



Improving awareness of bowel cancer screening and uptake in the older African community in Hackney

**Evaluation Report
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Summary

Improving uptake of cancer screening is one of the four priorities in the Health Activities stream for Hackney CCG. Cancer awareness and uptake of cancer screening has been shown to be lower in Black Africans resulting in later presentation and poorer prognosis.

Community African Network (CAN) was commissioned through Hackney CVS to do a project to increase awareness of bowel cancer and uptake of bowel screening in the black African community. Working with groups within the Community African Network, three methods were used, using trained local volunteers: outreach sessions in public spaces such as markets, awareness raising sessions in community centres with targeted populations and follow up sessions with patients in a Hackney GP practice who had not taken up screening.

The project was evaluated using 3 criteria: the numbers of people reached in outreach, community sessions and GP follow-up sessions, the proportion of people reporting increased awareness and intention to screen, the percentage uptake of screening in the GP practice in the 6 months before and during the project.

A total of 2918 people were contacted during the project, of which 360 were in workshops, 2415 in outreach and 142 in GP surgery. Around two thirds of the outreach and workshop respondents were women, a little over half (55%) of GP surgery respondents were men. A large majority were in the age groups eligible, or soon to be eligible for screening and 90% were of African or Caribbean ethnicity.

At the community awareness raising workshops participants were asked to fill in a pre- and post-session questionnaire to ascertain whether awareness improved. Pre-session questionnaires (n=142) indicated that less than half of participants were aware of bowel cancer symptoms or screening, this increased to 87% post-session.

In outreach sessions volunteers were asked to ask people about their intentions to take up screening following the conversation; nearly 80% said that they would do the screen. Many of the people who declined to do screening said it was because they believed God would look after them.

In the GP surgery less than half (44%) of the follow-up calls were able to contact the patient, possibly because the calls were largely daytime. Nearly three quarters of people who did reply appeared to have a positive response; some (17%) had already done the screening but nearly half (44%) asked for a replacement kit. The difficulty of getting a replacement kit was highlighted. However, 19% said they were not interested or had opted out.

Screening uptake rates for the practice were 43% in the 6 months prior to the project and 52% in the 6 months following/during the project, and uptake rates improved more in the project practice than in C&H as a whole and in any of the neighbouring practices. Unfortunately, the screening hub does not collect data on ethnicity, nor, due to issues of data confidentiality, was it possible to directly identify patients, and thus it is not possible to directly attribute any changes specifically to the project. However, the improvement in rates is encouraging and in at least one case a patient said he had returned his kit following a conversation with a volunteer.

Conclusions and limitations

The project successfully targeted nearly 3,000 people in mainly community settings, using trained volunteers from the target community to raise awareness and discuss concerns about bowel cancer screening. However, a majority of the respondents were women, and this reveals a gap in engagement with men.

The workshops revealed that a lot of people in the black community had been unaware of bowel cancer symptoms and screening, however the workshops appeared to have been very successful in raising awareness and were received very positively. In the outreach settings many positive responses were received about people's intention to screen. Similarly, three quarters of patients contacted in the GP surgery said they intended to screen. This reflects well on the interactions in the project, but this may not necessarily translate into action for screening so detailed examination of screening uptake rates is necessary. Lack of ethnicity data in the screening data set may make this problematic. However positive improvements were shown.

A significant group of people put their faith in God and were not interested in screening

Recommendations

- Future outreach work should target men as they are less likely to be informed about health issues
- Further work with faith leaders is recommended to work with them to try and ensure that religious belief is not a barrier to screening.
- Lack of ethnicity data in the Screening Hub dataset prevents systematic examination of uptake by ethnicity. It is recommended that this be included in the dataset.
- The project highlighted that it was very difficult for people to get replacement kits and this will hinder screening uptake. It is recommended that this process be more streamlined to facilitate this
- Interactions by trained volunteers to support GP work has a lot of potential, particularly in integrated models of care and particularly for communities who may not respond to traditional forms of communication. The practical barriers to this need to be well thought through to ensure that potential is realised.

