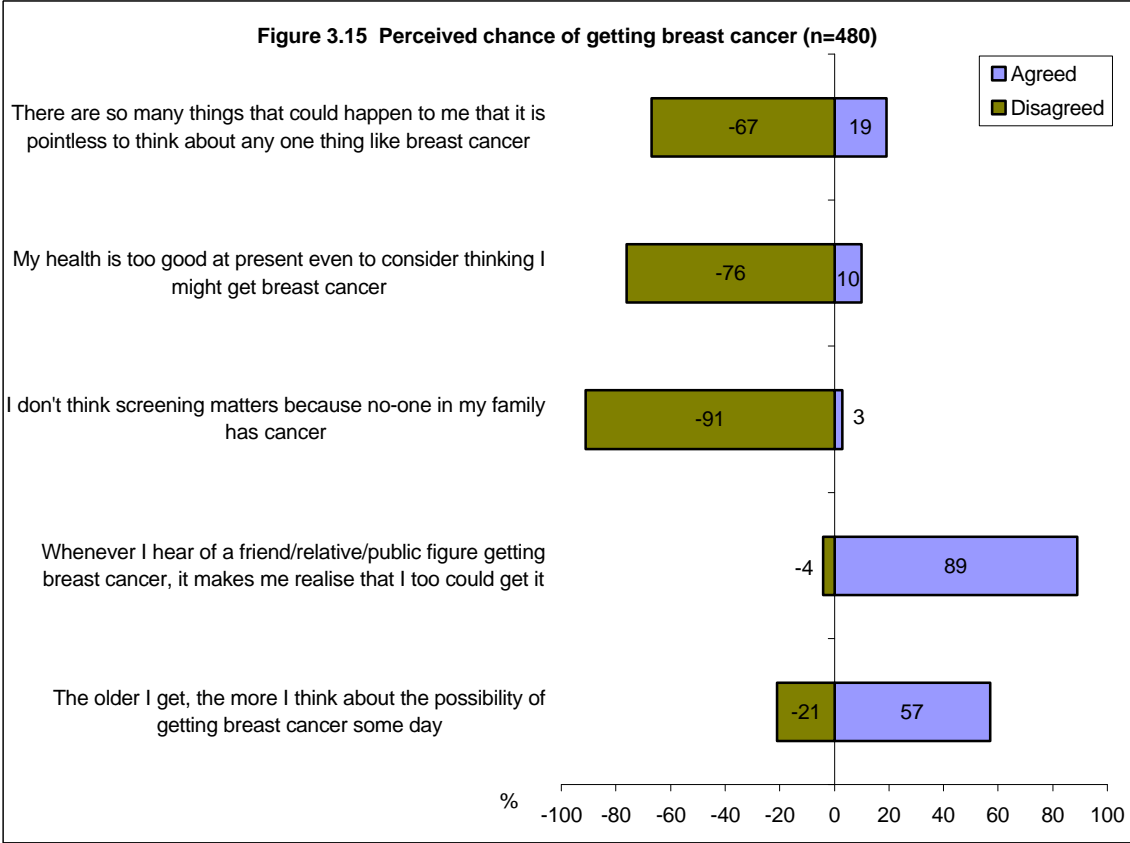
Similar proportions of women who had attended (87%) for breast screening and women who had not (79%) knew someone with breast cancer. However those who had attended were significantly more likely than those who had not to have known a friend with breast cancer (58% and 39%).

SUSCEPTIBILITY

Most women (85%) regarded their chance of getting breast cancer to be the same as for other women, 7% thought they had a greater chance and 4% less chance. One in five women (19%) were very worried about getting breast cancer, 61% were a little worried and 15% said they were not at all worried. A fifth of women who attended (21%) and 11% of non-attenders were very worried about getting breast cancer.

Most women perceived it possible that they might develop breast cancer in the future. The vast majority (91%) rejected the statement ‘I don’t

think screening matters because no-one in my family has cancer'. Neither were they likely to have thought that their health was too good to consider thinking that they might get breast cancer (76% disagreed with this statement). Most (89%) agreed that whenever they hear of a friend, relative or public figure getting breast cancer, it makes them realise that they too could get it. However one fifth (21%) disagreed that the older they get the more they think about the possibility of getting breast cancer and a similar proportion (19%) thought it pointless to think about any one think like breast cancer because there are so many things which could happen.



Differences were observed in relation to how attenders and non-attenders perceived their chance of developing breast cancer. Attenders (91%) were more likely than non-attenders (74%) to have agreed that whenever they hear of a friend, relative or public figure getting breast cancer, it makes them realise that they too could get it. Attenders were more likely to reject that it is pointless to think about any one thing like breast cancer because there are so many things which could happen to

