

# Factors associated with non-participation of women in a breast cancer screening programme in a town in northern Italy

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## Abstract

**Study objective**—The aim was to investigate the reasons for the high percentage of women refusing to attend a breast cancer screening programme in the Health District of Brescia, Italy.

**Design**—This was a survey of a sample of non-attenders to the programme, who were interviewed using a structured questionnaire.

**Setting**—Non-attenders all lived in a central area of the town near the screening centre.

**Participants**—Of the 612 non-attenders eligible for interview, 183 could not be interviewed: one had died, 86 were away from home at two different visits, 32 were no longer resident at the known address, eight had serious health problems, 17 had undergone mastectomy, and 39 refused the interview. Overall, a total of 429 of the 612 eligible women were interviewed (70.1%).

**Measurements and main results**—Attenders and non-attenders were compared with respect to demographic and socioeconomic factors, use of preventive medicine, and prevalence of risk factors for breast cancer. The response was higher among less educated women, married and widowed women, and those born in the province than among more educated, single or divorced, and immigrant women. Most of the women interviewed gave practical reasons for non-participation, but lack of interest/distrust and fear/worry/anxiety also seemed important. The number of non-attenders who had had a Papanicolaou test within the previous three years was three times higher than those who had had mammography, suggesting that non-attenders were more interested in types of preventive medicine other than screening for breast cancer by mammography. Attenders and non-attenders appeared similar as regards distribution of conventional breast cancer risk factors.

**Conclusions**—Greater effort in the information campaign might increase the participation rate in screening for breast cancer, although to a lesser extent than expected: if non-attenders potentially recruitable in our screening were added to attenders, overall compliance of the programme was about 75%, lower than that observed in some programmes in northern Europe.

Many studies have demonstrated the effectiveness of mammographic screening in reducing breast cancer mortality in women over 50 years of age.<sup>1-5</sup> Response by the invited population is of great importance among other factors affecting the benefit of screening, as confirmed by recent results of the UK Trial of Early Detection of Breast Cancer, in which women at high risk of dying from breast cancer tended to be non-participants.<sup>6</sup>

In the screening programmes for breast cancer in the 1970s in North Europe, attendance rates at the first round for women in the 50-60 year age range were from 74 to 93%,<sup>2 4 7-10</sup> and about 60% in the province of Florence, Italy.<sup>5</sup> In the province of Brescia, in Northern Italy, two screening programmes for breast cancer have begun during the last few years, with an attendance rate at the first round of about 65%.<sup>11 12</sup> At present, other mammographic screenings for breast cancer are being implemented in Italy<sup>13 14</sup> and the problem of achieving a sufficiently high compliance among the population appears of considerable interest. Knowing which factors influence women's decisions in declining the invitation might suggest how their participation could be increased. So far, no studies have been carried out to investigate the reasons for non-attendance in Italy. This paper compares some sociodemographic characteristics of participants and non-participants in a mass screening for breast cancer in the Health District of Brescia, and describes the reasons for non-attendance given by a sample of women who declined the invitation.

