

## Article

## Intermittent attendance at breast cancer screening

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## Significance for public health

All breast cancer screening programmes strive to achieve and maintain a high level of attendance, as this is essential to reduce breast cancer mortality, together with cancer detection. While non-attendance has been widely studied, little is known about intermittent attenders. It is unclear why a woman chooses not to attend her breast screening appointment but then decides to respond positively to screening invitation two or more years later. The literature identifies many reasons why some women choose not to attend; but this study distinguishes those who then change their mind and return to screening. This study explores a sub-set of non-attenders which have, to date, been largely ignored, or grouped with people who never attend. This study will inform those struggling with non-attendance in their population based health programmes and will help to tackle the problem of non-attendance, which has adverse affects both economically and epidemiologically.

## Introduction

Reduction in breast cancer mortality has been widely accredited to organised population based mammographic screening programmes.<sup>1-3</sup> All breast cancer screening programmes strive to achieve and maintain a high level of attendance, as this, together with cancer detection, is essential to reduce breast cancer mortality.<sup>4</sup> BreastCheck, the National Breast Screening Programme in the Republic of Ireland was established in 2000. BreastCheck invites women aged 50-64 years to be screened by personal invitation on a two year cycle, with a pre-arranged appointment date and time. In the first round of screening a woman will receive a reminder letter with a pre-arranged appointment date and time if she does not attend the first appointment. In subsequent rounds, a woman who did not attend in the previous round will receive only one invitation with a prearranged appointment date and time. Mammograms and resultant assessments or treatment following screening are free of charge. Initially screening was confined to women resident in the eastern half of the country, but since 2007 screening is offered to women throughout the country. Prior to the roll-out of BreastCheck in a region, asymptomatic women were referred privately for screening mammograms and symptomatic women were referred either to the public symptomatic breast service or to a consultant in the private sector, where they would have had a mammogram.

Screening is carried out at four static units and at a number of associated mobile units. The BreastCheck eligible population uptake rate for screening in 2010 was 74%.<sup>5</sup> Women in follow up care for breast cancer, women not contactable by the postal services, women who have a physical or mental incapacity which precludes screening and women with terminal illness who have contacted the programme to inform BreastCheck of their prognosis are deemed ineligible to be screened through the national programme. Women may be suspended from BreastCheck if they are on extended vacation or working abroad, have had a mammogram outside the national programme within the previous year or decide to defer an appointment until the next round. All other women in the age range 50-64 are invited for screening.

In addition to those women who fail to attend ever, there is a group of women who skip rounds, either one or several, and then return to a screening programme. For the purpose of this study we define a *Previous non attender* (PNA) as a woman who has failed to attend in the previous round or multiple previous rounds including the penultimate, but was re-invited in 2010 and attended. While non-attendance has been studied,<sup>6-13</sup> little is known about intermittent attenders. For first screening PNAs it is unclear why a woman chooses not to attend when first invited but then decides to respond positively two years later. For subsequent screening PNAs these women arise from a minority group, as 88% of all women screened by BreastCheck returned for subsequent screening in 2010.<sup>5</sup> The literature identifies many reasons why some women choose not to attend;<sup>6-13</sup> but what distinguishes those who then change their mind and return to screening is uncertain. Significantly more of those who have attended

## Abstract

**Background.** To determine why women skip rounds and factors influencing return of previous non attenders (PNAs) to breast screening.

**Design and methods.** Retrospective, quantitative, structured questionnaire posted to 2500 women. First PNAs did not attend their first screening appointment in 2007/2008 but then attended in 2010; First Controls first attended in 2010 without missed previous appointments. Women who attended screening in 2006 or earlier then skipped a round but returned in 2010 were Subsequent PNAs; Subsequent Controls attended all appointments.

