

## Women who decline breast screening

UNA MACLEAN, DOROTHY SINFIELD, SUSAN KLEIN, AND BETTY HARNDEN

*From the Department of Community Medicine, University of Edinburgh*

**SUMMARY** The health related behaviour and attitudes of a random sample of 125 women aged 45–64 who declined to accept an invitation to attend a breast screening clinic are described. The women differed from attenders in their socioeconomic class and in their customary use of measures to promote health. They were basically unsympathetic towards the idea of screening and the invitation had caused them considerable anxiety. Policy implications are raised.

Edinburgh is one of eight UK centres involved in a study of women aged 45–64 to test, over seven years, the effectiveness of different forms of regular screening in the detection and early treatment of breast cancer.<sup>1 2</sup> By 1981 the local project committee were concerned at the relatively low response rate (62%) among women sent a first letter of invitation to attend the breast screening clinic. Since their reluctance could invalidate the final results, the committee wanted a rapid investigation of women's expressed reasons for non-attendance. They optimistically considered that the results might suggest ways of encouraging a better response from successive cohorts of women before the screening period came to an end. Although a lengthier piece of research would ideally have included a sample of clinic attenders, in the circumstances attention was concentrated on non-attenders.

### Context of present study

Given the current medical view of screening as a sensible preventive strategy, the behaviour of such women might be construed by some doctors as "non-compliance,"<sup>3</sup> but this would be inappropriate, since attendance at the breast screening clinic was not initiated by any of the women offered this facility. On the contrary, the invitation had come out of the blue to symptomless women who were under no obligation to fit in with the aims of an experimental screening trial. Alternatively, women's failure to respond might well relate to what is already known about "delay" in reporting breast symptoms. Much has been written concerning women's apprehensions regarding breast cancer and reactions to the suspicion that they might have fallen victim to this disease.<sup>4–12</sup> However, just as it is wrong to apply the notion of non-compliance to women who fail to accept an

unsought invitation to a strange screening clinic, so we cannot equate symptomless women with those who have discovered a breast lump. Yet it is reasonable to suppose that fears similar to those aroused when someone suspects that they have breast cancer might also be involved in women's reactions to proposed breast screening and so prevent rather than hasten consultation.

An associated field of research concerns women's experiences and responses after mastectomy. Such women face profound changes, both physical and in their feminine self-image.<sup>13–17</sup> In one sense, a healthy woman who receives an unexpected invitation to a breast screening clinic is far removed from someone who has actually lost a breast, but the former will surely fear sharing the plight of the latter. There is inevitably a connection in women's minds between breast cancer and mastectomy and possibly, therefore, between breast screening and the latter.

While most of those who provide breast screening are genuinely convinced of its value, it is scarcely to be accepted that all women will fully share the protagonists' missionary zeal. The idea of screening for hidden pathology is comparatively new in this country, and investigations into women's reactions to relevant procedures are infrequent.<sup>18–20</sup> In Edinburgh, the promoters of breast cancer screening regarded the entire population of women aged 45 to 64 as being at some degree of risk to breast cancer but recognised that the reactions to this disease of individual women and others close to them could differ widely. This research, originally prompted by a single question, may help us to understand how a group of women see the chances of influencing their well-being and what their customary "health-promoting behaviour" amounts to.

There may, of course, be practical reasons why people do not respond to an unexpected screening

invitation. There are limits to what any one person can do in a day and what they consider to be worth while. For lay people health may not constitute the primary and overriding consideration that it represents for doctors. This study therefore tried to include a wide range of explanations and contexts for non-attendance.

**Method**

The general practitioners of the women were first informed and then a random sample of 150 classified non-attenders were visited at home by a skilled interviewer. The response rate was over 90%. Questions relating to cancer and to the clinic invitation came near the end of an hour-long discussion concerning women's health beliefs, experiences, and various actions taken to promote health. The interview was largely precoded, with opportunities to enlarge upon sensitive topics.

During the fieldwork we were surprised to discover that 21 of these women had attended the breast screening clinic, suggesting that computer listings had not been brought up to date fast enough to take account of late responses to some first and subsequent invitations. With much information already collected, it was decided to go ahead and obtain a full account from these "reluctant attenders." Four further women were rejected, two because of language difficulties, and two who had already had mastectomies—a fact possibly explained by the reluctance of some GPs to scan lists of invited women's names.

Having unexpectedly acquired information regarding 21 clinic attenders, the further decision was taken to include them in the analysis. We emphasise that we do not claim that the experience and views of this small incidental group are necessarily representative of attenders, but they appear to have certain different characteristics from those who never came for screening.