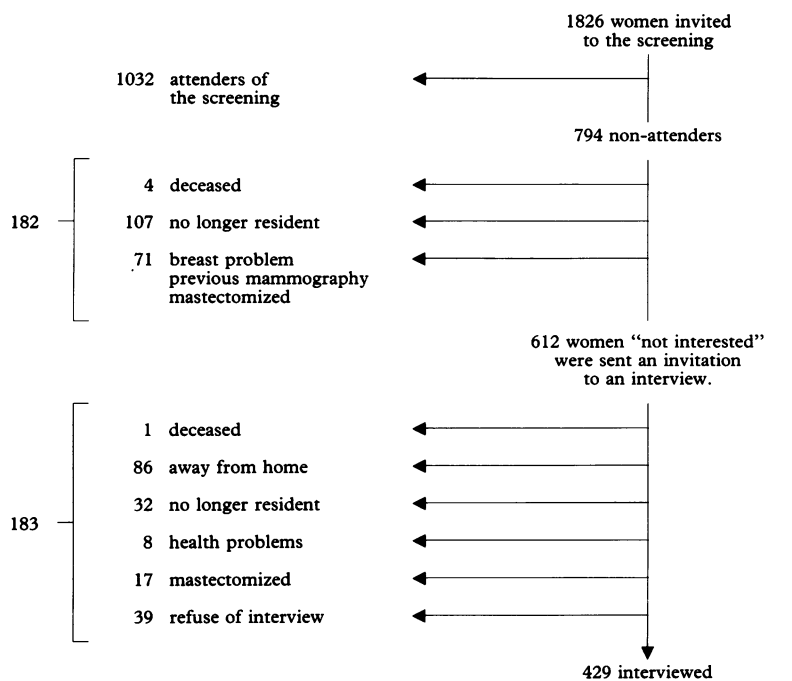
## Methods

In Health District No 41 in the Lombardy Region, Northern Italy, which includes the town of Brescia and 23 surrounding municipalities (about 326 000 inhabitants in 1987), a clinical and mammographic screening of women aged 50-60 started in June 1987. The women were invited with a personal letter giving a specific date and time for attendance (followed by a second one in the case of non-attendance), based on the urban area or municipality of residence. At the beginning of the programme, 1826 women living in the centre of the town were invited and 794 of them (43.5%) did not participate in the programme in the six months after the original appointment. Of these 794 women, four (0.5%) were dead at the time of screening, 107 (13.5%) did not receive any letter as they were no longer living at the recorded address, and 71 (8.9%) told the centre personnel they did not wish to answer the invitation because they had recently

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Accepted for publication May  
1990



Flow diagram of attendees and non-attendees of the screening, women eligible for interview and interviewed.

undergone mammography, or were under treatment for breast problems (figure). Overall, 182 women had well known reasons for non-attending the screening, and they were regarded as not eligible for the survey. The remaining 612 non-attendees were all considered to be not interested in the programme. They were considered eligible for interview and sent a letter informing them of the subsequent approach, and then received a phone call or were directly met by the interviewer. Following the phone call and/or visit by the interviewer, we found that 183 of them could not be interviewed: one had died, 86 were away from home at two different visits, 32 were no longer resident at the known address, eight had

serious health problems, 17 had undergone mastectomy, and 39 refused the interview (figure). Overall, a total of 429 of the 612 eligible women were interviewed (70.1%).

Interviews were conducted by trained volunteers from the Italian League Against Cancer, Department of Brescia (Lega italiana per la lotta contro i tumori, Sezione di Brescia), and were preceded by a personal letter and a telephone call to explain the aim of the survey and ask for the women's collaboration. General practitioners in the Health District were also sent a personal letter explaining the purpose of the survey. Most of the interviews were carried out in the non-responders' own homes, but some women agreed to answer only on the telephone. A structured questionnaire was used for the interviews, partly similar to one used in a population survey in Turin, Italy.<sup>15</sup> The interviews took an average of 15 minutes. In some cases, another attempt was made to convince the women to attend the screening. However, no more than 20 women of the 429 interviewed agreed to be screened after the interview. Data on age at invitation, education, marital status, and birthplace of invited women were collected from the Council Registry. For a sample of 477 of 1032 responders (46.7%), data on the women's and their husbands' education and occupation, and commonly recognized risk factors for breast cancer<sup>16 17</sup> were collected by the screening centre personnel at the first examination. The occupations of the women and their husbands were considered indicators of social class. The  $\chi^2$  test statistic was used for the comparison of proportions.<sup>18</sup>

## Results

Analysis of participation in the screening shows that acceptance rates did not change substantially with age at invitation (table I) and decreased significantly with increased level of education (table II). Thus the percentage of women who had only been to Elementary School was 59.9% among attenders, and 49.0% among the non-attendees. Among the 477 attenders, the social class classification of women attending was similar to that of non-attendees, as shown in table III. Housewives represented 42.1% of attenders and 42.2% of non-attendees, and the proportion of women with a manual job was not different in the compared groups (15.3% v 14.5%). Married and widowed women attended the screening more than single and separated/divorced women, as

Table I Number and percentage of women invited, attenders and non-attendees according to age.