**Results.** More First Controls than First PNAs had family history of cancer (72.7% vs 63.2%; P=0.003); breast cancer (31.3% vs 24.8%; P=0.04). More PNAs lived rurally; more First PNAs had 3<sup>rd</sup> level education (33.2% vs 23.6%; P=0.002) and fewer had private insurance than First Controls (57.7% vs 64.8%; P=0.04). Excellent/good health was reported in First PNAs and First Controls (82.9% vs 83.2%), but fewer Subsequent PNAs than Subsequent Controls (72.7% vs 84.9%; P=0.000). Common considerations at time of missed appointment were *had mammogram elsewhere* (33% First PNA) and *postponed to next round* (16% First PNA, 18.8% Subsequent PNA). Considerations when returning to screening were similar for First PNAs and Subsequent PNAs: *I am older* (35.4%, 29.6%), *I made sure I remembered* (29%, 23.6%), *could reschedule* (17.6%, 20.6%), *illness of more concern* (16.5%, 19%). More First PNAs stated *my family/friends advised* (22.3% vs 15.2%) or *my GP* (12.6% vs 4.6%) *advised me to attend, heard good things about BreastCheck* (28.8% vs 13.6%).

**Conclusions.** Intermittent attenders do not fit socio-demographic patterns of non-attenders; GP recommendation and word of mouth were important in women's return to screening. Fear and anxiety seem to act as a screening facilitator rather than an inhibitor.

BreastCheck at least once return even after skipping one or more rounds than women who have never attended (45.7% vs 21.2%).<sup>14</sup>

Törnberg *et al.* examined participation in the Swedish breast screening programme and found a cohort of women they referred to as *temporary participants*, i.e. women who participated in one to four of the five rounds offered overall (38.5%); 53% attended all five rounds, 72% at least four.<sup>6</sup> Similar to BreastCheck findings noted above,<sup>14</sup> for those women who were non-participants at the first round the likelihood of being a permanent non-participant was much greater than in those who had attended screening ever. Attendance at the first screening round appears to be of importance in order to convince women to return at further rounds in the future.<sup>6-8</sup> The aim of this study was to determine the reasons why women skip rounds and the factors influencing return of PNAs to breast screening.

## Design and Methods

A random sample was ascertained from all women on the BreastCheck database, who fitted the parameters of each of the four sub-groups. All four sub-groups were selected ensuring that the most recent attended appointment was in the same year (2010) in order to allow for other influencing factors such as media coverage and national health promotion campaigns. Women who failed to attend their first national population based BreastCheck appointment for screening in 2007 or 2008 but then attended in 2010 were termed *First PNAs*. We identified a similar sample of women who were first invited and attended in 2010, having not missed previous appointments, to serve as *First Controls*.

Women who attended all offered appointments for screening in 2006 or earlier, then failed to attend their subsequent appointment for screening in 2007 or 2008 but returned to screening in 2010, were termed *Subsequent PNAs*. Controls for this group were women who had attended all appointments for screening, including an appointment in 2010. We confined our sample to those with an outcome of normal mammogram. Women who were recalled for further investigation were excluded.

Recruitment was by letter sent with postal questionnaire. A Freepost envelope was included for return of questionnaire. The questionnaires were anonymous and subjects could not be identified. Consent to participate was implied by the return of completed questionnaire. A reminder with a copy of the questionnaire was sent to all participants to achieve the final response rate. Questionnaires were sent to arrive a minimum of five weeks after the most recently attended appointment, allowing sufficient time for a *normal results* letter to be received. Reminder letters and questionnaires were sent two weeks after the original batch were sent. The questionnaire was developed upon findings from published studies examining non-attendance at breast screening programmes.<sup>15-19</sup> A core questionnaire was devised for PNAs, modified slightly to reflect differences between First PNAs and Subsequent PNAs. The questionnaire initially addressed recall of the invitation for screening at most recent (attended) appointment and for previous (non-attended) appointment and level of agreement with a series of statements relating to breast screening. A list of possible considerations at the time of the missed appointment was presented and respondents were asked to tick all that applied. A list of possible considerations relevant at the time of the woman's return to screening in 2010 was then presented, and again respondents asked to select all that applied. Questionnaires for controls included all the applicable questions from the PNA questionnaire. All questionnaires gathered demographic information including age, level of education, area of residence, membership of private health insurance and eligibility for means tested general medical services (GMS).<sup>20</sup> Questionnaires were

first piloted to five women in each of the four cohorts to assess potential difficulties in comprehension or completion. The questionnaire was then sent to 2500 women, 625 in each cohort. A final response rate of 75% was estimated, based on a previous BreastCheck survey of attenders for male radiographer study,<sup>21</sup> where response rate exceeded 85%.

