

An Intervention Service in a UK Asian Community to Promote Participation in the NHS Bowel Cancer Screening Programme: Results from the Pilot Study

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Abstract

Introduction: Bowel cancer screening uptake is low in inner North-East London, an area characterised by high levels of ethnic diversity and deprivation, and low awareness of the screening programme.

Study Design: Here we report on a pilot project providing an intervention in primary care services in the form of telephone contact and health education sessions to explore the impact on faecal occult blood test kit uptake, assess logistical feasibility and estimate formal sample size for a future study.

Material and Method: In 12 general practices in City and Hackney, Tower Hamlets and Newham, 532 subjects due for their first bowel cancer screening invitation were invited by letter followed-up by a telephone call, to a health education session at their general practice. 3,519 subjects from the remaining 128 practices in these former primary care trusts were not offered this intervention.

Results: Median uptake was 33.8% in the intervention practices and 31.3% in the comparison practices. Within the intervention practices, the odds of uptake were significantly larger for individuals who actually attended the health education sessions (N = 107) compared to those for whom neither face-to-face, nor telephone contact was achieved (OR = 3.4, 95% CI 1.99-5.87, $p < 0.001$). Increase in uptake among individuals who received information by telephone only was not significant (N = 55, OR = 1.7, 95% CI 0.89-3.28, $p = 0.1$).

Conclusions: Results suggest that it is feasible to change behaviour in relation to bowel cancer screening participation using health education provided by direct contact. A formal intervention trial has since been implemented.

Keywords Bowel cancer; screening uptake; guaiac faecal occult blood test (gFOBT).

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Introduction

Colorectal cancer is the fourth most common cancer in the UK and the second most common cause of cancer death after lung cancer; in 2010, 40,695 new cases of and 15,708 deaths were recorded [1]. The combined results of randomised controlled trials (RCTs) show that regular screening

with guaiac faecal occult blood test (gFOBT) can reduce mortality from bowel cancer by 16% [2]. Ensuring compliance of the population is key to the effectiveness of a screening programme [3]. In the RCTs, compliance at first screen for gFOBT ranged from 57 to 67% [4]; in the UK pilot study, uptake ranged from 54% in the Scottish regions to 56% in the English regions in men aged 60-64, while it ranged from 62% to 66%, respectively in women of the same age [5, 6]. As a result of these findings, the NHS Bowel Cancer Screening Programme (NHS BCSP) was deemed feasible and rolled out in England in 2006 achieving national coverage in 2010. Initially, all men and women between the ages of 60 and 69 years, resident in England and registered with a general practitioner (GP) were offered screening; in 2010, the programme was extended to include individuals up to the age of 74 years, and older people may also self-refer into the programme through requesting a gFOBT kit by telephone [7]. Individuals eligible for screening receive an invitation letter sent by their regional screening hub explaining the programme together with an information leaflet. Unless they indicate otherwise, they are then sent a gFOBT kit about a week later, along with step-by-step instructions for completing the test at home and returning the samples by post to the hub laboratory. The test is then processed and the results sent back to them within two weeks. Those who test positive are then offered further investigations [8]. In the prevalent round of the NHS BCSP, participation rates were shown to be 49.6% in men and 54.4% in women, which is below the rates achieved during the pilot studies and below the national target of 60%. Overall uptake was lowest in the London hub (40%) and in the most deprived areas of London (33% and 39% in the 4th and 5th index of multiple deprivation (IMD) quintiles, respectively) [8]. Deprivation status was also found to negatively influence uptake of gFOBT screening in the UK pilot, as was being from a Indian subcontinent ethnic background [9]. The former Primary Care Trusts (PCTs) of City of London & Hackney, Newham and Tower Hamlets which make up inner North East London (NEL) are among the ex-PCT areas with the highest levels of social deprivation and Asian populations in the country [10].

Barriers to screening participation specific to attitudes about the gFOBT kit have been identified. A survey conducted in the UK has shown lower levels of awareness and understanding of risk factors for bowel cancer in less educated populations, and these factors have been associated with lower intention to participate in bowel cancer screening [11, 12]. In addition, a lack of understanding and awareness of screening concepts and tests has been found to be associated with lower participation in cancer screening programmes [13-15]. Minority groups showed particular lack knowledge of cancer and screening [16] and research in inner NEL using the validated Cancer Awareness Measure (CAM) demonstrated low awareness of the bowel cancer screening programme. Awareness was lowest amongst people of South Asian origin: less than 20% of people of Bangladeshi, Indian and Pakistani origin knew that there existed a screening programme compared to 36% of people of White and Black origin [17].