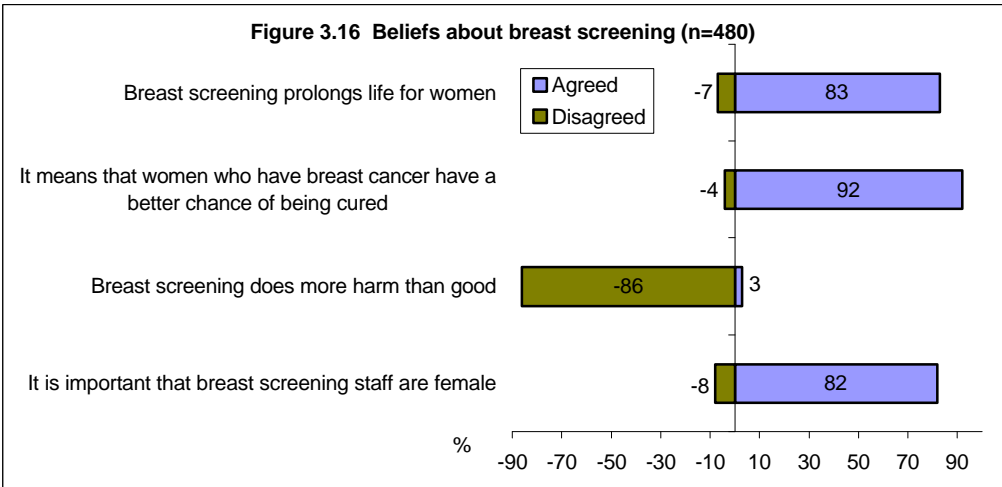
them (68% and 49%). They were also more likely to disagree that screening doesn't matter because no one in their family has cancer (93% and 64%).

Table 3.13 Perceived susceptibility

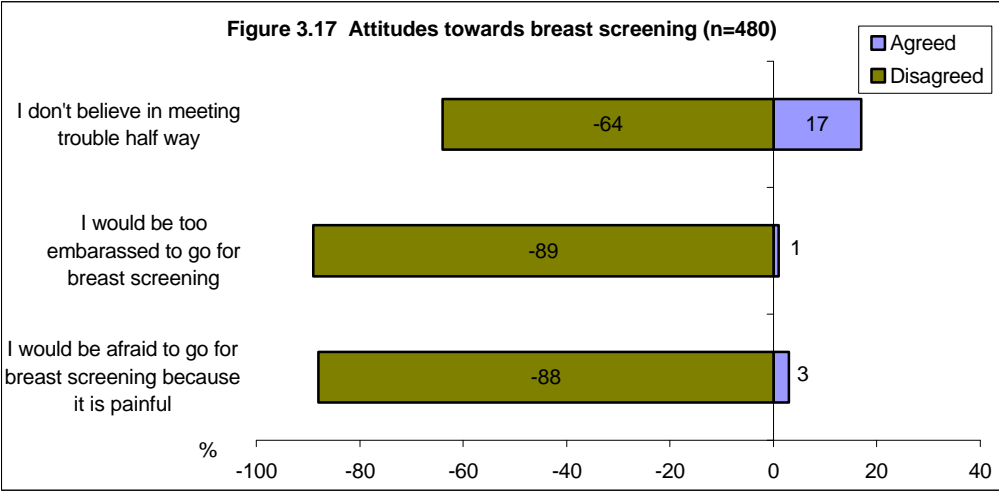
	Attenders (n=441)	Non-attenders (n=39)
	% disagreed	
There are so many things that could happen to me that it is pointless to think about any one thing like breast cancer	68%	49%
I don't think screening matters because no-one in my family has cancer	93%	64.1%
	% agreed	
Whenever I hear of a friend /relative /public figure getting breast cancer, it makes me realise that I too could get it	91%	74%

ATTITUDES TOWARDS BREAST SCREENING

The vast majority of women (92%) believed that breast screening enables women who have breast cancer to have a better chance of being cured. They also thought that screening prolongs life for women (83%) and rejected that it does more harm than good (86%). Most (82%) considered it important for the breast screening staff to be female.



The majority of women disagreed that they would be too embarrassed to go for breast screening (89%) and that they would be afraid because it is painful (88%). Just under two thirds disagreed with the statement that they don't believe in meeting trouble half way and 17% agreed.



The attitudes of attenders and non-attenders differed significantly on two of the above issues. Women who attended were more likely to reject that they would either be too embarrassed or afraid to go for breast screening. Ninety-one percent of attenders disagreed that they would be too embarrassed to go for screening compared to 72% of non-attenders. Ninety percent of attenders also rejected that they would be afraid to go for screening because it is painful compared to 74% of non-attenders.

Table 3.14 Differences in attitudes towards screening

	Attenders (n=441)	Non-attenders (n=39)
	% disagreed	
I would be too embarrassed to go for breast screening	91%	72%
I would be afraid to go for breast screening because it is painful	90%	74%

Attenders were more likely to rate attendance at breast screening as very important (95%) than non-attenders (54%). One in 10 non-attenders (11%) did not consider it important unless pain develops, 3% thought it unnecessary and a further 3% said it was not important.

Table 3.15 Importance of attending for breast screening

	Total (n=480)	Attenders (n=441)	Non-attenders (n=39)
Very important	92%	95%	54%
Important	5%	3%	28%
Unnecessary	-	-	3%
Not unless develop pain	1%	-	11%
Not important	-	-	3%

FUTURE ATTENDANCE

A higher proportion of women who attended this round of screening said they were very likely to attend for breast screening if invited in the future (93%) than women who did not attend (53%). Over one in 10 non-attenders (11%) said they were very unlikely to attend and a quarter (24%) were uncertain.

Table 3.16 Likelihood of future attendance

	Attenders (n=441)	Non-attenders (n=39)
Very likely	93%	53%
Likely	4%	13%
Uncertain	1%	24%
Unlikely	-	-
Very unlikely	1%	11%

The vast majority of attenders (98%) and 79% of non-attenders said they would encourage others to attend.