Introduction

Improving uptake of cancer screening is one of the four priorities in the Health Activities stream for Hackney CCG. Hackney has a very ethnically diverse population. Cancer awareness and uptake of cancer screening has been shown to vary across different ethnic populations (1,2,3). Black Africans have been identified as having low awareness of cancer symptoms and cancer screening in the UK (2,3,5) and in East London (1) and are thus more likely to present later and have poorer prognosis. Black African elders tend to be less susceptible to mainstream promotion methods because of poorer access to promotional materials and language barriers. Research suggests that face to face health promotion methods, video and culturally sensitive educational materials and community engagement (5) and GP endorsement (4,6) can be effective in improving cancer screening uptake in ethnic minority populations.

The uptake of bowel screening is generally low in Hackney but varies by GP practices in Hackney from 27% to 55% (2015/16). Many of those practices with low uptake are situated in areas of Hackney that have significant African populations.

The purpose of this project was to increase awareness of bowel cancer and bowel cancer screening with the aim of increasing uptake of bowel cancer screening in the black community in Hackney, specifically targeting black Africans.

Methods

A preliminary set of focus groups was held with four different communities to tease out some of the perceived issues and barriers to cancer screening in those communities. One of these groups targeted older African women, another targeted older African men. Emerging issues from these groups helped to frame the training and outreach conversations to increase awareness and raise screening uptake. Lack of information about bowel cancer, lack of understanding of the screening process and stigma about cancer emerged as key issues.

A group of local volunteers from the African community were recruited by the Community African Network (CAN) and trained in motivational interviewing techniques and in how to advise people about bowel cancer and the process of bowel screening.

Group sessions for raising awareness of bowel cancer and screening were held in local community venues, targeting black African and Caribbean residents. Participants were given brief questionnaires before and after the session about what they knew/had learnt.

The trained volunteers ran outreach sessions in Ridley Road market, which is a well-known local market catering for African, Afro-Caribbean and other ethnic groups, selling a range of foods and other items. The volunteers targeted older black people, engaging them in conversations about bowel cancer to enable sympathetic, culturally relevant dialogue and discussion about knowledge, barriers and support. Volunteers were encouraged to ask people about their intentions about doing screening and to record responses.

A partnership with a GP practice in East Hackney, which has a large African population, was set up to enable/facilitate the trained volunteers to do telephone follow up with identified African and Afro-Caribbean patients who had been invited to participate in screening but had not yet done so, to provide help and advice about screening.

Evaluation methods

The project was evaluated by three criteria:

1. **Reach** – the numbers of people who participated in awareness raising sessions
 - the numbers of people contacted in outreach situations
 - Number of follow-up phone calls in GP surgery
2. **Improved awareness** – the numbers of people who reported increased awareness of screening, including intention to take up screening following – group sessions - Individual contacts
3. **Uptake of screening** – percentage uptake of screening in the GP practice in 6 months prior to project and uptake in 6 months following project

Training

Three training sessions were held for volunteers. Training was done by specialists from Bowel Cancer UK training team or by a specialist facilitator from the Bowel Screening Hub. Also included in the training was a session on motivational

interviewing techniques. A total of 41 volunteers were recruited and trained, twelve were retained throughout the project. The purpose of the training was to give the volunteers sufficient knowledge about bowel cancer and cancer screening for them, in outreach conversations, to help and inform others and to know when to advise someone to go to their doctor. Nine of the volunteers attended more than one of the training sessions. Four fifths of the volunteers were women.

Evaluation

1. Reach

A total of 2918 people were contacted as part of the project, and a further 41 volunteers (Table 1)

Table 1. Number of contacts made in the project

Type of contact	No of sessions	Total contacts	Male n (%)	Females n (%)
Workshop –specific	10	258	54 (21%)*	171 (62%)*
Workshop – general	3	102	40 (39%)*	50 (49%)*
Outreach	30 (days)	2415	903 (37%)	1512 (63%)
Phone conversation – GP surgery	11	143	78 (55%)	65 (45%)
Total		2918		

* gender question was incompletely answered so these do not sum to 100%

Demographic characteristics of the people contacted in the different locations are described in the sections below. Overall around two thirds of contacts were women, one third men.

2. Improved awareness

2.1 Training volunteers

All volunteers were black Africans and the majority aged between 45-64 years. At the end of the training sessions the volunteers were asked to fill in an evaluation questionnaire, 34 were completed. Following training all respondents except two felt that they were confident to talk about bowel cancer and the screening method, all felt confident in how to demonstrate how to use a screening kit (Table 2.)