Addressing health inequalities has been a key part of recent UK health policy to ensure uptake of screening programmes is equitable and reaches those most in need [18]. Here, we aimed to explore an approach targeted at reducing inequalities in gFOBT kit uptake between inner NEL and the rest of London.

Recommendation by a trusted health professional such as a GP has been found to be significantly associated with increased gFOBT kit uptake within an established screening programme in Italy [19] and in the south of England [20]. In addition, RCTs performed in the US have shown that providing invitees with detailed instructions on collection, storage and return of test kits additional to standard can significantly increase compliance in predominantly white [21] but also in ethnically-diverse populations [22]. Recently, an intervention in Tower Hamlets involving the use of telephone outreach by bi-lingual advocates calling on behalf of GPs to endorse screening contributed to significant increases in the uptake of breast screening and led to the introduction of a new service specification [23].

Table 1: Target population 59.5 – 60 years old (Second to fourth quarters 2011)

| Former PCT area | Comparison GP practices | | | Intervention GP practices | | |
|-----------------|-------------------------|-------------|-------------|---------------------------|-------------|------------|
| | Males (%) | Females (%) | Total | Males (%) | Females (%) | Total |
| City & Hackney | 688 (55.8) | 544 (44.2) | 1232 | 81 (61.8) | 50 (38.2) | 131 |
| Newham | 750 (50.4) | 738 (49.6) | 1488 | 103 (56.9) | 78 (43.1) | 181 |
| Tower Hamlets | 403 (50.4) | 396 (49.6) | 799 | 97 (44.1) | 123 (55.9) | 220 |
| Total | 1841 (52.3) | 1678 (47.7) | 3519 | 281 (52.8) | 251 (47.2) | 532 |

Here we report on a GP-based intervention providing information and support for persons offered bowel cancer screening for the first time in inner NEL with the aim of increasing gFOBt kit uptake. The quality improvement project was designed as a pilot study to a potentially larger intervention to explore the impact on uptake, assess logistical feasibility, and estimate formal sample size required to demonstrate efficacy in a future study. We present the results of the pilot study and discuss how these inform the design of a definitive evaluation.

Material and methods

Recruitment and participants

GP practices

Four large GP practices from each of the three inner NEL former PCTs were offered the opportunity to participate in the pilot evaluation following practice visits. The GP practices were provided with detailed information about the project and were asked to sign an agreement consenting to their participation in the pilot. No financial remuneration was offered to the practices involved.

Remaining practices in inner NEL (n = 128) were not informed of the intervention and acted as comparison practices.

Participant recruitment

All subjects aged 59 years and 6 months to 60 years (approaching their first screening invite) in the 12 intervention practices were targeted. Subjects were identified from practice registers. Those for whom it was inappropriate to offer health education in relation to bowel cancer screening,

such as those under treatment for bowel cancer or those receiving supportive and palliative care for any reason, were identified by the GPs and excluded from the intervention. None of the subjects in the comparison practices were targeted by the intervention; they received NHS BSCP standard letter and information leaflet only [7].

Intervention

Priming letter & health education sessions

A GP endorsement letter was drafted by the bowel cancer screening team at the inner NEL PCTs. The letter emphasised the key risk factors for bowel cancer, explained the evidence behind the screening programme, the importance of early detection, and included a brief explanation of the gFOBt kit. Furthermore, building on the finding that recommendation by a trusted health professional such as a GP increased gFOBt kit uptake [20], a sentence stating that the GP endorsed the screening programme was added. Letters were printed on each subject's GP's headed paper and included an invitation to a brief health education session at the practice premises (date, time and venue information included), and information on how to complete the test. Where possible, two alternative sessions were offered (ideally one on a weekend and one on a weekday after work hours). The time elapsed between receipt of GP-endorsed letter and receipt of gFOBt kit for an individual was not available to the analysis team.