REASONS FOR DECISIONS

Respondents were asked to explain in their own words why they choose to attend or not to attend for breast screening. These responses were analysed to identify the key influential factors.

- **Non-attenders reasons**

Just over two thirds (n= 26) of non-attenders outlined their reasons for their decision. These included being afraid, not wanting to think about negative things, unsuitable arrangements and not receiving the invitation. Some of these women had attended for screening on a previous occasion.

“Just not interested.”

“Fear.”

“Still afraid of what I’ll hear.”

“Hope. I did not think a lot about it.”

“I am a positive thinker and don’t dwell on issues of serious illnesses.”

“I am unemployed at present – on job seeking allowance – I cannot afford to travel for breast screening. It is a great pity it’s not still carried out in Daisy Hill Hospital.”

“I would have attended, but I have not lived at the address for the past four years. I never received the invite.”

“The time is just assigned to you without any regard for personal circumstances. Also, the clinic system means you often wait past the scheduled time. The system is impersonal and cold. The NHS is run as a 9-5 business for the convenience of professionals.”

“Not sure of my reasons for not having breast screening.”

“Both invitations were during working hours in my home locality whilst I work in Belfast. Therefore, I would have to take a day off work which didn’t suit. Perhaps prospective attendees should be given an opportunity to attend an evening session.”

“My previous experience was so horrible – I felt I couldn’t go through with it again.”

“I had an A-level exam class at the time of the appointment and it was too near the exams to miss the class...”

Some women who had indicated that they hadn’t attended for breast screening when they were invited had previously attended, some within the previous year. These women tended to outline the reasons why they had attended on a previous occasion rather than why they did not attend this time. These women tended to have arranged their own consultation because of having a family history of breast cancer or because they experienced symptoms.

“The discovery of a breast lump in my 40s.”

“I had a biopsy in March 1998 and am being kept under review.”

“Because of having two sisters with breast cancer.”

“In my case I had what is referred to as nodular breast make-up and was experiencing some pain.”

“Discharge which prompted me to apply for private consultation which was then followed by breast screening.”

- **Attenders reasons**

Most of the women (78%), who attended for breast screening, outlined their reasons for doing so. These were analysed according to the main themes and 6 main factors were identified. These factors are presented separately below but many women gave a number of reasons which were due to a combination of the six factors. Therefore some of the quotes used to explain one factor may also be equally relevant for another factor.

1. Susceptibility

Some women said they chose to attend for breast screening because they felt susceptible to developing breast cancer. A number of reasons were highlighted for this. In some cases symptoms such as a lump, pain or discharge had been experienced.

“Had a breast lump.”

“Some 3 years ago I had pain and a discharge. I was referred for a mammogram.”

“Previous cysts which were aspirated.”

“I would feel my left breast tender and wanted to make sure everything was alright.”

In other cases, there was a family history of breast cancer.

“Sister died from breast cancer, and I have a painful left breast for thirteen years. It comes and goes.”

“My mother died due to breast cancer.”

“Sister dying from breast cancer and other sister had mastectomy but has recovered.”

“Family history of death from breast cancer makes it imperative to be caught early should it strike me.”

“My sister died from breast cancer aged 45 years.”

In other cases, women felt they were susceptible to developing breast cancer because of their age or because they were on hormone replacement therapy (HRT).

“The older I get the more I think about the possibility of getting breast cancer some day, and as I had friends who had breast cancer I realise the importance of early detection by breast screening.”

“I have a HRT implant I feel that this increases the possibility of getting breast cancer due to the side effects of HRT.”

“Because I was over fifty more likely to get breast cancer.”

“I have been on HRT for the past 19 years and I now think it is very important to have regular breast screening and smear tests.”

Other women just felt generally susceptible because of the incidence of breast cancer or because they knew someone (other than immediate family members) with breast cancer.

“Because cancer is so common in the breast and I have known a few people who have had it detected in the very early stages because of breast screening. I think it is very necessary.”

“So many females developing breast cancer nowadays.”

“Some of my friends had developed breast cancer and it had made me very aware of how common it has got.”

2. Recognised benefits

One commonly mentioned factor why women attended for breast screening was because they recognised the benefits of it. They believed that early detection equated to a higher chance of cure.

“I realise I could get breast cancer and the sooner it is detected the better chance there is of being able to cure it.”

“To take advantage of early detection that cannot be gained from self-examination and therefore the strong possibility of complete cure, and maybe the avoidance of radical surgery.”

“My reasons for attending are that early detection of any abnormalities can be treated successfully.”

“Death from breast cancer is preventable but only if you catch it really early enough, therefore early detection is essential to have a chance of recovery.”

Some women mentioned the success of the screening programme in detecting breast cancer at an early stage.

“Proven value of screening in early detection and subsequent successful treatment.”

“Because of success of screening programme.”

“Because cancer is so common in the breast and I have known a few people who have had it detected in the very early stages because of breast screening.”

“Friends suffering from breast cancer found after breast screening – wouldn’t have known otherwise.”

3. Psychological reasons

Two psychological reasons were mentioned as reasons why women attended for breast screening. One of which was to seek reassurance. Respondents went along to be reassured that they did not have breast cancer.