Table 2. Volunteer training evaluation

Evaluation question	Yes	No	Not sure
Are you confident to talk about bowel cancer?	32	1	1
Do you know how to refer a patient who needs a bowel screening kit?	33		1
Can you demonstrate how to use the screening kit?	34		
Do you know how to safeguard a vulnerable adult?	26		3

2.2 Community workshops/events

Community workshops on bowel cancer and bowel screening were run by the project co-ordinator (n=12) or by the head of CAN volunteer programme (n=1).

Specific sessions: Ten community events were organised for older African residents specifically to learn about bowel cancer and cancer screening. In general, these sessions were organised through the programmes of existing community organisations and relied on those networks to recruit participants. The numbers of participants per session ranged from 5 to 43, the total number was 258.

Participants were asked to fill in a brief questionnaire before and after the session. In two workshops it was not possible to complete evaluation forms for logistical reasons. A total of 142 questionnaires were completed. The profile of the participants who completed evaluation forms is detailed in Fig 1.

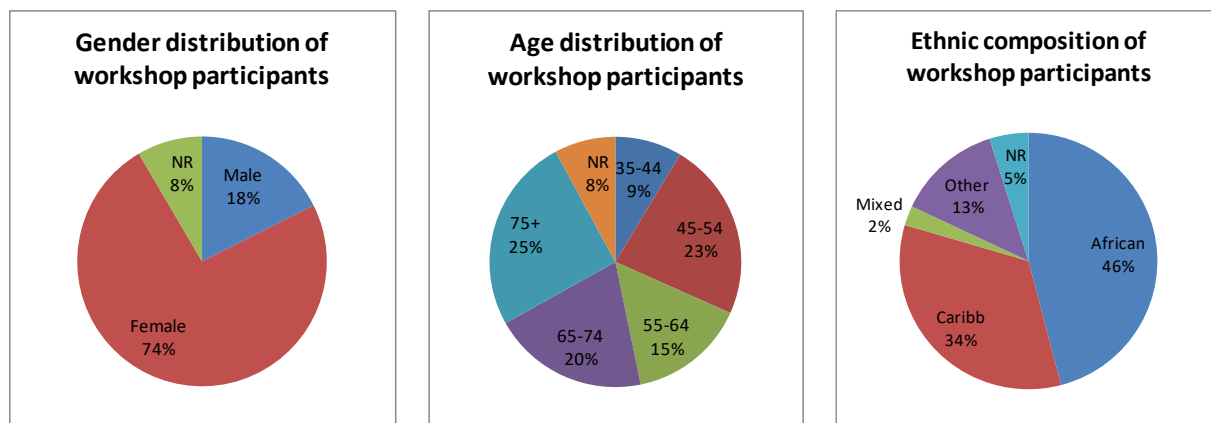
Three quarters of participants who completed forms were women. Not all participants fell within the age range for bowel screening, 35% were aged 55-74 years. Younger participants were encouraged to tell friends and family about it; older participants, although no longer eligible for screening, needed to know about symptoms of bowel cancer.

Eighty percent of participants were black African or Caribbean and most workshops were entirely black participants. One workshop had a predominantly white audience.

Participants were asked questions about what they knew before the session, then also were asked the questions after the session. They were also asked if they had previously attended a session on bowel cancer. A small proportion (16%) said

they had attended a session on bowel cancer previously, the majority had not.

Fig 1. Demographic characteristics of workshop participants completing evaluation forms



In answer to the pre-session questions a majority of participants (53-56%) said they were not aware of or were unsure about symptoms and risks of bowel cancer and how to get bowel screening.

Following the session, the perceived understanding/awareness of symptoms, risks and access to screening increased substantially from 44-47% to 80-89% of participants (Fig 2, Table 3.).