## Ethics

Ethical approval for the study was granted by the Research Ethics Committee from the Faculty of Public Health Medicine and Faculty of Occupational Medicine in the Royal College of Physicians of Ireland.

## Statistical analysis

The chi square test was used for comparison of proportions. Logistic regression was used to adjust for socio-demographic factors. Welch's t-Test was used to compare mean travel times. SAS was used for analysis (version 9.1, SAS, North Carolina, USA).

## Power considerations

The achieved sample size has power of 80% to detect 9% difference between PNAs and regular attenders and between First PNAs and Subsequent PNAs.

## Socio-demographic variables

### Comparison of First PNAs and First Controls

As the national rollout of BreastCheck began in 2007 First PNAs and First Controls arise from prevalent screening of women across the full age range of 50-64. A greater proportion of First controls than First PNAs had a family history of cancer, a family history of breast cancer and private health insurance. Significantly more First PNAs had third level education (university level or equivalent) and resided in a rural area, compared to First Controls (Table 1).

### Comparison of Subsequent PNAs and Subsequent Controls

Subsequent PNAs and Subsequent Controls were very similar in regard to socio-demographic variables with the exception of area of residence, where a significantly greater proportion of Subsequent PNAs lived in a rural location when compared to Subsequent Controls (Table 1).

## Results

The overall sample size achieved was 1797 (72%). The response rate was higher for the control groups (86% for the Subsequent Controls and 81% for the First Controls) than for the PNA groups (62% for the Subsequent PNAs and 58% for the First PNAs). First PNAs and First Controls were similar in terms of age profile and medical card status (Table 1).

Table 2 compares opinions towards breast cancer screening following the responders' most recent BreastCheck mammogram in 2010. For some this would have been their first mammogram; for others they may have based their opinion on cumulative experiences.

### Comparison of First PNAs and First Controls

Similar proportions of First PNAs and First Controls (45.1% vs 40.3%;  $P=0.17$ ) spoke to their own GP about breast cancer sometimes/a lot. *Good* or *Excellent* levels of health status was reported in both First PNAs and First Controls (82.9% vs 83.2%;  $P=0.90$ ). Significantly more First PNA women who described their health status as *Fair* or *Poor* were likely to agree or strongly agree with the statement *I would rather*

not know if I had breast cancer than those who consider their health as *Excellent* or *Good* (16.7% vs 9.3%,  $P=0.09$ ). There was a significant difference between First PNAs and First Controls in their attitude to the ability of mammography to find small impalpable lumps. Significantly fewer First PNAs agreed with the statement *A mammogram could find a small breast lump even if I cannot feel it*. All differences in proportions remained significant after adjustment for socio-demographic factors and family history of cancer (Table 2).

### Comparison of Subsequent PNAs and Subsequent Controls

Similar proportions of Subsequent PNAs and Subsequent Controls (40% vs 42.7%;  $P=0.41$ ) spoke to their own GP about breast cancer

sometimes/a lot; however a significantly lower proportion of Subsequent PNAs reported health status as excellent or good compared to Subsequent Controls (72.7% vs 84.9%;  $P<0.001$ ). Significantly more Subsequent PNA women who described their health status as *Fair* or *Poor* were likely to agree or strongly agree with the statement *I would rather not know if I had breast cancer* than those who considered their health as *Excellent* or *Good* (23.7% vs 10.5%,  $P=0.0015$ ).

There was a significant difference between Subsequent PNAs and Subsequent Controls in their attitude to the ability of mammography to find small impalpable lumps. Significantly fewer Subsequent PNAs agreed with the statement *A mammogram could find a small breast lump even if I cannot feel it*. Additionally significantly more Subsequent PNAs than Subsequent Controls agreed that they would rather not know if they had breast cancer. Significantly more Subsequent Controls

