



# The prevalence of medical reasons for non-participation in the Scottish breast and bowel cancer screening programmes

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## Abstract

**Objective:** Increasing uptake of cancer screening is a priority for health systems internationally, however, some patients may not attend because they are undergoing active treatment for the cancer of interest or have other medical reasons that mean participation would be inappropriate. This study aims to quantify the proportion of non-participants who have a medical reason for not attending cancer screening.

**Methods:** Medical reasons for not participating in breast and bowel screening were defined a priori on the basis of a literature review and expert opinion. The notes of 700 patients at two GP practices in Scotland were reviewed, to ascertain the prevalence of medical reasons amongst non-participants. Simple proportions and confidence intervals were calculated.

**Results:** 17.4% of breast and 2.3% of bowel screening non-participants had a medical reason to not participate. The two most common reasons were previous breast cancer follow up (8.86%) and recent mammogram (6.57%).

**Conclusion:** These patients may not benefit from screening while also being distressed by receiving an invitation. This issue also makes accurate monitoring and target-setting for improving uptake difficult. Further work is needed to estimate robustly the extent to which medical reasons account for screening non-participation in a larger population.

## Keywords

Scotland, Screening, Breast, Bowel, Attendance, non-participation

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## Introduction

Cancer screening programmes internationally often experience challenges in maximizing uptake.<sup>1–3</sup> In Scotland, breast screening (via three-yearly mammography) and colorectal cancer screening (involving biennial faecal occult blood testing) have uptake rates of 74.5% and 54.9% respectively. Improving screening uptake for these two programmes has been prioritized by the Scottish Government's Detect Cancer Early campaign.<sup>4,5</sup> The many reasons why people do not attend screening include fear of results and not liking the test.<sup>6,7</sup> Feedback from clinicians locally suggested that some invited participants have a specific medical reason for not being screened. This could mean that screening would be inappropriate (eg. if the patient is being treated palliatively for a terminal condition), or that greater surveillance is already being undertaken and so screening programme participation is not necessary. This study aims to quantify the percentage of patients in two Scottish GP practices with medical reasons for non-participation in breast and bowel screening programmes.

## Methods

Case notes were analyzed from 700 patients who had not participated in the previous round of breast or bowel screening. The sample size was chosen to allow reasonable

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precision of estimates. These patients were registered to one of two GP practices: practice one, located in an affluent area, with a “Scottish Index of Multiple Deprivation” score in the least deprived quintile with around 11,000 patients, and practice two, located in the middle quintile for deprivation, but where over half of the around 12,500 patients are in the two most deprived quintiles. The patients were randomly selected from non-participants in the 2012 bowel screening programme and from the most recent (2009–2012) breast screening programme.

There is no clear guidance on what is considered a medical reason not to be invited for screening in Scotland, so criteria were defined by local experts before data collection. For breast screening medical reasons were considered to be: bilateral mastectomy, recent mammogram (within the last 6 months), pregnancy, familial screening, terminal illness, lack of capacity to undergo screening, and cancer follow-up. For bowel screening, medical reasons were: no functioning bowel, recent colonoscopy, familial screening, terminal illness, lack of capacity to undergo screening (ie. a doctor deemed the invitation inappropriate), and cancer follow-up. Patients who had moved or died were excluded because the electronic notes available were not adequate to determine if there was a medical reason for non-participation. Confidence intervals based on proportions were calculated using Minitab (v 16).

## Results

Of the 700 non-respondents, 69 patients had a medical reason for not participating (Table 1). Of those with a medical reason, the largest two groups for both breast and bowel screening were current follow-up for breast cancer with 8.86% (95% CI: 6.10, 12.3) and recent investigation (mammogram) with 6.57% (95% CI: 4.21, 9.70). Other reasons accounted for a much smaller percentage (from 0.29% to 1.14%). The largest group in each screening programme was “no medical reason”, with 82.6%

(95% CI: 78.2, 86.4) breast screening non-participants and 97.7% (95% CI: 95.6, 99.0) of bowel screening non-participants. Rates did not differ significantly between practices (results not shown).