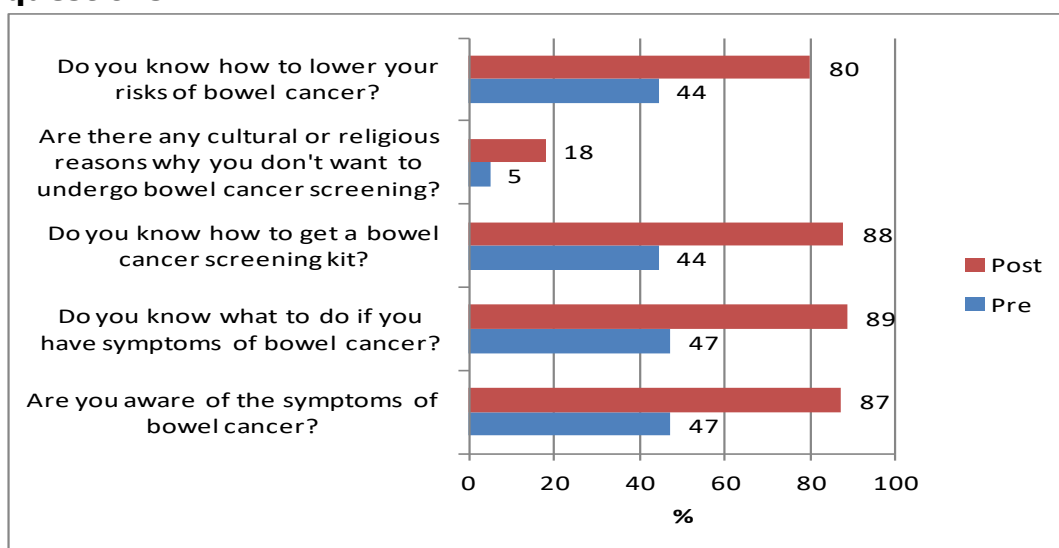
Table 3. Workshop participants' responses to pre- and post-session questionnaire on knowledge (n=142)

Question	Pre session*			Post session*		
	Yes	No	Not sure	Yes	No	Not sure
Are you aware of the symptoms of bowel cancer? n	47.1 66	42.9 60	9.3 13	87.1 122	5.7 8	2.9 4
Do you know what to do if you have symptoms of bowel cancer? n	47.1 66	41.4 58	10.7 15	88.6 124	4.3 6	2.9 4
Do you know how to get a bowel cancer screening kit? n	44.3 62	38.6 54	15.0 21	87.9 123	2.9 4	2.9 4
Are there any cultural or religious reasons why you don't want to undergo bowel cancer screening? n	5.0 7	87.9 123	6.4 9	17.9 25	72.9 102	2.9 4
Do you know how to lower your risks of bowel cancer? n	44.3 62	42.1 59	9.3 13	80.0 112	5.0 7	4.3 6

* 1-4% of pre-session responses and 5-12% of post session responses were missing

In addition, very positive comments were received about the benefits and quality of the sessions, all responses rated the subject matter and content excellent or good. However, it seemed there was an increase in the number of people expressing cultural/religious reasons for not screening, from 5% before the session to 18% post-session. It is unclear why this is the case; plausibly, if people did not know anything about bowel cancer screening, they may not have been aware of the issues it might raise for them, which emerged when they knew more.

Fig 2. Percent of participants responding 'Yes' to pre and post session questions



General sessions: A further three sessions were held as part of broader community information/engagement sessions. There was only one evaluation question in these sessions on the bowel cancer component. A total of 102 people attended these sessions, fifteen completed the evaluation question (Table 4), of whom 14 responded positively.

Table 4. Evaluation responses – Mixed sessions

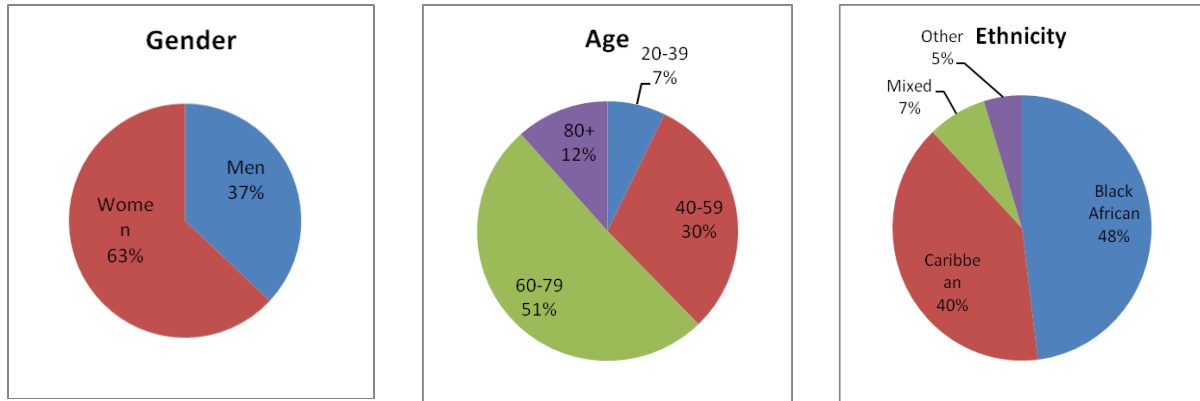
Evaluation question post session	Yes	No	Not sure	n
Do you know how to access bowel screening and support?	14		1	15