“Reassurance – I knew that self-examination was a good idea but the screening could show changes which may not have been felt.”

“For reassurance that nothing was amiss, and for my own peace of mind, I believe early detection is the key to saving women who may have breast cancer.”

“To relieve worry.”

The other psychological reason mentioned was fear. Respondents were frightened of developing breast cancer and this prompted them to attend.

“Fear of breast cancer made me attend.”

“Fear of breast cancer and not being detected until too late.”

“Fear of the unknown.”

4. Service provision

Another factor which was influential in women’s decisions to attend was the availability of the service. Some women attended because they thought they should take the opportunity when the service was offered to them.

“I think it is vital for women to avail themselves of every opportunity for breast screening, especially as it is prevalent today. The more women who support the programme, the greater the chance for increasing the range of services. Besides a great effort had been made in this area by many people to improve facilities and we should support this effort.”

“If the facility is there to help me then I think it only right to take advantage of it.”

“When one is offered a health check it is wise to take it up.”

“I do appreciate breast screening, and anyone who is called should take the opportunity.”

Some women mentioned the convenience of the service – both the location, the flexibility of arrangements and the actual screening process.

“The service is there, very reassuring, fast results, very worthwhile service.”

“...It’s painless, quick and the staff were very reassuring I would strongly recommend it for all women.”

“...it was convenient to attend local hospital for screening.”

“Screen testing available free of charge. Screen testing at local hospital. Quick results of testing. Option to change time and date to suit you.”

Other women mentioned that they simply accepted the invitation to attend.

“Invitation.”

“I don’t know the letter comes and I just go I suppose my mother and sister had it. My sister had breast screening done and early detection helped her along, she lived 5 years.”

“My GP sent out the invitation and I felt out of courtesy I should attend. Happy to do so.”

5. External Influences

External influences was another factor which emerged. These influences came from a number of different sources – one was advice from health professionals and another was pressure from family members.

“Encouraged by my GP.”

“My daughter made me.”

“Family persuasion.”

“Advice and information given by doctor and practice nurse. Experiences of women thankful for early diagnosis of malignancy through breast screening.”

“Advice of doctor and I am prone to breast lumps and have been for the past 19 years.”

Another source of external influence was publicity/information about breast cancer particularly through the media.

“I always had very good health I heard so much about breast cancer I thought I should go for a breast mammography.”

“Firstly through all the advertisements I have seen in the newspapers I thought it worthwhile to attend for breast screening.”

“Media information about prevalence of breast cancer in women and the importance of early diagnosis for life saving...”

6. Health maintenance

The sixth factor identified related to health maintenance. Some women thought it important as part of generally looking after their health. They thought breast screening was a sensible approach to staying in good health.

“Health care, a sensible ‘maintenance’ for my body. My mother had a mastectomy late in life.”

“It’s stupid not to be screened when the appt. is made for you to attend – All clear gives reassurance for the coming two years.”

“I think it is very important to get it done and women are very silly if they don’t go but that’s their life.”

“I think it’s just common sense to accept preventative or early diagnostic services when they are offered.”

“It seemed sensible as it is a safeguard for my own health.”

“Sensible attitude towards my own health. Early detection of any cancer which I may have, not only breast cancer, should increase the possibility of successfully fighting the disease.”

Other women considered it a way in which they could play a role in maintaining their health, it was one aspect which they could take control over. The issue of responsibility was commonly mentioned - they considered they had a responsibility to take whatever actions they could to maintain their own good health.

“It is a free service made available to women. Early detection could prevent loss of life. I am taking responsibility for my good health.”

“Awareness of health issues and realisation that we are all responsible for maintaining optimum health.”

“Because I like to stay healthy as long as possible and as both parents died of cancer I aim to look after myself and avail of screening.

“I would consider it irresponsible not to take the opportunity offered to have screening of any kind, it is my health and I would like to be healthy as long as possible. Also I think we are fortunate to have this service, especially at Daisy Hill.”

ENCOURAGEMENT FOR FUTURE ATTENDANCE

- **Non-attenders**

A number of women who had never before attended for breast screening indicated what would encourage them to attend. These factors fell into two categories; the development of symptoms and a suitable appointment time. In addition one woman was anxious about the negative publicity surrounding levels of radiation from screening.

“Listening to, and reading media reports, I have noted the x-ray (mammography) screening, are dangerous in the high levels of radiation

a woman's body is exposed to. No one from the breast-screening unit warns women of this, or ask if they are prepared to except it."

"Any change or pain."

"If I could schedule it to fit with my work commitments and I was sure I wouldn't have to spend half a day."

"If I felt any discomfort in my breast."

"If I discovered a lump."

- **Attenders**

Some attenders said they would not need any encouragement to attend for breast screening in the future. Others mentioned the same type of factors which were pertinent to them deciding to attend for screening in the first place:

- Feeling susceptible because of the prevalence of breast cancer, family history or the development of symptoms.
- Benefits of early detection.
- Psychological reasons - reassurance and peace of mind which screening provides or the fear of developing cancer which prompts attendance.
- External pressure from family, GPs and publicity/information about breast cancer or screening.
- Health maintenance – recognised the need/benefit of check-ups. They felt a responsibility to attend for screening because it was a sensible thing to do.
- Service provision – encouraged to attend by the accessibility, convenience and efficiency of the service. A previous positive experience, good notification of the date and staff attitude were also mentioned. Some women said they would be encouraged to attend in the future if the facilities and equipment were improved. In particular if the actual screening itself could be less painful and/or uncomfortable.
- In addition to these some women said simply receiving the invitation would encourage them to attend.