**Results**

Few of the 125 non-attenders had formal educational qualifications, but the differences from our 21 attenders in this respect was not statistically significant. The non-attenders were somewhat older than the attenders whom we interviewed; this difference also was not significant.

We compared the social class of the non-attending women whom we interviewed with that of Edinburgh households generally<sup>21</sup> and with a 10% sample of 1982 attenders at the clinic<sup>22</sup> (table 1).

Our random sample of non-attenders were not markedly dissimilar in social class from the 1971 sample census of all Edinburgh households, although

we encountered fewer professional and intermediate class members (20% v 26%) and more lower social class members.

Table 1 *Social class of women in study compared with Edinburgh census and those attending breast screening clinic*

Social class	This study		Edinburgh households† %	Breast screening clinic attenders* %
	Non-attenders %	Attenders %		
Professional and intermediate	20	29	26	48
Skilled non-manual	21	9	18	} 37
Skilled manual	30	33	28	
Semi/unskilled manual	27	29	23	
Not classified	2	—	5	—
Number on which percentage is based (= 100%)	125	21	14 416	1963

\*Sample of women, 1982, Edinburgh Breast Screening Clinic Report.<sup>22</sup>

†Excludes households in which the head is a student or economically inactive. Source 1971 Census, 10% sample, Census Office, Ladywell House, Edinburgh.<sup>21</sup>

It is noteworthy that nearly half (48%) of a sample of the women seen at the breast screening clinic in 1981 had come from the professional and intermediate occupational categories. Clearly, those who went to the clinic were a selected and unrepresentative group of women from the general population of Edinburgh,\* in spite of the care taken to invite all women aged 45–64 years from randomly selected general practices in the city.<sup>23</sup>

**HEALTH RELATED BEHAVIOUR**

Nearly 37% of the non-attenders expressed concern at the possibility of developing cancer, which they considered much more alarming than heart disease or nervous troubles.

Table 2 illustrates aspects of customary health promoting behaviour among our non-attenders and attenders. The paucity of significant differences may relate to the very small number of attenders.

Regarding the use of "health foods," for example, vitamins, tonics, herbal preparations and other items, 67% of the non-attenders denied choosing specific foods because of their supposed health giving properties. Among those who did use "health foods," 20% mentioned vitamins. By contrast, only eight (38%) of the small group of attenders said that they bought no specific health promoting foods or vitamins. Only 44% of the non-attenders took special action to try to keep healthy, such as exercising and going to keep fit classes, compared with 57% of the attenders.

\*The response in one Edinburgh practice has been reported elsewhere.<sup>23</sup>

**Table 2 Health related behaviour of clinic non-attenders and attenders**

		Non-attenders %	Attenders %
Use of "health foods"	p>0.10, NS	33	48
Do not use specifically "healthy" products	Significant, p<0.02	67	38
Regular exercise	p>0.20, NS	40	52
Keep-fit classes	p>0.95, NS	4	5
Never smoked	p>0.95, NS	28	28
Regular dental checks	Significant, p<0.05	26	58
Dental attendance only for problems	Significant, p<0.01	63	42
No GP surgery attendance in previous year	p>0.10, NS	39	24
1-2 attendances in previous year	p>0.20, NS	34	48
Hospital inpatient attendance in previous five years	Significant, p<0.01	26	57
Hospital outpatient attendance in previous five years	p>0.10, NS	44	62
Cervical smear test	Significant, p<0.01	41	71
Ignorance of well woman clinics	Significant, p<0.01	90	67
Invariable seat belt use	Significant, p<0.01	30	60
Children immunised	p>0.30, NS	89	95
Number of women (= 100%)		125	21

Regular dental care, which has a close connection with screening, also showed striking and statistically significant differences between our non-attenders and attenders. Of clinic attenders 58% went regularly to the dentist compared with 26% of non-attenders. Of the non-attenders only 63% went for help with a problem and clearly saw the dentist as someone who fixed rather than checked their teeth.

When asked about visits to their general practitioner in the previous year it appeared that almost 40% of non-attenders had felt no need to go to the surgery compared with 24% of the breast clinic attenders whom we saw. Attenders were more inclined to consider that their doctor knew them very well (48%) or quite well (33%) compared with the non-attenders, only 31% of whom thought their GP knew them very well. Of non-attenders 21% maintained that their GP scarcely knew them. Since the original invitation from the breast screening clinic had quoted the approval of a woman's doctor this may have meant more to attenders than to non-attenders, to whom the doctor was a comparatively distant figure.