2.3 Outreach

Volunteers held outreach sessions in public venues, such as Ridley Road market, community centres/libraries and on street encounters, and offered information, advice and leaflets on bowel cancer and bowel cancer screening. The target

groups were older black men and women. Demographic characteristics of outreach encounters are in Fig 3.

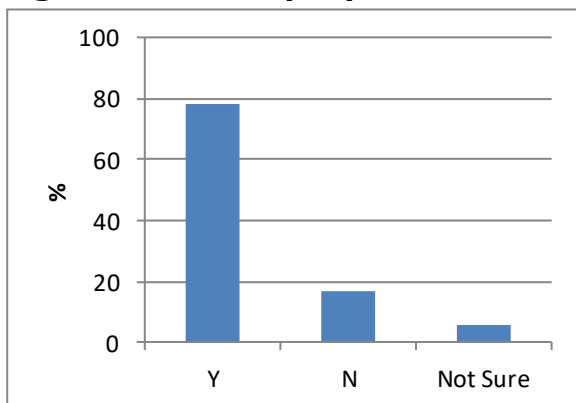
Fig 3. Demographic characteristics of people contacted in outreach situations



Nearly two thirds of outreach encounters were with women. This probably reflects the gender balance of people shopping in markets. Over half of respondents were in the 60-79 years age group which includes the group eligible for bowel screening age (60-74yrs). Flexi-sigmoidoscopy tests for people from 55 years are also being rolled out in Hackney so the younger age group, 40-59 years, would need to know about it and some may have already had an invitation. Eighty percent of people contacted were within age groups eligible, or soon to be eligible for screening. Recorded comments from some of the younger respondents were that they would take the information back to older family members. Nearly 90% were in the target group of black African or black Caribbean.

Volunteers were asked to ask people at the end of conversations whether they would take up screening in the future (Fig 4)

Fig 4. Percent of people who said they would do screening



Seventy eight percent of people said that they would take up screening, and a further 6% said they were not sure. Comments recorded on the monitoring sheets by the volunteers suggest that many of the people who said they would not take up screening did so for religious reasons; primarily a belief that God would look after them. This suggests that religion is not a barrier as such but could be seen as an alternative viewpoint. Future projects might fruitfully work with religious groups to try and address this issue.

Volunteers recorded some free text comments from respondents about why people didn't return the kits. These included religious beliefs, cultural issues around cancer, stigma associated with a cancer diagnosis, lack of therapeutic support and the fact that the screening leaflet was not very explanatory.

2.4 Screening calls

A GP practice was willing to be a partner in the project to encourage more black patients to take up bowel screening. Trained volunteers spent one day a week in the practice and were given a list of black patients identified by the practice staff who had been invited for screening, but their records showed that they had not yet taken it up. The intention was for the volunteers to telephone the patients to offer support and advice about screening and to encourage them to take it up. Due to data confidentiality issues it was not possible to identify on recording sheets whether a patient had been called more than once: the data presented therefore represent calls made rather than people.

Over 300 telephone calls were made in eleven sessions at the practice between October 2018 and March 2019 (Table 5). There were almost equal numbers of men and women on the list. A response was received from 142 (44%). Mostly, non-response was where the call remained unanswered; in some cases, the telephone numbers were incorrect, or invalid. More men (55%) than women (45%) answered the calls.