**Table 1. Socio-demographic variables; comparisons of First PNAs and Subsequent PNAs with respective controls.**

	First PNA		First Control		P	Subsequent PNA		Subsequent Control		P
	N	%	N	%		N	%	N	%	
Age group										
50-54	176	49.4	251	50.4	0.466	16	4.2	26	4.8	0.885
55-59	106	29.8	131	26.3		194	51.2	277	51.6	
60+	74	20.8	116	23.3		169	44.6	234	43.6	
GMS card	122	34.1	146	29.5	0.155	124	32.7	154	28.6	0.184
Private insurance	202	57.7	319	64.8	0.036*	219	59.7	344	65.0	0.103
Third level education	118	33.2	118	23.6	0.002**	105	28.0	147	27.4	0.835
Area of residence										
Rural	131	37.3	255	51.4	<0.001**	146	38.9	196	36.4	0.009**
Town	111	31.6	142	28.6		137	36.5	161	29.9	
City	109	31.1	99	20.0		92	24.5	181	33.6	
Family history of breast cancer	88	24.8	154	31.3	0.038*	100	26.5	162	30.5	0.192
Family history of cancer	220	63.2	360	72.7	0.003**	267	70.8	378	70.9	0.975

First PNA: failed to attend BreastCheck appointment in 2007/08; attended in 2010; First Control: attended first invited appointment with BreastCheck in 2010; Subsequent PNA: attended BreastCheck appointment in 2006 or earlier, failed to attend in 2007/08; attended in 2010; Subsequent Control: attended all BreastCheck appointments from 2000-2010. \* $P<0.05$ ; \*\* $P<0.01$ .

**Table 2. Agreement with statements regarding breast cancer screening, following most recent mammogram in 2010**

Statement	Percentage agreeing/strongly agreeing with statement							
	First PNA	First Control	Unadjusted OR (95% CI)	Adjusted OR $\pm$ (95% CI)	Subsequent PNA	Subsequent Control	Unadjusted OR (95% CI)	Adjusted OR $\pm$ (95% CI)
A mammogram could find a small breast lump even if I cannot feel it	90.7%	94.6%	0.56* (0.33-0.95)	0.58* (0.33-1.00)	88.2%	94.5%	0.43** (0.27-0.70)	0.42** (0.26-0.69)
Having treatment is better than having the disease	94.4%	95.0%	0.89 (0.49-1.65)	0.92 (0.49-1.73)	96.8%	97.8%	0.70 (0.31-1.57)	0.72 (0.31-1.65)
I would rather not know if I had breast cancer	10.6%	11.7%	0.89 (0.58-1.39)	0.84 (0.53-1.33)	14.4%	7.7%	2.03** (1.31-3.14)	1.94** (1.24-3.05)
Breast cancer can be cured if found early	92.0%	92.7%	0.90 (0.54-1.50)	0.94 (0.55-1.60)	90.9%	93.5%	0.69 (0.42-1.14)	0.68 (0.41-1.13)
Having a mammogram is painful	31.8%	31.7%	1.01 (0.75-1.35)	1.04 (0.77-1.41)	34.2%	33.1%	1.05 (0.80-1.40)	1.02 (0.77-1.36)
Having a mammogram is embarrassing	15.1%	15.3%	0.98 (0.67-1.44)	0.99 (0.66-1.46)	16.9%	12.8%	1.39 (0.96-2.03)	1.34 (0.91-1.99)
Having a mammogram is quick	91.6%	91.7%	0.99 (0.60-1.63)	1.09 (0.64-1.83)	92.4%	94.8%	0.67 (0.39-1.15)	0.62 (0.36-1.09)
My family/friends have positive experiences of breast screening	73.7%	76.4%	0.86 (0.62-1.19)	0.92 (0.66-1.29)	72.7%	80.8%	0.63** (0.46-0.87)	0.61** (0.44-0.85)

Adjusted for age, urban/rural residence, GMS eligibility, private medical insurance status, education level, family history of cancer and family history of breast cancer. \* $P<0.05$  \*\* $P<0.01$ .

agreed that their family or friends have had positive experiences of breast screening. All differences in proportions again remained significant after adjustment for socio-demographic factors and family history of cancer (Table 2).

The interrelationships between responses to the first four statements in table two regarding attitudes to breast cancer and beliefs about screening were explored. Agreement with the statement *I would rather not know I had breast cancer* was not significantly associated with agreement with the other three.