Age (years)	Invited No	Attendees		Non-attendees		Away from home, health problems, deceased		Not interested	
		No	(%)	Total No	(%)	No	(%)	No	(%)
50-54	750	436	(58.1)	314	(41.9)	87	(11.6)	227	(30.3)
55-59	875	497	(56.8)	378	(43.2)	82	(9.4)	296	(33.8)
60	201	99	(49.3)	102	(50.7)	13	(6.5)	89	(44.3)
Total	1826	1032	(56.5)	794	(43.5)	182	(10.0)	612	(33.5)

Table II Number and percentage of women invited, attenders and non-attendees according to education.

Education (years)	Invited No	Attendees <sup>a</sup>		Non-attendees		Away from home, health problems, deceased		Not interested	
		No	(%)	Total No	(%)	No	(%)	No	(%)
Elementary School (3-5 years)	1007	618	(61.4)	389	(38.6)	80	(7.9)	309	(30.7)
Elementary School (6-8 years)	339	200	(59.0)	139	(41.0)	35	(10.3)	104	(30.7)
High School (12-15 years)	298	164	(55.0)	134	(45.0)	32	(10.7)	102	(34.2)
University	90	42	(46.7)	48	(53.3)	8	(8.9)	40	(44.4)
Unknown	92	8	(8.7)	84	(91.3)	27	(29.3)	57	(62.0)

<sup>a</sup>  $\chi^2$  for linear trend = 9.12; p = 0.003

Table III Number and percentage of a sample of attenders and non-attendees according to social class.

Social class	Attendees No (%)	Interviewed non-attendees No (%)
Upper, middle, intermediate (I and II)	68 (14.3)	78 (18.2)
Non-manual skilled (III N)	111 (23.3)	74 (17.2)
Manual skilled (III M)	127 (26.6)	116 (27.0)
Partly skilled, unskilled (IV and V)	111 (23.3)	84 (19.6)
Nuns	31 (6.5)	23 (5.4)
Not classified	29 (6.1)	54 (12.6)
Total	477 (100.0)	429 (100.0)

Table IV Number and percentage of women invited, attenders and non-attenders according to marital status.

Marital status <sup>a</sup>	Non-attenders			Total No	Total (%)	Away from home, health problems, deceased		Not interested	
	Invited No	Attenders No	Attenders (%)			No	(%)	No	(%)
Married	1053	633	(60.1)	420	(39.9)	90	(8.5)	330	(31.3)
Widowed	227	135	(59.5)	92	(40.5)	12	(5.3)	80	(35.2)
Separated		56	30	26	(46.4)	3	(5.4)	23	(41.1)
Divorced	444	231	(52.0)	213	(48.0)	59	(13.3)	154	(34.7)
Single	46	3	(6.5)	43	(93.5)	18	(39.1)	25	(54.3)
Unknown									

<sup>a</sup> Married and widowed *v* separated, divorced, and single women:  $\chi^2 = 8.65$ ;  $p = 0.003$

Table V Number and percentage of women invited, attenders and non-attenders according to birthplace.