Health education session

The aims of the health education session were to familiarise the invitees who were new to the screening programme with the kit, as well as to

Table 2: Uptake of gFOBT kit over all GP practices (Second to fourth quarters 2011)

| Former PCT area | Comparison GP practices | | Intervention GP practices | |
|-----------------|------------------------------------|--|--|--|
| | Number screened/ Number invited | Median % uptake per GP practice (IQR) | Number screened / Number invited | Median % uptake per GP practice (IQR) |
| City & Hackney | 401 / 1232 | 29.9 (23.7-37.5) | 46 / 131 | 35.0 (31.25-37.3) |
| Newham | 505 / 1488 | 31.9 (23.5-41.25) | 69 / 181 | 33.2 (32.1-37.0) |
| Tower Hamlets | 257 / 799 | 31.8 (22.25-41.4) | 80 / 220 | 34.8 (32.2-38.8) |
| Total | 1163 / 3519 | 31.3 (23.5-39.1) | 195 / 532 | 33.8 (32.1-37.3) |

IQR: Interquartile Range

answer any questions or concerns. Disposable gloves, a locally produced pictorial guide providing step-by-step instructions about how to complete the kit, and leaflets in various languages were also offered to those attending the session. Health education sessions focused on the benefits of participating in screening, addressed barriers to non-participation in addition to discussing the signs and symptoms of bowel cancer and its risk factors.

Telephone reminders and health education by telephone

Approximately three days prior to each health education session, up to three attempts were made to telephone targeted subjects to find out if they were able to attend the session. Twenty-nine percent of the subjects were able to attend the session, thirty-four percent were not contactable by phone while a telephone message was left for 12% of subjects; the remaining 24% were unable to attend the first session. Among those, 55 subjects (15% of the total targeted) were willing to receive health education over the telephone. They were briefly informed about the screening programme and given a summary about the purpose of the gFOBT kit, including when they could expect to receive it. The subjects who were not contactable by telephone (and did not attend the first session) were re-invited in writing and given another opportunity to attend a second session unless they had asked not to be contacted again. Bengali-speaking telephone callers were available in Tower Hamlets for targeting the Bangladeshi community.

Statistical analysis

Aggregate data comparison of Intervention versus non-intervention practices.

Kit completion data were available at practice level for 12 intervention and 128 comparison practices for the second (Q2), third (Q3) and fourth (Q4) quarters of 2011 (final data collection was performed 6 months after the end of the intervention). The uptake rate for each practice was calculated as the ratio of screened to invited patients (both males and females), and the median uptake for each borough was derived as a summary measure to avoid making any strong distributional assumption for the rates.

In order to evaluate the effect of the intervention on gFOBT kit uptake, the difference in median uptake rates between intervention and comparison practices was assessed using non-parametric Mann-Whitney-Wilcoxon testing with general practice as the unit of analysis. A grouped logistic regression model [24] was also fitted to the aggregate practice data for the Q2 to Q4 period. The effect of the health intervention type (none, face-to-face health education or health education over the telephone) was investigated. The analysis of aggregate data was based on intention to treat, and did not take account of successful contact rates and uptake of the intervention.

Individual data analysis of intervention uptake

Anonymised individual data linking telephone contact and attendance at the sessions to

Table 3: Uptake of gFOBT kit by intervention type.

For this analysis, individual data were available for 10 intervention practices (All former PCTs combined)

| Intervention Type | Number who actually received an invitation during Q2-Q4 (%) | gFOBT uptake = Yes (%) | gFOBT uptake = No (%) | OR | 95% CI | P-value |
|--|---|------------------------|-----------------------|-----|-----------|---------|
| No contact made | 125 (34.3) | 39 (31.2) | 86 (68.8) | 1.0 | – | – |
| Telephone message, no health education | 44 (12.1) | 11 (25.0) | 33 (75.0) | 0.7 | 0.34-1.60 | 0.4 |
| Telephone call, no health education | 33 (9.1) | 11 (33.3) | 22 (66.7) | 1.1 | 0.49-2.50 | 0.8 |
| Health education by telephone | 55 (15.1) | 24 (43.6) | 31 (56.4) | 1.7 | 0.89-3.28 | 0.1 |
| Health education at session | 107 (29.4) | 65 (60.7) | 42 (39.3) | 3.4 | 1.99-5.87 | <0.001 |
| Total | 364 | 150 (41.2) | 214 (58.8) | | - | - |

OR: Odds Ratio; CI: Confidence Interval

completion of gFOBT kit were also available for 10 out of the 12 intervention GP practices. Subjects whose invitation was not delivered in 2011 were excluded from the individual data analysis. A logistic regression model was fitted to the individual subject data to assess the effect of the different types of intervention on gFOBT kit uptake. The model was adjusted for sex.