The 3 most common factors which attenders said would encourage them to attend in the future were; for reassurance, early diagnosis and receiving an invitation.

OTHER ISSUES

Respondents were invited to make additional comments about their experiences of breast screening, the facilities or breast screening in general. Just under one in five (19%) did so. Some of the comments referred to the targeted age group for screening. Some felt that both younger and older women should also be included in the screening programme.

“...I do feel very strongly, however, that in view of the incidence of breast cancer among women in the UK the service should be widened to include women in other age ranges. I will soon be out of the 50-64 age band, which means that I will no longer be eligible for inclusion in the current programme. This worries and concerns me.”

“Screening should begin much earlier. Know some-one of thirty who has just had a breast removed.”

“Age limit to be increased as people are living longer.”

“I think that with the high incidence of breast cancer in this area, screening should be made available to younger women – say from 35 onwards.”

“I feel breast screening should be continued over the age of 65 years.”

“I personally think that women over the age of 70 should also have breast screening.”

Some women thought screening should occur more often than every 3 years.

“...I personally feel they should be not so far apart.”

“I believe that breast screening should be a yearly check for all women of 45 years and over...”

“I would just like to say that three years is too long between screening. So many changes can occur in that time, I would be happy to go every year.”

Some women made comments about the importance of retaining the breast screening service at Daisy Hill Hospital. Other women thought that the service was no longer provided at Daisy Hill hospital.

“I hope breast screening will continue in Newry as I hate travelling by car.”

“Breast screening facilities remain in Daisy Hill. That follow-up appointment be in Daisy Hill.”

“I am glad I don't have to travel far as there is a breast screening service in my local hospital, which is Daisy Hill Hospital. I think that if this service was ever taken away it would be likely a lot of people would not attend their mammograms.”

“If the facilities at Daisy Hill were closed and one had to travel to Craigavon then I would not be happy to do that and could probably not attend Craigavon...”

“...This service should be maintained within the local area hospital as an essential service to women's health and wellbeing.”

“I was disappointed to hear that breast screening was no longer held in Daisy Hill, I think this will deter people from attending.”

“I think the screening process should have continued at Daisy Hill Hospital and not have been moved to Lurgan. It will make it a lot harder for women to avail of this excellent service.”

Some women suggested that more health promotion information should be provided on breast cancer and screening to promote uptake of screening services. It was suggested that this should begin in school and should also target partners and other family members.

“Talks in community centre throughout the country – Roadshows – to inform Women’s groups about the benefits of breast screening.”

“...everyone, this includes partners and family in general, should be made aware of the possibility of breast cancer; maybe through adverts on TV?...”

“...More information should be targeted at the younger age group, who seem not to be considered as likely victims of breast cancer.”

“More information from staff about latest research, into breast cancer in women of all ages.”

“...Educate and mention in schools from an early age the necessity to have breast screening at a later stage in women’s lives. That way they will not feel that they are the only one to receive an invitation to attend for breast screening.”

“...There should be more information aimed at younger women to encourage them to check their breasts for lumps.”

Some women were apprehensive about the effects of the x-rays.

“It makes me a little apprehensive after reading, if a lump was found it could spread by having this x-ray done...”

“I am concerned that the painful process could actually cause cancer...”

“I know nothing about x-rays i.e. How many can one safely be exposed to? Would the machine for looking at babies in the womb not do the same job?”

4. DISCUSSION

RESPONSE RATE

Information was not available prior to the study being conducted on whether or not the sample of 800 women had actually attended for breast screening. Based on the proportions of women who did attend between April 1996 to March 1999 it was expected that 62% of the 800 women (496) would have attended and 38% (304) wouldn't have. These proportions do not reflect the sample of women who responded to the survey. Of the total 480 women who responded 92% had attended and 8% had not. This suggests a lower response rate from women who did not attend for breast screening.

This limits the generalisability of the findings in relation to the women who didn't attend because the sample size was small and the responding non-attenders may have been different to the non-attenders who didn't respond. This difficulty has also occurred in other studies (Aro et al 1999; Hunt et al 1988; Fallowfield et al 1990) and additional steps were taken in this study try to encourage responses. Sharp et al (1996) found that it proved difficult to get women who had already declined two invitations for screening to agree to be interviewed about their reasons for making this decision. Pearson and Parkinson (1994) concluded that while it was straightforward to use a postal survey to obtain feedback from non-attenders it was often unrewarding because of the low response rate.

However while this aspect of the study was disappointing, the study does provide information on why some women do not attend for routine mammography. In addition the study provides valuable information from the perspective of the women who did attend for screening. Reasons for attendance are identified as well as the views and experiences of women of the actual screening process when they do attend.

HEALTH STATUS

Women who didn't attend for breast screening were more likely to have been in poor or very poor health (23%) whereas attenders were more likely to have said their health was very good, good or average (90%). While Meischke et al (1998) concluded that current or anticipated health problems were not related to screening behaviour, women who perceived themselves at low risk for getting breast cancer and/or who perceived another disease as an equal or greater threat were less likely to have been regular mammography attenders.