### Comparison of First PNAs and First Controls

Among the considerations at the time of first invite (2007/08 for First PNAs and 2010 for First Controls) the following issues were reported significantly more by First Controls compared to First PNAs: *feeling shy; thought mammogram would be/was unpleasant; thought the mammogram would be/was painful; found the invitation reassuring; fear of operation; GP examines breast; GP will refer if needed and had no symp-*

*toms*. Additionally, significantly more First Controls than First PNAs had concerns that *breasts were too large or too small* and had *never heard of BreastCheck before I got invitation* (Table 3). Following exclusion of women from the analysis who had received a mammogram previously (outside of the national programme), concerns about breasts being too large or too small were no longer significantly different ( $P=0.114$ ), whereas the proportions confirming *I thought/earlier mammogram would be/was painful* remained significantly greater among First Controls than First PNAs (18.7% vs 15.3%,  $P<0.001$ ).

The only consideration at the time of first invite (2007/08 for First PNAs and 2010 for First Controls) which was reported significantly more by First PNAs compared to First Controls was *could not reschedule appointment*. While a small number of controls stated they *could not reschedule appointment* for some reason, they still attended the scheduled appointment.

Some questions were only relevant to PNAs to probe the reasons that they did not attend their previous appointment. The following reasons

**Table 3. Considerations at time of missed appointment (PNAs)/attended appointment (Controls).**

Time of first invitation Time of missed appointment	(2007/08)		(2010)		P	(2006 or earlier) (2007/08)		(2008 or earlier)		P
	First PNA		First Control			Subsequent PNA		Subsequent Control		
	N	(%)	N	(%)		N	(%)	N	(%)	
Felt shy	16	(4.4)	65	(12.9)	<0.001**	3	(0.8)	43	(8.0)	<0.001**
Not comfortable asking for time off work	12	(3.3)	20	(4.0)	0.604	12	(3.1)	27	(5.0)	0.151
No screening at weekends/evenings	13	(3.6)	27	(5.4)	0.216	10	(2.6)	28	(5.2)	0.047*
Loss of wages	5	(1.4)	9	(1.8)	0.634	6	(1.5)	13	(2.4)	0.358
Could not reschedule appointment	21	(5.8)	5	(1.0)	<0.001**	32	(8.2)	2	(0.4)	<0.001**
Trip too difficult	24	(6.6)	37	(7.3)	0.671	25	(6.4)	15	(2.8)	0.007**
Disliked attending mobile	7	(1.9)	16	(3.2)	0.257	11	(2.8)	25	(4.6)	0.160
Breasts too large or too small	5	(1.4)	19	(3.8)	0.034*	7	(1.5)	30	(5.6)	0.004**
I thought/Earlier mammogram would be/was unpleasant	34	(9.3)	137	(27.2)	<0.001**	32	(8.2)	51	(9.4)	0.521
I thought/Earlier mammogram would be/was painful	17	(4.7)	94	(18.7)	<0.001**	28	(7.2)	76	(14.1)	0.001**
I thought/Earlier mammogram would be/was too long	11	(3.0)	17	(3.4)	0.773	0	(0.0)	4	(0.7)	0.089
Too busy	42	(11.5)	66	(13.1)	0.493	55	(14.1)	89	(16.5)	0.330
Invitation reassuring	14	(3.8)	373	(74.0)	<0.001**	18	(4.6)	396	(73.3)	<0.001**
Invitation unclear	3	(0.8)	2	(0.4)	0.412	0	(0.0)	2	(0.4)	0.230
Invitation frightening	28	(7.7)	39	(7.7)	0.980	9	(2.3)	32	(5.9)	0.008**
Concern re radiation	12	(3.3)	27	(5.4)	0.148	12	(3.1)	34	(6.3)	0.026*
Fear of operation	25	(6.9)	77	(15.3)	<0.001**	4	(1.0)	68	(12.6)	<0.001**
GP examines breasts	21	(5.8)	83	(16.5)	<0.001**	14	(3.6)	38	(7.0)	0.025*
GP will refer if needed	8	(2.2)	30	(6.0)	0.008**	5	(1.3)	12	(2.2)	0.293
No symptoms	18	(4.9)	193	(38.3)	<0.001**	24	(6.2)	141	(26.1)	<0.001**
Never heard of BreastCheck before I got the invitation	12	(3.3)	32	(6.4)	0.043*	-	-	-	-	N/A
<b>Options for PNAs only (not relevant to controls)</b>										
Already had mammogram elsewhere	120	(33.3)	-	-	N/A	55	(14.1)	-	-	N/A
Screening does not work	1	(0.3)	-	-	N/A	1	(0.3)	-	-	N/A
Not interested	3	(0.8)	-	-	N/A	0	(0.0)	-	-	N/A
Did not receive invite	42	(11.5)	-	-	N/A	19	(4.9)	-	-	N/A
On holiday	16	(4.4)	-	-	N/A	45	(11.6)	-	-	N/A
Ill/hospitalised	12	(3.3)	-	-	N/A	42	(10.8)	-	-	N/A
Postponed to next round	61	(16.8)	-	-	N/A	73	(18.8)	-	-	N/A
Forgot appointment	45	(12.4)	-	-	N/A	72	(18.5)	-	-	N/A
Already having treatment for cancer	8	(2.2)	-	-	N/A	8	(2.1)	-	-	N/A