Birthplace	Non-attenders			Total No	Total (%)	Away from home, health problems, deceased		Not interested	
	Invited No	Attenders No	Attenders (%)			No	(%)	No	(%)
Province of Brescia	1310	781	(59.6)	529	(40.4)	119	(9.1)	410	(31.3)
Lombardy (excluding Brescia)	164	90	(54.9)	74	(45.1)	14	(8.5)	60	(36.6)
North Italy (excluding Lombardy)	137	73	(53.3)	64	(46.7)	11	(8.0)	53	(38.7)
Central Italy	44	16	(36.4)	28	(63.6)	7	(15.9)	21	(47.7)
South Italy	76	34	(44.7)	42	(55.3)	9	(11.8)	33	(43.4)
Foreign countries	44	17	(38.6)	27	(61.4)	11	(25.0)	16	(36.4)
Unknown	51	21	(41.2)	30	(58.8)	11	(21.6)	19	(37.3)

<sup>a</sup>  $\chi^2$  for linear trend = 20.68;  $p < 0.001$

shown in table IV. Place of birth also seems related to acceptance of the invitation: the percentage of responders was significantly higher among women born in the province of Brescia than among those born in other areas of Italy (table V). A significant linear trend was observed of increasing percentage of non-responders as distance of birthplace from the town increased.

Table VI sets out reasons for non-attendance. Some women gave more than one reason, so the total is more than 100%. Among them, 42.9% gave practical reasons, 33.8% were not interested in or distrusted screening, 22.4% were afraid, worried or anxious about the examination. About one quarter of the women did not respond to the invitation because they had recently undergone a physical or instrumental breast examination, and only 7% said they were insufficiently informed about screening.

Table VI Reasons for not attending the screening programme.

Category	No	%
Not interested/distrusting	145	33.8
Distrust of public health policy	30	7.0
Distrust of screening for breast cancer	13	3.0
Not interested, feeling no breast symptoms	92	21.4
Advised against attendance by GP	9	2.1
Lack of time	18	4.2
Lack of information	30	7.0
No invitation received	18	4.2
Not well informed about the programme	12	2.8
Fear, worry, anxiety	96	22.4
Not willing to talk about it	8	1.9
Anxiety about the examination	38	8.9
Fear of undergoing mammography	40	9.3
Fear that a breast cancer may be detected	42	9.8
Practical reasons	184	42.9
The centre is not easy to reach	5	1.2
Work commitments	51	11.9
Family commitments	49	11.4
Health problems	56	13.1
Away from home at the time of invitation	54	12.6
Recent breast examination	107	24.9
Physical breast examination	80	18.6
Mammography	59	13.8
Other instrumental breast examinations	4	0.9
Other reasons	15	3.5

The percentage of non-participants theoretically recruitable in the screening programme can be roughly estimated on the basis of municipality and interview data. Among the women interviewed, only the 56 with serious health problems and the 50 with a mammogram in the last two years were not considered recruitable at all. Therefore, excluding from the 794 non-attenders those who had died, were away from home, no longer resident, suffering from health problems, in care for breast diseases, or who had undergone mastectomy or had a recent mammography, at most 360 non-participants (19.7% of the 1826 invited) might have been convinced to attend the programme, besides those who had already attended, as shown in table VII. As previously stated, only 20 women changed their minds after the interview and attended the

Table VII Number of women invited to the screening, attenders and non-attenders.

	No	%
Invited to the screening	1826	100.0
Attenders	1032	56.5
Non-attenders	794	43.5
Deceased	5	0.3
No longer resident	139	7.6
Away from home at the time of interview	86	4.7
Suffering for health problems	64	3.5
In care for breast problems, recent mammography, undergone mastectomy	140	7.7
Not interested/distrusting; lack of information; fear, worry, anxiety; practical reasons excluding health problems; recent breast examination excluding mammography; other reasons; refused interview	360	19.7

screening, but the survey was not properly designed with the purpose of convincing women to participate in the programme, so no suggestion can be drawn on the usefulness of a direct meeting with each reluctant woman.

As regards the health related behaviour of non-attenders, about one quarter had previously received an instrumental breast examination, usually mammography. Very few women had more than one mammography (5.1%), and 12.1% had had at least one in the past two years, while a greater percentage had had a physical breast examination (43.4%). Among the sample of 477 acceptors, 19.1% had had a mammogram, and 9.4% at least one in the past two years.