REACTION TO THE INVITATION

Women who didn't attend for breast screening were less likely to have expected the invitation. Half the non-attenders expected the invitation compared to 86% of women who did attend. Their reactions to the invitation tended to be different. Attenders were more likely to have been pleased and relieved whereas non-attenders were more likely to have had neutral or ambivalent reactions. These findings are similar to previous research. Pearson and Parkinson (1994) also reported that non-attenders were significantly more likely than attenders to describe a negative or neutral reaction to the invitation.

INFORMATION LEAFLET

A higher proportion of attenders than non-attenders said they received an information leaflet about breast screening with their invitation. Three quarters of those who attended (76%) recollected receiving the information leaflet compared to 51% of women who did not attend. As the information leaflet is routinely sent out with all invitations, this difference may have been due to recall bias. In a study which examined recall relevant to a person's behaviour, Roberts (1985) found that non-smokers recalled more anti-smoking material than smokers and seatbelt wearers recalled more pro-seatbelt information than non-wearers. Similarly attenders may have recalled receiving the breast screening information leaflet because it was relevant to their behaviour.

The vast majority of respondents who recalled receiving a copy of the information leaflet rated it positively. Most (99%) found it easy to understand, 98% said it was informative, 95% said it answered any questions they had about breast screening, 93% did not consider it too long and 81% said it persuaded them to attend for breast screening.

THE SCREENING EXPERIENCE

Overall there were high levels of satisfaction among attenders with their most recent experience of breast screening. The vast majority were satisfied with the information, facilities, time taken to receive the results and privacy while being screened. However 7% were dissatisfied with one or more aspect of the screening process including the time taken to get the results, privacy and facilities for screening and staff attitude. Four percent said screening caused them embarrassment.

The vast majority considered their experience of breast screening to have been worthwhile (89%) and reassuring (88%). However just under two thirds (65%) considered it uncomfortable, nearly one in three found it painful (29%) and 10% said it was distressing. Previous literature has identified pain and discomfort as a feature for some women however the proportions of women who found the process uncomfortable and painful in this study are higher than figures reported in previous research. Gram and Slenker (1992) reported that 11% of women found the screening examination somewhat painful. Jackson et al (1988) reported that 11% found the procedure very uncomfortable and 3% found it intolerable. Stomper et al (1988) found that 11% of women had experienced moderate or greater discomfort and 1% reported it painful.

Non-attenders who had previously been screened were less likely to have found that experience very worthwhile (54%) than attenders (87%) and more likely to have found it very or quite distressing (23%, 8%). This is consistent with previous findings. Orton et al (1991) found that women who did not re-attend for breast screening were more likely than those who did to report the previous test as distressing and were significantly less likely to have found it worthwhile or reassuring

KNOWLEDGE ABOUT BREAST CANCER AND SCREENING

Women who attended for screening were more likely than those who didn't to have known that the eligible age group for screening was women aged 50-64 years and that they should attend every three years.

The most commonly perceived purpose of mammography was for early diagnosis of breast cancer (85%). Just over two thirds (68%) thought it was to detect early changes in the breast when it was difficult to feel a lump, 48% thought it was to detect non-cancerous lumps/abnormalities and 35% perceived it was to investigate lumps already known about.

In terms of the symptoms of breast cancer, the majority of women agreed that a change in shape or appearance of the breast (87%) or discharge from the nipple (86%) may be symptoms of breast cancer. Most also agreed that a lump in the breast (81%) or pain or discomfort (67%) may also be symptoms. However one in five women did not think that pain or discomfort may be symptoms of breast cancer.

There were no significant differences between attenders and non-attenders in their knowledge about breast cancer and breast screening. Marshall (1994) also found no difference between these two groups in their knowledge of breast cancer.

ATTITUDES

The majority of women, both those who attended (97%) and those who didn't (82%), considered it important to attend for breast screening. Similarly Marshall (1994) found that the majority of non-attenders thought that screening was worthwhile as it increased the cure rate from breast cancer. The author concluded that either these women were insufficiently motivated or found some aspect of the screening experience a disincentive.

However women who didn't attend for breast screening were more likely than those who did to have believed that breast screening was only important if pain developed in the breast. One in 10 (11%) did not consider it important unless pain developed and 3% said it wasn't at all important. Similarly, Rimer et al (1989) found that non-compliers were more likely to have considered mammography unnecessary in the absence of symptoms and that it was too much trouble and inconvenient.

Attendees were significantly more likely than non-attendees not to have been too embarrassed to go for breast screening nor to have been afraid because it was painful. Aro et al (1999) found that the expectation of pain at mammography was predictive of non-attendance.

INFLUENCE OF OTHERS

Three quarters (74%) of all women who responded to the survey had visited their GP within the previous 6 months. However only 31% had ever spoken to their GP about breast screening. Just over a quarter (28%) said their GP influenced their decision to attend. Women whose GP practice was in Warrenpoint were more likely than women whose GP practice was in Newry to have said that their GP influenced their decision (35% & 20%).

Just over a third (34%) of respondents indicated that their husband or partner had some influence over their decision to attend. Encouragement from friends and family members including daughters or sisters also motivated some women to attend.

Respondents suggested that more health promotion information should be provided to promote the uptake of breast screening services. It was suggested that this should begin in school and that partners and other family members should also be targeted to encourage uptake.