All statistical analyses were performed in R version 2.13.0 (The R Foundation for Statistical Computing, <http://www.r-project.org/foundation>).

Result

The intervention took place between February and December 2011 in inner NEL. Since April 2011, gFOBT kit uptake is defined as the proportion of invited subjects who return a test kit within 26 weeks and are 'adequately screened' (definitive positive or negative test result) (Stephen P Halloran, personal communication).

For analysis purposes, gFOBT kit uptake data for the period between the 1st of April and the 31st December 2011 was used (Q2-Q4). Subjects aged between 59 years and 6 months and 60 years old who were invited to the bowel cancer screening programme for the first time were included in the pilot study. Table 1 shows the overall participation among the invited population group. In total, 532 inner NEL subjects were sent a GP-endorsed letter

inviting them to participate in a face-to-face health education session prior to their completion of the gFOBT kit. Fifty-three percent of the targeted subjects were male. 3,519 subjects of the same age (52% male), who did not receive any intervention, were identified in the comparison practices.

Kit uptake by former PCT area is presented in Table 2. The overall median uptake from April to December 2011 (Q2-Q4) was only slightly higher in the practices which were offered health education (33.8, interquartile range (IQR) 32.1-37.3) compared to the non-intervention practices (31.3, IQR 23.5-39.1, Mann-Whitney-Wilcoxon p-value = 0.2). Although median uptake was consistently higher in the intervention practices in each of the former PCT areas, the increase in odds of uptake between the intervention practices and the comparison practices was not statistically significant (OR = 1.17, 95% CI 0.97 - 1.42, p = 0.10). Interestingly, variability was consistently larger among comparison practices in each PCT as evidenced by the respective IQRs (Table 2).

We were also able to analyse individual-level outcome data for 10 out of the 12 intervention practices. Uptake rates by intervention received are summarised in Table 3 for the 364 subjects who received both the intervention and a standard NHS BCSP invitation between April and December 2011. Receiving a telephone message or call but no health education by telephone was not

significantly associated with a change in uptake rate (N = 44, OR = 0.7, 95% CI 0.34–1.60, p = 0.4 and N = 33, OR = 1.1, 95% CI 0.49–2.50, p = 0.8, respectively) compared to no contact beyond the standard NHS BCSP communication. In contrast, receiving health education over the telephone was associated with a 10% absolute increase in uptake (corresponding to a 70% increase in odds of uptake) although this increase was not statistically significant at the 5% level (N = 55, OR = 1.7, 95% CI 0.89-3.28, p = 0.1). Finally, there was a clear significant increase in the odds of uptake among those who actually received the health education face to face (N = 107, OR = 3.4, 95% CI 1.99-5.87, p<0.001, Table 3) compared to standard NHS BCSP procedure. This effect was observed in each individual former PCT area (data not shown).

Discussion

In the English pilot, no evidence of a substantial fall in compliance with the NHS BCSP was found over three rounds of invitations [5], suggesting that achieving individual compliance at first invitation is likely to translate into compliance at later invitations.

Despite the fact that the programme consists of key features that might be expected to reduce inequalities (the individual incurs no costs, no time off work is needed, the test is delivered to and completed by the individual at home and is returned in a freepost envelope provided, [25]), a close association between deprivation and low uptake of bowel cancer screening has become apparent since the inception of the programme in the UK [9, 26, 27]. Von Wagner *et al.*, (2009) [25] demonstrated that low uptake of gFOBT in London was significantly related to deprivation, but also to ethnic diversity amongst other factors.

Maximising uptake of screening services can pose a challenge in areas in England where there are relatively large populations of ethnic minority groups, independently of their deprivation levels [28]. Of the many factors that have emerged for poor engagement with screening amongst ethnic minority groups, language and socio-cultural

values have been identified as potential barriers to colorectal screening, and there is evidence that these can be addressed by culture-sensitive interventions [23, 29-30].

Our intervention aimed to target lack of awareness of bowel cancer screening in men and women invited for bowel cancer screening for the first time aged 59-60 in an area characterised by considerable ethnic diversity and large sub-populations of low socioeconomic status. This was done by offering health education over the telephone or during a face-to-face session held at the invitee's own general practice, discussing the rationale behind the bowel cancer screening programme and the practicalities of the screening test. The initial offer was via a GP-endorsed and culturally sensitive invitation letter, followed by telephone contact using advocates competent in people's first language where possible. This project was designed as a pilot study to assess logistical feasibility, and estimate formal sample size required to demonstrate efficacy in a future study.