As regards the use of other preventive health practices, 55.9% of the interviewed women had had at least one Papanicolaou (Pap) test in their life, and 32.6% at least one in the past three years. No information was available on how many attenders had undergone a Pap smear in the past.

The distribution of the most commonly recognized risk factors for breast cancer in the non-attenders is substantially similar to that seen in attenders, as shown in table VIII. As regards having one or more first degree relatives with breast cancer, more attenders than non-attenders had a positive family history, and this difference was statistically significant at  $p < 0.05$ . No other difference in proportions at risk between participants and non-participants achieved statistical significance, for any of the risk factors investigated. Combining the conventional risk factors for breast cancer, we found that the percentage of attenders with one or more risk factors was similar to that of non-attenders (table IX).

Table VIII Number and percentage of attenders and non-attenders according to risk factors for breast cancer.

Risk factors	Attenders		Non-attenders	
	No	%	No	%
Number of first degree relatives with breast cancer				
0	398	83.4	381	88.8
1	70	14.7	43	10.0
≥2	9	1.9	5	1.2
Age at first live birth (years)				
<20	23	4.8	30	7.0
20-24	99	20.8	93	21.7
25-29	141	29.6	113	26.3
30-34	50	10.5	45	10.5
>34	12	2.5	15	3.5
Nulliparous	149	31.2	133	31.0
Unknown	3	0.6		
Number of live births				
0	149	31.2	133	31.0
1	82	17.2	89	20.7
2	153	32.1	111	25.9
3	67	14.0	57	13.3
>3	26	5.5	39	9.1
Age at menarche (years)				
<13	143	30.0	135	31.5
13-14	233	48.8	210	49.0
>14	100	21.0	73	17.0
Unknown	1	0.2	11	2.6
Age at menopause (years)				
<45	76	15.9	60	14.0
45-49	116	24.3	108	25.2
50-54	178	37.3	189	44.1
>54	19	4.0	39	9.1
Not in menopause	84	17.6	28	6.5
Unknown	4	0.8	5	1.2

Number of first degree relatives: 0 v ≥1:  $\chi^2=4.97$ ; p=0.03

Age at first live birth: <30 v ≥30 years:  $\chi^2=0.84$ ; p=0.4

Number of live births: 0-2 v ≥3:  $\chi^2=0.96$ ; p=0.3

Age at menarche: <13 v ≥13 years:  $\chi^2=1.57$ ; p=0.2

Age at menopause: <50 v ≥50 years:  $\chi^2=1.24$ ; p=0.3

Table IX Number and percentage of attenders and non-attenders according to number of investigated risk factors for breast cancer.

Number of risk factors <sup>a</sup>	Attenders		Non-attenders	
	No	%	No	%
0	91	19.1	69	16.1
1	193	40.5	166	38.7
2	144	30.2	147	34.3
3	47	9.9	45	10.5
4	2	0.4	2	0.5
≥1	386	80.9	360	83.9

<sup>a</sup> Investigated risk factors for breast cancer: positive family history, age at first live birth ≥30 years or nulliparous, age at menarche ≤12 years, age at menopause ≥50 years

## Discussion

Since a low response rate to breast cancer screening may invalidate the effectiveness of the programme, various studies have been carried out to study reasons for low participation.<sup>19-23</sup> The first group of women invited in our programme, living in a central area of the town, showed a lower response rate (56.0%) than that observed among women invited in the rest of the year of activity, who lived in other areas of the town or in municipalities around it (66.8%).<sup>24</sup> Poor knowledge about the programme at the beginning and the time of the year chosen for invitation (summer months) may have contributed to the particularly low participation observed in this first invited group.