REASONS FOR ATTENDANCE

Six main factors were identified as promoting attendance at breast screening:

- **Susceptibility:-** This included experiencing symptoms, having a family history of breast cancer, or feeling susceptible because of their age or receiving HRT. Some of the other findings of the study reinforced this as a motivating factor for attendance. Women who attended for screening were more likely than those who didn't (91%, 74%) to have agreed with the statement 'whenever I hear of a friend/relative/public figure getting breast cancer, it makes me realise that I too could get it.' Attenders were more likely than non-attenders to have rejected the following two statements 'there are so many things that could happen to me that it is pointless to think about any one thing like breast cancer' and 'I don't think screening matters because no-one in my family has cancer.'
- **Recognised benefits:-** Some women quoted their reason for attendance as being due to their belief that screening detected breast cancer at an early stage and early detection led to a better chance of cure. However no significant differences were found in relation to the beliefs of attenders and non-attenders about screening. The vast majority believed that breast screening enabled women who have breast cancer to have a better chance of being cured. They also thought that screening prolonged life for women and rejected that it did more harm than good. These findings are different to those of other studies. Orton et al (1991) found that re-attenders were more likely to believe that screening can detect breast problems at an early and curable stage and Marshall (1994) found that re-attenders had a more positive view on the efficacy of breast screening than did non-reattenders.
- **Psychological reasons:-** Other women attended because they were seeking reassurance that they didn't have breast cancer and others were prompted to attend because of their fear of developing breast

cancer. Saidi et al (1998) also identified peace of mind that they do not have breast cancer as a motivating force behind attendance for women.

- **Service Provision:-** Some women attended screening because they thought they should take the opportunity to do so because the service was offered to them and was convenient.
- **External Influences:-** External influences such as advice from a GP, encouragement from family members or media publicity also acted as a prompt for attendance. Fullerton et al (1996) also identified the recommendation of a healthcare provider and familiarity with mammography via the media as major motivators for attendance at screening.
- **Health maintenance:-** Some women attended in order to maintain their health and they regarded screening as a common sense way in which they could take responsibility for and control their own health.

REASONS FOR NON-ATTENDANCE

Women who had not attended for screening on this occasion were less likely to have had attended on a previous occasion. However 59% had previously attended. Eleven of the 39 women who indicated they did not attend for breast screening when invited said their reason for non-attendance was because they had attended on a previous occasion. Seven had done so within the previous two years. Aro et al (1999) found that women were less likely to attend for screening if they had had a mammogram during the previous 6 months. Sutton et al (1994) commented that these women were following recommended practice and should not be a cause for concern.

Other reasons for non-attendance included; inconvenience, work or home commitments, illness, fear and/or anxiety, transport, screening considered unnecessary, lack of interest, they were in good enough health and they didn't receive the invitation. When asked what would

encourage them to attend in the future non-attenders indicated the development of symptoms and the convenience and suitability of an appointment time.

Fullerton et al (1996) identified fear of pain and radiation and lack of perceived need as important barriers to attendance for mammography. Marshall (1994) and Aro et al (1999) concluded that expectation of pain was predictive of non-attendance. As 59% of non-attenders had attended on a previous occasion their expectations may have been based upon their previous experience. As indicated previously non-attenders who had previously been screened were less likely to have found the experience very worthwhile and more likely to have found it very or quite distressing. Orton et al (1991) found that women who did not re-attend were significantly more likely than those who did to report the previous screening test as embarrassing or distressing and were less likely to have found the clinic staff helpful or attendance for screening worthwhile or reassuring.

ELIGIBLE AGE GROUP

Some women at the upper age band for eligibility for breast screening were worried because they would no longer be invited to attend once they reached 65 years. They thought that screening should extend beyond the age of 64 years.

The Forrest report, although recognised that older women were more likely to develop breast cancer, recommended that they should not be routinely invited for screening because of the low cost-effectiveness from a likely low uptake and shorter life expectancy. Instead women over 64 years are entitled to self-refer. However Rubin et al (1998) obtained preliminary results which indicated that those women who had previously attended for breast screening would continue to do so if invited after the age of 64 years but only a small proportion of them (7%) would self-refer. Chen et al (1995) concluded that screening for breast cancer is as effective in reducing mortality from the disease in women aged 65-69 as it is in women aged 50-64. The women in this study who expressed

concern that they would no longer be eligible for screening after the age of 64 did not appear to have been aware that they could self-refer. Therefore they would be unlikely to do so even though they considered it important that women beyond 64 years continue to receive screening. In light of these findings, those of previous research and the Equality agenda, serious consideration should be given to extending the age group of women eligible for routine mammography.

Some women also commented on the occurrence of breast cancer among women below the age of 50 years and thought that they too should be eligible for routine screening.

SUGGESTIONS TO INCREASE UPTAKE

In trying to identify ways in which attendance for mammography screening could be increased it is useful to consider the factors which motivated women to attend as well as the reasons for non-attendance. This is particularly so given the low response rate of non-attenders and therefore the shortage of data.