\* $P<0.05$  \*\* $P<0.01$

were given by First PNAs: *already had a mammogram elsewhere; did not receive invite; on holiday; ill/hospitalised; postponed to next round; forgot appointment; already having treatment for cancer; not interested; screening does not work* (Table 3).

#### Comparison of Subsequent PNAs and Subsequent Controls

Subsequent PNAs were also asked to consider possible reasons for their missed appointment in 2007/08. Subsequent Controls were asked to highlight issues which they considered before or during their attended appointments. Among the considerations which were reported significantly more by Subsequent Controls compared to Subsequent PNAs were *feeling shy; screening was not available at weekends or evenings; breasts were too large or too small; thought the mammogram would be/was painful; found the invitation reassuring; the invitation was frightening; fear of operation; concerns about radiation; GP examines breasts and had no symptoms*.

The only two considerations which were reported significantly more by Subsequent PNAs compared to Subsequent Controls were; *could not reschedule appointment and trip too difficult*. Again while a small number of controls stated they *could not reschedule appointment* for some reason, they still attended the scheduled appointment (Table 3).

Some questions were only relevant to Subsequent PNAs to probe the reasons that they did not attend their previous appointment and the following reasons were given: *already had a mammogram elsewhere; did not receive invite; on holiday; ill/hospitalised; postponed to next round; forgot appointment; already having treatment for cancer and screening does not work* (Table 3).

Table 4 outlines considerations pertinent to PNA women at the time of re-invitation to screening in 2010. Among the more frequent were; *I am older; I made sure to remember the appointment this time; Breast cancer is now of particular concern to me; All illness is now of more concern to me; I was able to reschedule to a suitable time*. First PNAs were significantly more likely to consider the following items than Subsequent PNAs: *My GP advised me to attend; My family or friends*

*advised me to attend; I heard good things about BreastCheck; I had heard more about BreastCheck; The invitation seemed more clear this time* (Table 4).

Upon examination of mean travel times to the screening unit we found that there were very small but statistically significant differences between First PNAs compared to First Controls (27.8 minutes vs 24.5 minutes;  $P=0.016$ ). When examining reasons for First PNAs attending their 2010 screening appointment; 11.8% of First PNAs cited *Trip to screening centre easier because different location*, as one of the reasons for attending, while 5.5% of First PNAs agreed that the *Trip to screening centre (was) easier because better transport available now* (Table 4).

There were similar very small but statistically significant differences between Subsequent PNAs compared to Subsequent Controls also (27.6 minutes vs 24.7 minutes;  $P=0.043$ ). For Subsequent PNAs attending their 2010 screening appointment; 10% cited *Trip to screening centre easier because different location*, as one of the reasons for attending, while 7.5% of Subsequent PNAs agreed that the *Trip to screening centre (was) easier because better transport available now* (Table 4).