Of the people who answered the call nearly three quarters (74%) appeared to have a positive response and said they would screen. Nearly a fifth (n=24, 17%) said that they had already completed the kit and sent it back. Nearly half (44%) asked for a replacement kit. Nine percent of people said that they would send it back soon. However, it was highlighted that it was difficult to get a replacement kit.

Nearly a fifth (19%) of respondents said they were not interested in screening and

had already opted out. Indeed, some were annoyed to receive the call as they had already informed the practice of their decision to opt out.

Table 5. Responses to screening calls in GP practice

Call response	Outcome of call	Total
Calls made		326
Response received		142 (44%)
	Agreed to screen	105 (74%)
	Refused screening	27 (19%)
No response		184(56%)
	Response to call*	
	Asked for replacement kit	63 (44%)
	Already done screen	24(17%)
	Kit not yet received	10 (7%)
	Will do soon	13 (9%)

* Reasons/responses were not always recorded

3. Screening uptake

Records of screening uptake were obtained from the screening hub for the periods 2016/17 to 2018/9, by quarter, and compared to see if there was any change in screening uptake in the practice before and during the period of the intervention. Because of issues about use of practice data and data confidentiality it was not possible to look directly at the results of the people with whom the intervention had taken place, nor at results by ethnic group as these data are not collected by the screening hub. Uptake rates were also compared with wider uptake across Hackney (Table 6, Fig 5.), and with adjoining practices (Fig 6).

The main interventions in the practice took place in Q3 (8 sessions) with some (4 sessions) in Q4 of 2018/9. Comparison of uptake data for Qs3&4 in 2017/18 show an improvement in uptake rate from 31%(Q3) and 49%(Q4) in 2017/18 to 50%(Q3) and 54%(Q4) in 2018/19. For City and Hackney as a whole the corresponding uptake rates are 38% and 43% in 2017/8 and 44% and 47% in 2018/19 (Fig 5, Table 6).

Fig 5

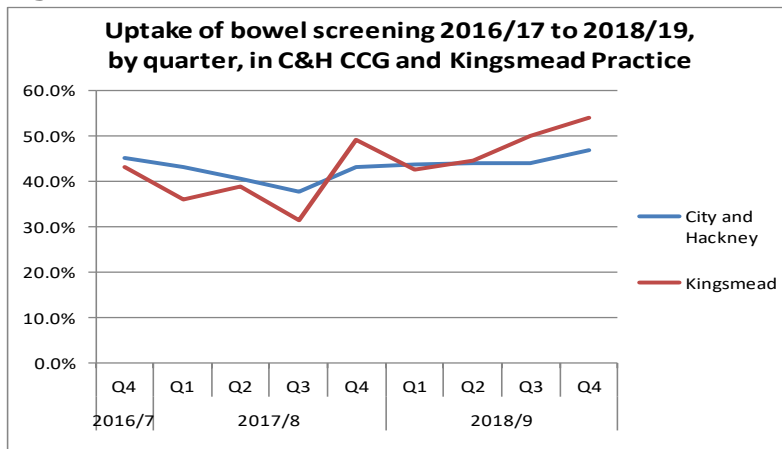
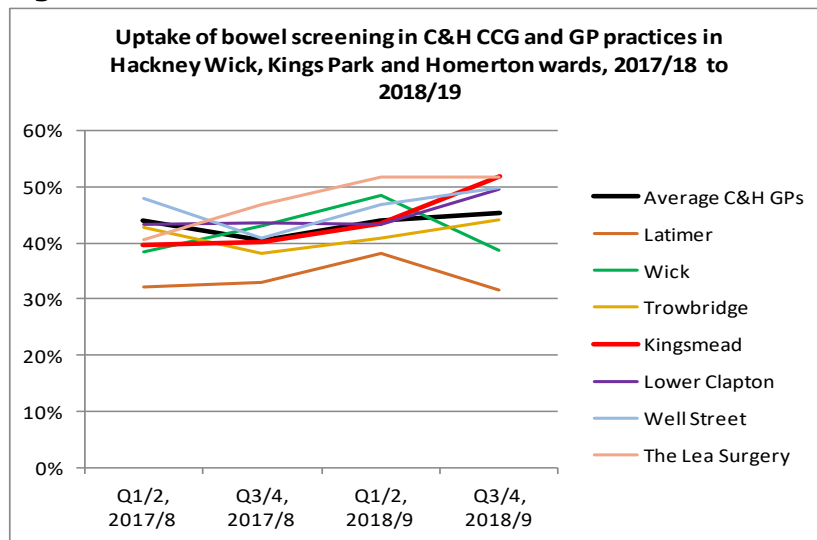