It is notable that 71% of the attenders reported having had a cervical smear done as compared with only 41% of non-attenders. Over 90% of the non-attenders had never heard of well woman clinics, whereas they were familiar to one third of the

attenders. These were statistically significant differences.

Car users were asked about seat belts (before legislation required it) and 30% of non-attenders always wore belts compared with 60% of attenders, a significant difference.

**ATTITUDES TO BREAST SCREENING**

When the topic of breast screening was eventually broached, women were asked to choose from listed possible reasons for not attending the clinic and were then given an opportunity to expand on the circumstances or feelings that had influenced their response to the written invitation. Subsequent content analysis of this qualitative material supplemented the responses to direct questioning. Both approaches to women's attitudes uncovered the worries and difficult decisions that the invitation had provoked. The eventual categories comprised: practical reasons (46%); fears, worry, and anxiety (39%); a belief that screening was unnecessary (38%); the view that one should not seek trouble (23%); postponement (21%); negative feelings about the imagined clinic experience (37%); family influences (7%); the fact of currently attending another medical facility (14%) (see table 3).

**Table 3 Commonest reasons for non-attendance (content analysis of qualitative material)**

Category	%	Percentage mentioning category
Practical reasons		45.6
Family responsibilities	16.0	
Work	9.6	
Disability	7.2	
"Too old"	5.6	
On holiday	4.8	
Some expression of fear (whether or not actual word was used)	39.2	39.2
Screening not necessary (at least for respondent, who feels perfectly well and would seek medical help if she thought it was needed)	38.4	38.4
One should not go looking for trouble (one should not tempt fate; it is best to leave well alone)	23.2	23.2
Postponement (something coming in the way, too busy at the time, should have gone, meant to go, etc)	20.8	20.8
Negative reactions to envisaged clinic experience		36.8
Dislike of physical examination	16.0	
Dislike of doctors/clinics	11.2	
Dislike of interference in self care	3.2	
Prefers seeking medical care spontaneously	1.6	
Dislike of presence of other women at clinic	1.6	
Dislike of thought of positive diagnosis being made	1.6	
More than one negative reaction	1.6	
Family influence		7.2
Family advised attendance	4.0	
Family advised against attendance	3.2	
Currently attending other medical facility	14.4	14.4
Number of women (= 100%)		125

*Women who decline breast screening*

Among practical reasons for non-attendance given, family responsibilities were predominant. Postponement is a related response; about one fifth of the women had intended to go but were prevented from doing so. In view of the risk of breast cancer increasing with age, it is remarkable to realise that some women considered they were too old to need screening.

Deep fears and concerns about possible breast cancer were voiced by almost 40% of the women. As they elaborated on their reactions, their anxiety found expression in many ways. Women spoke of the chance of dreaded cancer being diagnosed, of what might happen to them "if anything was found," and how they disliked even being obliged to contemplate something that was, in their minds, connected with cancer. Some women had reacted with great alarm because they fancied that the original letter of invitation, endorsed by their doctor, must mean that he or she considered they had cancer.

Nearly 40% of the women did not comprehend or sympathise with the whole idea of screening. They felt themselves to be perfectly well at the time and were emphatic that they would go for medical attention for breast trouble if they thought they needed it. Screening might be all right for others, they implied, but the notion that they themselves should look for trouble seemed not merely pointless but positively foolhardy.

Over 20% of the non-attenders were explicit about this, feeling that one ought not to tempt fate or that, in other words, it was best to leave well alone. To them the entire philosophy of screening was foreign and they could see no point in searching for hidden, invisible ills within their bodies. On the contrary, they seemed to fear, irrationally, that the very enterprise might bring sickness into being, not simply into sight, and they would prefer to have nothing whatsoever to do with such unnecessary and, they believed, potentially threatening activities.

Mention of the breast screening clinic itself conjured up many negative images in the minds of close on 37% of women. Apprehension over the inevitable breast examination was often mentioned; others disliked doctors' surgeries in general and public clinics in particular. Some hated the idea of having to go alone.

**WOMEN'S VIEWS ON BREAST CANCER AND BREAST SELF-EXAMINATION**

Although not tabulated here, we can report that bumps and knocks were thought by 43% of the non-attenders to be causes of breast cancer, but 46% rightly considered that the cause of the disease is unknown. Of the non-attending women 90% considered that a lump was the way in which breast

cancer was first manifested; only 4% knew that there might be pain, and one mentioned nipple abnormalities; 70% had heard of breast self-examination but only one third had ever tried it themselves, and most could not describe a recommended method. The small group of attenders held a significantly higher opinion of this procedure.