Age of the women at invitation, education, and social class are the main known sociodemographic determinants for accepting population screening for breast cancer. In our survey, when using the occupation of women and their husbands as indicators of social class, no difference was found between attenders and non-attenders as regards social class, in disagreement with the results of other surveys.<sup>19-21-23</sup> This lack of difference in the response rates according to social class may be due to the imprecise indicator used for determining social class, such as profession of husband and/or woman. When education rather than profession

was regarded as an indicator of social class, a difference was seen between more and less educated women: education was found to be inversely correlated with attendance, the lowest response being observed among the most educated women. This finding may be explained by the relatively common use of private health services in Italy: better educated women are probably more sensitive than less educated ones to recommendations for preventive medicine, but they distrust public services and prefer to have a mammogram in a private centre. In fact, among the 59 non-attenders interviewed who had undergone a previous mammography, this examination was associated with both education and social class: the percentage of women with a previous mammography increased with education (elementary school: 10.7%, high school: 16.4%, university: 27.0%;  $\chi^2$  for trend: 7.86, p=0.005); and social class (unskilled and partly skilled: 5.1%, manual skilled: 15.8%, non-manual skilled: 15.9%, upper-middle-intermediate: 29.3%;  $\chi^2$  for trend=16.93; p<0.001). Therefore, many women aware of the usefulness of screening for breast cancer may have had this examination before being called by the screening centre, as the start of the programme was not preceded by an advertising campaign.

Immigrants were less interested in the programme than women born in the province: the observed trend of decreasing compliance with increasing distance of birthplace from the town suggests cultural difficulties in using the facilities of the National Health Service, as was also seen in a screening programme for cervical cancer in northern Italy.<sup>25</sup> The total percentage of non-attenders who agreed to be interviewed does not seem to be particularly high (70.1%), but women eligible for interview had already declined two invitations for screening, so the interview approach must be considered as a new attempt to involve reluctant women in the survey. A considerable percentage of non-attenders did not receive the invitation, as they were no longer resident locally or were away from home. On the other hand, some participating women complained of not having received the letter, in spite of being included in the target population. A more accurate and rapid updating of population registries might reduce the number of mistakes, but a considerable number of people resident in Brescia are really away from the town for most of the time. In this survey, practical reasons for non-attendance were given by most people interviewed: overall, one or more "practical reasons" were given by 184 women, 72 of whom also gave other reasons, such as "not interested", "feeling no breast symptoms", "having had a recent physical breast examination", and others. In some cases, an effort could be made to satisfy these requests, such as extending the screening centre hours from 4 to 5 or 6 pm. However, it must be emphasized that reasons for non-attendance among non-interviewed women may be different from those given in the interviews, as some authors suggest.<sup>21</sup> Most of the practical reasons given for not attending the programme do not seem very important, and may conceal other unsaid reasons. The distance from the screening centre, for example, is not an important factor, as

the highest response rate during the first year of screening was seen in an area outside the town, including some small municipalities 10–15 km from the centre. It therefore seems that most women refusing the screening for breast cancer were not really aware of its effectiveness, and also that attitudinal factors might be of great importance, in agreement with the results of other surveys.<sup>20 21</sup>

The overall proportion of women recruitable in the screening programme appears to be no more than 76.2% of those invited, including attenders (56.5%) and all the non-attenders who gave no good reason for refuse of participation (19.7%). This percentage is not too far from that observed in other European programmes for this age group,<sup>3 4 6 9</sup> but the estimate of a theoretically recruitable proportion must be interpreted cautiously, because some women will never accept the invitation, despite advertising campaigns and other sources of information.