## Discussion

### Methodological limitations

Maintenance of breast screening uptake is a serious challenge. The large sample size and the response rate of 72% add weight to our findings and is comparable to other published postal surveys.<sup>22</sup> A limitation is the poorer response rate in PNAs overall (60%) and particularly First PNAs (58%). While the variation between sub-groups does not impact on the validity or reliability of the statistical analysis, it does highlight the correlation between non-participation in the programme and willingness to complete the questionnaire. 489 (27%) respondents provid-

**Table 4. Considerations at time of return to screening in 2010.**

	First PNAs		Subsequent PNAs		P
	N	%	N	%	
I am older	129	35.4	115	29.6	0.085
I made sure I remembered the appointment this time	86	23.6	113	29	0.092
I rang up and was able to reschedule appointment to suitable time	64	17.6	80	20.6	0.298
All illnesses now of more concern to me	60	16.5	74	19	0.363
Breast cancer in particular is now of more concern to me	82	22.5	73	18.8	0.202
My family or friends advised me to attend	81	22.3	59	15.2	0.013*
My GP advised me to attend	46	12.6	18	4.6	<0.001**
I had heard more about BreastCheck	56	15.4	16	4.1	<0.001**
I had heard good things about BreastCheck	105	28.8	53	13.6	<0.001**
Serious personal illness or hospitalised in past two years	14	3.8	20	5.1	0.392
A friend or family member got cancer in past two years	51	14.0	49	12.6	0.568
I had heard of celebrities developing breast cancer	19	5.2	17	4.4	0.585
Trip to screening centre easier because different location	43	11.8	39	10	0.431
Trip to screening centre easier because better transport available now	20	5.5	29	7.5	0.276
I was less busy at work/home	35	9.6	34	8.7	0.677
Invitation seemed more reassuring this time	19	5.2	18	4.6	0.707
Invitation seemed more clear this time	21	5.8	10	2.6	0.027*
I had symptoms	11	3.0	13	3.3	0.803

First PNAs: failed to attend BreastCheck appointment in 2007/08; attended in 2010; Subsequent PNAs: attended BreastCheck appointment in 2006 or earlier, failed to attend in 2007/08; attended in 2010. \* $P<0.05$   
\*\* $P<0.01$ .

ed their contacts details for a potential follow up study, and of these, two women had sent the questionnaire back twice. The duplicate questionnaires were excluded from the dataset. Women who were recalled for further tests after having a mammogram were excluded from the sample; therefore any reasons for non-attendance resulting from being recalled for assessment were not examined. Questionnaires were based on internationally published work in the area of non-attendance. Due to the explorative nature of the study, there was scope given for women to add additional comments. It is acknowledged that asking women to recall why they did not attend their appointment two years prior to their 2010 screening may raise some reliability concerns of answers provided due to the length of time since missed appointment; also a woman's current view of breast screening may cognitively bias her reflection of previous decision making.

While there is much written about non-attenders we were unable to find any other study that has addressed specifically why intermittent attenders return to breast screening. These women differ from persistent non-attenders as they have returned to screening. In common with other studies,<sup>9,23,24</sup> controls (women who attend mammographic screening) were more likely to have a family history of cancer or breast cancer than intermittent attenders. Subsequent PNAs who attended once and then skipped one or several screening rounds before returning in 2010 were significantly less likely than the controls to report their health status as good or excellent. This finding corresponds with the main considerations given for returning in 2010 *i.e. all illness is now of more concern to me, breast cancer is now of particular concern to me*. These findings support a US study which found that breast cancer worry may motivate screening behaviour rather than deter it.<sup>25</sup> A 2004 critical review of twenty two studies regarding how fear, anxiety and worry influence cancer screening behaviour found no conclusive evidence of whether these emotions act as a barrier or facilitator of screening.<sup>26</sup> Compared to PNAs, women who have attended all invited appointments were significantly more likely to be concerned about shyness, size of breasts, pain of mammogram and fear of operation at time of first invite; however such fears did not deter women from attending. First Controls were additionally concerned about unpleasantness of mammogram, while Subsequent Controls had concerns about radiation and found the invitation frightening. These findings may highlight unexpected concerns women only become aware of after attending screening, although these concerns do not seem to create a barrier. These findings lend support to research suggesting the need for more transparency in the information provided to women and its contribution to informed decision making.<sup>27-29</sup> However a substantial proportion of the population must participate for screening programme to operate successfully. Recent research offers conflicting evidence on the impact that the provision of comprehensive information on the risks of screening has on uptake. A study in Switzerland has shown that informing potential participants about the risks of cancer screening may reduce participation regardless of beneficial information provided,<sup>30</sup> while a randomised controlled trial of a colorectal cancer screening programme in Germany showed that the provision of evidence based risk information increased informed choices and improved knowledge, with no adverse affects on uptake of screening.<sup>31</sup> An outcome of this study highlights that Subsequent Controls, having experience of the programme and who by default are more informed of the process and any potentially negative aspects, are not deterred from attending subsequent rounds.