Suggestions as to how attendance rates could be improved relate to 3 key areas:-

- **Administration/systems: -**

There is a need to look at how the information on attendance for breast screening is recorded. The NHS Breast Screening Programme has responsibility for inviting all women within the eligible age group to routine screening however it is not the sole provider of mammography services in Northern Ireland. Voluntary organisations such as Action Cancer also conduct breast screening and therefore there may be some overlap in the women invited to attend or who actually present for screening. However the systems operate separately and there is no communication as to who has or has not attended. In addition some women may be referred to a breast clinic by their GP on the basis of being symptomatic. Therefore the recorded level of uptake of the NHS breast screening service may actually underestimate the number of

women who are screened at regular intervals. Some of the women in this study had in fact been screened within the previous two years but because they didn't attend for the routine screening under the NHS Programme when invited they would have been recorded as non-attenders.

1. Accurate figures should be compiled on the overall numbers of women who do not receive regular screening from any source. Consideration should be taken of those receiving screening from other service providers as well as the NHS Breast screening Programme.

Some women who didn't attend for screening said their reason for not doing so was due to not having received the invitation. The Breast Screening Programme depends upon the co-operation of GPs for accurate information and contact details of women to be invited for screening. Prior Notification Lists (PNLs) are sent to GPs for checking and verification in advance. It is recognised that the completion of PNLs in a Practice is time-consuming but it is a vital exercise in order to ensure the Breast Screening Programme has up-to-date and meaningful data.

2. GPs should ensure verification of the Prior Notification Lists.

Some women indicated that they did not attend for breast screening because of work or other commitments.

3. The Breast screening programme should consider introducing the provision of screening appointments outside the normal 9-5 hours in order to facilitate women who would like to attend but cannot during this time.

• Actual screening process: -

For some non-attenders a previous breast screening experience had been distressing and considered not worthwhile. Reducing the level of distress experienced by women could increase the level of re-attendance. Issues at Daisy Hill which could be addressed include;

- improving privacy while changing and also during the screening process
- the provision of gowns while waiting to be screened.
- reducing the number of staff present during the screening who are not directly involved in the individual episode.
- Making women feel comfortable and offering reassurance.
- Offering and providing information.

4. Steps, such as those outlined above, should be taken at Daisy Hill Hospital to reduce the level of distress experienced by some women.

A higher proportion of women in this study reported the experience as painful than has been reported by other studies. McTiernan (2002) highlighted an urgent need for developing better methods of screening for breast cancer. The main impetus for this argument was in relation to the controversy over the effectiveness of screening in detecting breast cancer. However the issue of the screening being painful and causing distress to women is an argument in favour of developing better screening methods. Some of the women in the study suggested the experience of breast screening could be improved by making it less painful. As one participant commented ‘...*why is it necessary to squash a round breast between two plates – the brain isn’t squashed to scan it.*”

5. The NHS Breast Screening Programme should explore alternative screening methods which would reduce the level of pain, discomfort and distress of the experience.

- **Information/promotion/education: -**

6. The promotion of routine breast screening should focus on the 6 factors identified as motivating attendance – susceptibility, recognised benefits, psychological reasons, service provision, external influences and health maintenance

Some of the women who were non-attenders said they would be motivated to attend screening by the presence of symptoms. Just over 1 in ten non-attenders did not consider it important to attend unless pain developed. Rodriguez et al (1995) suggested that women who believed screening wasn't necessary and that it was better not to know about one's cancer status or expressed fear about the screening process may respond to special educational interventions that explain who can benefit from screening and dispel their fears.

7. It is important that education and promotion about breast screening stresses the benefit and importance of attending without waiting for symptoms to develop.

Respondents stress the importance of having the services available locally and suggested that information and roadshows should be taken out into the local communities – to women's groups.

8. Opportunities should be created to provide information about breast screening to women at a local level – such as within community groups etc.

Three quarters (74%) of all women had visited their GP within the previous 6 months therefore there was a high level of contact between women in the eligible age group for screening and their GP. However only 31% have ever spoken to their GP about breast screening. Fulleton et al (1996) identified the recommendation of a healthcare provider as a major motivator for mammography attendance. Lerman et al (1990) found that a doctor's recommendation increased participation in screening mammography. Similarly Clover et al (1992) concluded that a simple recommendation from the GP was as effective as an intensive health education intervention. Turner et al (1994) found that sending a personal letter from the GP to those women who had failed to attend after their first invitation was effective and feasible.

9. GPs, at routine appointments with women within (or approaching) the eligible age group for screening, should outline

the benefits of screening, encourage uptake and offer the opportunity to raise concerns about the screening process.

Sin and St Leger (1999) have pointed to the evidence from cervical screening and child immunisation programmes to suggest that payments to GPs might boost uptake rates for breast screening. Rudiman et al (1995) has suggested that the introduction of financial incentives for cervical screening and childhood immunisations has resulted in GPs concentrating their efforts in these areas with consequently less time and effort being devoted to other preventative programmes such as breast screening. Majeed et al (1995) highlighted this controversy over the possible introduction of target payments for breast cancer screening. The authors pointed to the need for further discussions between GPs, the Department of Health and the NHS Breast screening service.

10. A debate about the effect and effectiveness of introducing payments for GPs in relation to screening should take place.

Some women indicated that they were motivated to attend by encouragement/influence of other family members such as partners, daughters etc.

11. Information and promotion of routine breast screening should also target other family members such as partners and daughters of women within the eligible age group.

12. The idea of screening as a common sense, responsible health promoting behaviour should be developed and should start at an early age.

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