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Short Communication

Barriers to conducting research on breast screening: experience from a telephone survey with non-attenders in a UK inner city borough

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Breast cancer is the most common form of cancer among women worldwide, and is also a major public health issue. England has one of the highest rates of breast cancer in the world, with one woman in nine developing breast cancer during her lifetime.

In the absence of efficient methods of primary prevention, secondary prevention by mammography screening plays an important role in the detection of breast cancer at an early stage, when there is a good chance of a successful recovery.[1] To this end, there is a large body of evidence on the effectiveness of mammography screening in the reduction of mortality rates for women aged 50–69 years that attend screening.[1–3] However, screening can also lead to overdiagnosis and overtreatment, and is suggested to have a limited impact on prolongment of life.[4]

The provision of preventative health services in socially deprived urban areas, such as inner London, has long been recognized to be difficult.[5] In one such borough, Camden, there is a predominantly young, highly mobile, multi-ethnic population. The breast-screening coverage of women aged 50–64 years registered with a general practice in Camden in 2002–2003 was 51.7%. This figure was well below the national breast-screening target (70%) and National Health Service breast-screening programme figures (March 2003) for London and England (64.3% and 75.3%, respectively).[6]

To explore why the screening rates were so low in Camden, a telephone questionnaire survey was administered to determine the factors influencing the accuracy of breast-screening rates, and to

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identify barriers to breast-screening uptake among non-attenders in Camden. The inclusion criteria were: women aged 50–64 years[a]; living and registered with a general practice in Camden; and failure to attend screening following invitations sent between 2001 and 2003. Given the resources available, it was decided to include 384 women in the survey, anticipating a non-response rate of 20%. Those approached were selected at random from the list of non-attenders held by the screening office.

The telephone questionnaire was designed to explore the most common reasons/barriers influencing breast-screening uptake among non-attenders in Camden, and included both closed- and open-ended questions. The telephone interviews were conducted over an 8-week period between June and August 2004. The interviewer attempted to contact each potential respondent on up to five occasions. The Camden Primary Care Trust (PCT) Research Ethics Committee granted ethical approval, and the project was registered with the North London Community Research Consortium.

Due to the small sample of non-attenders interviewed, the findings of this survey are not generalizable. Thus, the primary focus of this paper is to present and discuss the methods and weaknesses of conducting research on breast-screening attendance in an inner city borough. A copy of the full research report is available from the Camden PCT website.[7]

The initial sample of 384 women was taken from 45 general practices, staffed by 97 general practitioners (GPs). Of the 97 GPs approached regarding involvement in the study, 79 GPs (81.5%) agreed to participate. The size of the initial sample was reduced to 366 women due to inaccurate information on the screening database. As a consequence, 18 women were excluded from the initial list (4.7%).

Throughout this paper, the initial study sample has been considered to be 366. These 366 women received notification of the research study by letter. A prepaid envelope addressed to the research team was provided to enable those who wished to be excluded from the survey to signify their intention.

The recruitment process was divided into three stages and a number of factors were found to reduce participation in the study at each stage. In Stage 1, the GPs identified 134 women (36.6%) who were ineligible for the study and were excluded. Women who had left the practice accounted for 13.1% of the exclusions at this stage. Other reasons included: GP did not respond (5.2%); woman was reported to have breast cancer (4.4%); and GP indicated that the patient's English was inadequate for participation in the study (3%).

In Stage 2, invitations to participate in the study were sent to the remaining 232 (63.4%) eligible women. Of these, 50 (13.7% of the original sample) were not contacted, mainly due to a number of GP-related reasons such as no recorded telephone number for the patient. Only 3% of women refused to participate at this stage.

In Stage 3, 122 (33.3%) women were telephoned. It was not possible to contact 37 (10.1%) women as they were not at home or were unavailable at the time of calling; 21 (5.7%) women were not known at the telephone number provided; 15 (4.1%) women refused to participate; and in 14 cases (3.8%), a family member reported that the women did not speak adequate English to participate. In addition, 28 (7.7%) women telephoned at this stage reported that they had undergone a mammogram in the last three years and the interviews were terminated.

The remaining 48 women were interviewed over an eight-week period, representing 13.1% of the initial sample (or 39% of the women who were attempted to be contacted by telephone at the end of Stage 3). The stages of the survey and reasons affecting the response rate are illustrated in Fig. 1.

This survey was the first to address issues related to uptake rates of breast screening among non-attenders in Camden. The study methods had a number of limitations; in particular, the initial sample size and high non-participation rate meant that the number of women interviewed was small. As such, it was not possible to generalize from the findings of this study. It was also not possible to interview women whose English was poor. Other study methods, such as focus groups with a same-language interviewer, may be more appropriate in such groups.

Undertaking this type of research locally is vital for the improvement of screening rates, but this project identified a number of barriers. These barriers are highly salient to others in the field and, as described, many relate to information and administration issues. Some discrepancies existed with the updating and accuracy of screening provider (CELBSS) records, which meant that the sample included women with breast cancer and women who had undergone mammographies. These issues were closely related to the problems that already existed with the information held by GP practices. For example, the GP had no telephone number or an incorrect number for 44 (12%)

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[a] Since this survey was undertaken, the Department of Health has extended the screening age from 64 to 70 years.