A per-protocol analysis at the individual subject level suggested that attending the health education session had a large effect on the likelihood of the invitee returning their kit, while receiving health education over the telephone had a lesser, although potentially worthwhile, effect on uptake. There are limitations to the interpretation of those results. The significant improvement in uptake in those who received face-to-face health education (N = 107) may be due to a strong effect of the intervention, but could also be the result of prior greater health awareness and/or self-motivation among those who were contactable and agreed to receive health education (healthy volunteer bias). The relative lack of significance for the effect of over-the-telephone health education could alternatively be the result of the relatively smaller number of subjects in this group (N = 55).

The failure to observe a significant effect in the intention-to-treat analysis using overall uptake data may be due either to ineffectiveness of the intervention or insensitivity of the evaluation design due to lack of statistical power or non-

delivery of the intervention to substantial numbers in the intervention practices.

A recent randomised controlled trial in Scotland found that a pre-notification letter increased participation rates, in all deprivation categories [31]. Another trial will evaluate the effectiveness of a GP-endorsed reminder in improving patient participation in the NHSBCSP in the West Midlands [32]. The efficacy of a patient decision aid (fridge magnet with telephone help-line and website) distributed by community-based family physicians is also being evaluated in a Canadian trial [33]. Automated telephone calls providing a description and health benefits of gFOBt were also found to significantly improved uptake rates in a US trial [34]. None of these intervention are focussed specifically on Asian or ethnically-diverse populations. In view of the possibility that the telephone promotion might not have had the statistical power to show a significant effect, and of the fact that it is more practicable and affordable at a population level than the organisation of face-to-face sessions, we proposed a formal evaluation of both approaches. A larger, randomised, intervention of health education over-the-telephone and at face-to-face sessions was rolled-out in inner NEL in 2012.

This is a pilot study, non-randomised and with potential differences in size and other factors between intervention and comparison practices. The results are sufficiently interesting, however, to suggest further study, with an experimental design.

Conclusions

The results of this pilot intervention suggest that it is possible to achieve a change of behaviour in terms of increase uptake of bowel cancer screening among a target population with high levels of deprivation as well as ethnic and cultural diversity. A tailored telephone reminder may be an effective alternative to face-to-face intervention and it is likely to be less costly. The cost-effectiveness of a reminder targeted towards deprived populations has recently been

empirically demonstrated [35]. A study with a larger intervention group, i.e. 2,000 and a comparison group of 2,000 individuals would have at least 90% power to detect a difference in uptake rates of the order of 30% versus 35% using a two-sided 5% significance test.

Based on those results, a larger randomised study targeting this deprived population has been implemented and will be reported in due course.

Learning points

This pilot study suggests that it is possible to achieve a change of behaviour with respect to gFOBt uptake in ethnically-diverse populations with high levels of deprivation. Culturally-sensitive telephone reminders should be considered alongside letter reminders and the implementation of face-to-face health education sessions. This intervention service should be implemented on a larger scale and in a randomised fashion to enable formal quantification of the effect.

List of abbreviations

| | |
|-------|----------------------------------|
| gFOBt | Guaiac Faecal Occult Blood test |
| GP | General Practitioner |
| IMD | Index of Multiple Deprivations |
| IQR | Interquartile range |
| NEL | North East London |
| BCSP | Bowel Cancer Screening Programme |
| PCT | Primary Care Trust |
| RCT | Randomised controlled trial |

Author's contribution

NJM performed the statistical analysis, interpreted the results and co-wrote the manuscript.

LAK was project manager, implemented the study in Newham, Hackney and parts of Tower Hamlets and co-wrote the manuscript.

JS designed the project and provided public health advice.

SA and **AG** provided public health advice.

SR assisted with accessing patient level data.

SWD provided general statistical guidance and co-wrote the manuscript

All authors reviewed and approved the final manuscript.

Conflict of Interests

The authors declare that there are no conflicts of interests.

Ethical Considerations

The study was approved by the Institutional Ethics Committee

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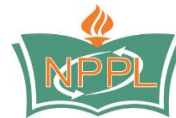
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