**Table 4** *Opinion of breast self-examination*

Opinions	Non-attenders		Attenders	
	No	%	No	%
Good practice	37	29.6	17	81.0
Quite good practice	39	31.2	—	—
Not good practice	16	12.8	1	4.8
Bad practice	28	22.4	—	—
Unsure/no opinion	5	4.0	3	14.3
Number of women (= 100%)	125		21	

( $p < 0.01$ )

**FATALISM**

Both groups of women responded to a set of statements designed to elicit attitudes regarding possible future misfortunes and means to avoid them. Only one of these statements, "You shouldn't go looking for health problems—you'll know soon enough if anything is really wrong," revealed a significant difference between non-attenders (78% agreed) and attenders (43%).

**INFLUENCE OF SOCIAL CLASS ON NON-ATTENDANCE**

The reasons non-attenders gave for their behaviour are analysed by social class in table 5. Women from the lower socioeconomic groups were considerably more likely to have felt anxious but mentioned less in the way of practical obstacles to attending.

**Discussion**

The dilemmas for policy formulation highlighted by women's responses to a breast screening invitation are common to many areas of contemporary community medicine where policy cannot wait upon proof.<sup>24</sup> As far as improving attendance at the screening clinic during the experimental period is concerned, the results of this study are discouraging since most of the attributes of women who declined the invitation are not subject to rapid modification. In the first place, those who did not attend are of a lower socioeconomic class than the predominantly middle class women seen by the clinic, and their record of using other preventive facilities is low. Secondly, their knowledge about breast cancer is limited. Thirdly, the prospect of breast screening

Table 5 Variation by social class in the proportion of women giving various reasons for not attending the breast screening clinic

Reason	Professional and intermediate %	Skilled non-manual %	Skilled manual %	Semi and unskilled manual %	All classes* %
Practical reasons (domestic, transport, work, etc)	76.0	53.8	63.2	50.0	60.8
Fear, worry, anxiety	20.0	23.1	52.6	52.9	39.2
Not necessary	56.0	42.3	34.2	26.5	38.4
Dislike of all things medical (doctors, clinics, physical examinations)	48.0	34.6	42.1	26.5	36.8
Don't want to tempt fate by looking for trouble	24.0	15.4	31.6	20.6	23.2
Procrastination (too busy, etc)	24.0	23.1	21.1	17.6	20.8
Number on which percentage is based†	25	26	38	34	125

\*Includes two women for whom the social class was not recorded.

†Percentages add to more than 100% as more than one reason can be given.

arouses profound anxieties in many who decide not to attend.

Both ethical and practical considerations oblige us to take serious note of what has come to light regarding women's views on the entire philosophy of screening for symptomless disease. Many women, it seems, do not automatically accept the value of such exercises. In this instance, their attitude has an undeniable logic, since we have not yet shown whether and for which age groups breast screening is effective. The possible risks of screening also need to be borne in mind. Even though we can feel virtually certain that mammography today is safe, we have shown the anxieties it can provoke. Screening may also produce "false negatives," that is, women who could thereafter retain special fears and stigma attaching to a temporary diagnosis of cancer. Before the final results of this investigation are known, how justifiable is it to try to bring further pressure to bear on women who choose not to attend for screening?

Women clearly also have practical reasons for non-attendance, and these private and incidental considerations cannot be arbitrarily altered by outsiders. Even if we did have any means of knowing which particular women were liable to be encountering domestic obstacles to cooperation, what justification could investigators have for interfering in another's priorities? While a personal doctor may well advise a woman with cancer to drop everything in the interests of early surgery, we are not in a position to expect someone who is well to go at once for screening. To add to the present pressures upon certain women, by trying more persuasion and

an even harder sell, would itself not be sensible or practical since an artificially high response rate in the existing experimental context could prove a poor guide to the operation and acceptability of breast screening facilities which may eventually be offered as part of general health services.

Meanwhile a strong contrary pressure, for more screening, from women who are already convinced of its value, including those currently being screened, has to be borne in mind. Difficult decisions are being made about what should be done shortly, in the interval between the end of the costly screening trial and the epidemiological analysis. We shall clearly have to come to terms with uncertainty, and confront issues of cost efficiency as well as effectiveness when considering whether to continue with breast screening in the interim. Such planning will take place against a background of conflicting demands, attitudes, and behaviour among the women concerned.

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Requests for reprints should be sent to Dr Una Maclean of the Department of Community Medicine at Edinburgh University.

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