A recent UK study has found that cancer screening uptake is generally lower in the urban setting than in rural areas,<sup>10</sup> however rural residency was proportionally higher among PNAs in this study compared to respective controls, similar to the findings in other comparative studies in the US and Canada.<sup>11,12</sup> Residing in a rural area was a deterrent to attendance within this cohort even though mobile units are

located at sites all over the country; First PNAs cited *the trip would be too difficult* as a reason for non-attendance and this was reiterated by Subsequent PNAs as a reason for non attendance, after attending a first time. There were very small but significant differences in mean length of time taken to travel to the screening unit, longer for PNAs compared to controls in both first and subsequent women. A study in Northern Ireland examining access found that while more non-attenders did not have access to private transport, few (4%) expressed a preference for more accessible clinics.<sup>13</sup> This UK study along with a Canadian study,<sup>11</sup> finding lower rural uptake of screening, conclude that the deterrent is more likely the attitude of rural residents towards breast screening rather than access. On the other hand, both First PNAs and Subsequent PNAs in this study cited *Trip to screening centre easier because different location* and *Trip to screening centre easier because better transport available now* as reasons for attendance in 2010.

A study of 10,228 people across nine European countries found that the vast majority of citizens systematically overestimate the benefits of mammography screening.<sup>32</sup> Similar findings were reported in Switzerland, US and UK.<sup>22,33</sup> An Australian study examining the effects of knowledge and beliefs on uptake of mammography found that women who believed mammograms at best were only *somewhat effective*, were unsure or did not think that mammograms save lives were significantly more likely to have never had a mammogram.<sup>34</sup> In this study we found that significantly fewer First PNAs and Subsequent PNAs compared to their respective controls believe that a mammogram could find a small impalpable lump, suggesting a lack of trust in the effectiveness of mammography among PNAs. Significantly more Subsequent PNAs than Subsequent Controls reported that they would rather not know if they had breast cancer suggesting some denial or fatalism in this group. A US study examining the influence of fatalism on cancer screening participation found that women with a fatalistic attitude also had a family history of breast cancer, believed that not much could be done to prevent breast cancer, believed that breast cancer could not be cured if found early and believed that treatment could be worse than the disease.<sup>17</sup> Our study also examined similar beliefs but we found that there were no significant correlations with PNA women who *would rather not know if they have breast cancer*; however these women were significantly more likely to consider their health status as poor or fair.

Family and friends appear to have a strong positive influence on Subsequent Controls commitment to re-attendance. In addition First PNAs were significantly more likely than Subsequent PNAs to have returned to screening because their family and friends advised them to attend. In a study of 300 attenders and 300 non-attenders in Northern Ireland, both groups obtained information more often from friends and relatives than from official sources.<sup>35</sup> These findings reinforce the importance of word of mouth as a means of screening promotion, supporting initiatives such as the New England *Tell a friend* programme,<sup>36</sup> and similar schemes in the US.<sup>37,38</sup> These initiatives have guided various community educational drives carried out by the screening promotion team in BreastCheck. While word of mouth is an important influence, such initiatives aim to ensure that information passed through word of mouth is based on factual information, rather than emotional and personal reasons. Consedine *et al.* identified four studies where women claimed to be more likely to get a mammogram if their physician recommended it,<sup>26</sup> which supports the findings in this study where both First PNAs and Subsequent PNAs listed *My GP advised me to attend* as a reason for returning to screening; however GPs were significantly more influential for First PNAs than Subsequent PNAs.

## Conclusions

There is little previously published regarding factors influencing such intermittent attendance at breast screening. Intermittent attenders do not fit typical socio-demographic patterns of non-attenders at screening; persistence in recommendation by GP and word of mouth are importance influences on women's return to screening, as are logistical considerations. Fear, anxiety and worry seem to act as a facilitator of screening rather than an inhibitor.

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