## Discussion

This study demonstrated that there are patients who have medical reasons that mean it may not be appropriate for them to be invited for either breast or bowel screening. There was a much greater number of patients who were potentially inappropriately invited for screening amongst breast cancer screening patients (17.4%) compared with bowel cancer screening patients (2.3%). These figures are less disparate when considering that 26.5% of those invited do not attend Breast screening compared with 45.1% for Bowel screening.<sup>4,5</sup> Patients with a medical reason for not participating represent 4.6% of the total number of people invited for breast screening and 1.04% for bowel screening.

This is the first study to quantify the number of patients with a medical reason for not participating in either breast or bowel cancer screening. A previous study in Birmingham, aiming to increase breast cancer screening uptake, identified 548 persistent non-attenders and invited them to attend for screening, of whom 482 gave a response.<sup>8</sup> It was found that eight women (1.66%) had recently had a mammogram and three (0.62%) were under care for other conditions. These figures are not directly comparable with the estimated 8.86% of non-participants in our study who were still in hospital follow-up and 6.57% had recently had a mammogram, most likely reflecting differences in study design. No similar studies were identified for bowel screening.

Our study was in a small population and would need to be replicated using a larger sample of representative practices across Scotland to gain more meaningful results. However, it establishes the principle that non-participation

**Table 1.** Medical reasons for non-participation in the Scottish 2009–2012 breast screening and 2012 bowel screening in a random sample of non-participants in two GP practices in the Edinburgh and the surrounding area. Total N = 700.

	Breast		Bowel	
	N	%	N	%
No medical reason	289	82.6 (95% CI: 78.2, 86.4)	342	97.7 (95% CI: 95.6, 99.0)
Hospital follow up	31	8.86 (95% CI: 6.10, 12.3)	4	1.14 (95% CI: 0.31, 2.90)
Recent investigation <sup>A</sup>	23	6.57 (95% CI: 4.21, 9.70)	2	0.57 (95% CI: 0.07, 2.05)
Familial screening	4	1.14 (95% CI: 0.31, 2.90)	0	0
Previous surgery <sup>B</sup>	2	0.57 (95% CI: 0.07, 2.05)	1	0.29 (95% CI: 0.01, 1.58)
Lack of capacity to undergo screening <sup>C</sup>	1	0.29 (95% CI: 0.01, 1.58)	1	0.29 (95% CI: 0.01, 1.58)
Terminal illness	0	0	0	0
Total	350		350	

A = either colonoscopy or mammogram within 6 months.

B = either bilateral mastectomy or total colectomy.

C = Patients without capacity to decide to participate in screening, whose healthcare team concluded not being screened is in their best interest.

for medical reasons could be important and require further investigation.

Despite this study's limitations, the results are of high policy relevance.<sup>9</sup> Identifying patients who should not be invited for breast and bowel screening would allow more accurate monitoring of the effect of interventions to increase attendance. It is also important to consider the psychological impact invitation for screening could have on patients with medical reasons for non-participation, and to reduce the risk of this occurring as much as possible.<sup>10</sup> Clear guidelines on medical reasons that mean a patient should not be invited for screening are necessary.

Currently only patients fitting very strict exclusion criteria (ie. have had a bilateral mastectomy or are terminally ill) are not invited for breast screening in Scotland. If the details of patients being followed-up for breast cancer, or patients who have recently had a mammogram could be sent to the breast-screening centres, 78% of patients deemed to have been inappropriately invited for breast screening in this study would not have been invited.

## Conclusion

This study demonstrates that patients with medical reasons for not being screened are present in both the breast and bowel screening programmes in two GP practices in Edinburgh and the surrounding area. Potential to prevent inappropriate offers for screening exists, but further work is needed to calculate the extent to which medical reasons account for screening non-participation in a larger representative population.

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