In the health district involved in our survey, recommended behaviour for early diagnosis of breast cancer does not seem to be widely diffused, in spite of the availability of free mammography in Italy, as 9.4% of attenders and 12.1% of non-attenders had received a mammogram in the past two years. Although the sample of women in the survey may be not representative of all women aged 50–60 years living in the health district, we may assume that only a small proportion of women in this age group has a mammogram every two years in Brescia. This is in agreement with the findings from a population study in Turin, where 14.5% of women interviewed aged 50–59 years had mammography in the preceding three years.<sup>15</sup>

Among the non-attenders, the proportion of women who had had a Pap test in the past three years (32.6%) was about three times that of women who had mammography in the past two years (12.1%), suggesting that non-attenders make use of some services for secondary prevention of cancer. The percentage of non-attenders who had had a Pap smear in the year preceding interview (19.3%) is not lower than that observed among women aged 50–59 years in a recent population survey in Italy (15.7%).<sup>26</sup> It suggests that non-attenders are as interested in some practices for secondary prevention of cancers as the general population.

The role of the general practitioner may also be important in convincing women. In our programme, general practitioners were invited to a meeting before invitations were sent to the women, but participation was very low (10–20%). Screening attendance would probably be greater if general practitioners invited women personally. However, some surveys indicate that primary care physicians are often reluctant to refer patients for screening mammography, and therefore more effort is needed to educate them as to the benefit of this procedure.<sup>27–29</sup>

The distribution of known risk factors for breast cancer appeared substantially similar in the two groups, with the exception of a positive family history of breast cancer, which is slightly more frequent among attenders than non-attenders (16.6% *v* 11.2%). These results do not support the hypothesis that women attending a breast cancer screening programme are at high risk of

developing the disease. However, the breast cancer detection rate in the 1032 women attending the screening in this area (1.2%) was higher than that seen among the other 4185 women screened during the first year of activity (0.7%).

Low participation in a screening programme has evident implications for both overall effectiveness and cost-benefit ratio. However, no attempt has ever been made to evaluate these variables according to response rates. Recent results of the Malmö mammographic screening and UK trial suggest that the potential benefit associated with screening can be reduced by a high rate of non-attendance.<sup>6 7</sup> An acceptance rate of 66.5% was found at the first round in Edinburgh and Guildford screening, which is similar to that in Brescia during the first year (67.0%), and is above the acceptable level recently suggested for breast cancer screening programmes by Day *et al.*<sup>30</sup> In spite of this relatively low acceptance rate, a reduction in breast cancer mortality has been seen among women aged 50 years or more from five years after the beginning in the UK trial, which was quantitatively comparable with the results of other trials.<sup>6</sup> Thus, it is reasonable to suppose that the benefit of screening is appreciable even with a relatively low response rate, although it may be observed longer after the beginning than in programmes with higher participation rates, because of the decreased size of the effect to detect. No less important, the cost of screening may become extremely high with low participation. In order to reduce screening personnel costs, the proportion of attenders among invited women was estimated in the Brescia programme from the beginning, so that a sufficiently large number of women were called to the centre every day to ensure that the personnel worked full time during every week day. We have not assessed the cost of screening per examination or per life saved so far, as we are waiting to complete the first round before drawing conclusions on these aspects. A compliance of 65–70% was seen in a screening programme organised in an area near Brescia during its first year of activity, and an overall cost of about US \$23 per woman per screening visit was assessed,<sup>11</sup> which is near to the estimate in the Swedish two county trial.<sup>31</sup>

Since this survey only concerned non-attenders living in one of the nine health areas of the town, no firm conclusion can be drawn. However, it suggests that greater effort in the information campaign might increase the participation rate, although at present the response rates observed in some northern European countries do not seem achievable in our country.

We thank Lega italiana per la lotta contro i tumori, Sezione di Brescia (Italian League Against Cancer, Department of Brescia) for the interviews; the personnel of the screening centre, the Health District of Brescia (USSL n. 41 of Lombardy), and the Municipality of Brescia for data on women who were invited and attended. We are grateful to Dr N Segnan and A Ponti for advice in organising the survey and for valuable comments on data analysis and interpretation. The results of the survey were also discussed with Dr D Palli and Dr E Paci of the "Centro per lo Studio e la Prevenzione Oncologica" (CSPO) of Florence, Italy, to whom we are grateful for their comments and suggestions.

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