Table 6. Uptake of bowel screening 2016/17 to 2018/19, by quarter, City and Hackney CCG and Kingsmead Medical Practice

	Quarter	Invited		Adequately screened		Uptake %	
		C&H n	K'mead n	C&H n	K'mead n	C&H %	K'mead %
2016/17	Q4	3037	81	1367	35	45	43.2
2017/18	Q1	3024	72	1306	26	43.2	36.1
	Q2	3294	72	1338	28	40.6	38.9
	Q3	3262	70	1229	22	37.7	31.4
	Q4	3256	61	1408	30	43.2	49.2
2018/19	Q1	3164	75	1385	32	43.8	42.7
	Q2	3014	63	1328	28	44.1	44.4
	Q3	3308	86	1456	43	44	50
	Q4	3306	104	1546	56	46.8	53.9

Comparison of the trends in bowel screening uptake in practices in neighbouring wards shows that uptake in Kingsmead practice increased more than in any other practice in neighbouring wards in the intervention period (Fig 6).

Fig 6



It is not possible to directly attribute any changes in uptake to the interventions in any of the venues in the project. However, the improvements shown are encouraging. Anecdotally, in at least one case a patient in the GP practice said that he had returned his kit following a conversation with a volunteer in the market. More rigorous data collection and matching would be required to establish direct attribution and it is recommended that future projects build this into the study design from the outset.

Conclusions and limitations

The project successfully targeted over 3,000 people in mainly community settings, using trained volunteers from the target community to raise awareness and discuss concerns about bowel cancer screening. The majority of respondents in both outreach venues and in workshops were women. Whilst this reflects the fact that women are more likely to shop in markets and to attend community events, it also reveals a gap in engagement with men, who are less likely to be well informed about health issues and who often pay less attention to their health than women. In future work it would be desirable to target or arrange men-only events to encourage engagement.

The workshop pre-session questionnaires revealed that a majority of people were unaware of bowel cancer and of screening. This was also reflected in the initial focus groups. The post session evaluation questions suggested that the participants had found the session very informative and useful, both in the response to the knowledge questions and in the general evaluation questions for

the session. However, it is of concern that the perceived cultural barriers seem to have increased rather than decreased.

A key question on the outreach evaluation forms was asking whether people had been screened before. Although this is potentially useful it is hard to interpret as people may have undergone other cancer screening tests, eg. cervical or breast screening, or PSA tests, or they may interpret the term 'screening' in a broader context, eg. having tests for a variety of conditions is often loosely described as screening. So, this question cannot reliably be interpreted as indicating that the respondent has previously done a bowel screening test.

A large majority of people talked to in the outreach encounters appeared to be positive about doing a screening test. This is positive, however, it is not necessarily an indication that it will be translated into action. Many positive comments were also recorded by the volunteers.

There seemed to be a fairly positive response for a majority of patients contacted via the GP surgery, with many asking for replacement kits and/or stated an intention to screen. However, stated intention does not always translate into action. Examination of actual screening rates is therefore important.

There was an improvement in bowel screening uptake in the intervention practice and this was greater than improvements in uptake overall in City and Hackney, and in adjoining GP practices. Although this does not prove that the intervention was effective it is an encouraging sign. Further work could help to establish whether this could be attributed to specific interventions. Data from the literature suggests that GP endorsement is effective. The model for this project was to build on the idea of practice endorsement using culturally specific approaches and volunteers to increase credibility and engagement with patients.

Practical issues of data confidentiality meant that the process in the GP surgery was less efficient than it might have been. Future projects would need to address this issue.

There is a significant group of people who put their faith in God to look after them and stated that they were definitely not interested in screening, in both the outreach encounters and the screening calls in the GP surgery. Other approaches than giving information will need to be developed with this group if we want to try and change the behaviour for their benefit.

Recommendations

- Future outreach work should target men as they are less likely to be informed about health issues.
- Further work with faith leaders is recommended to work with them to try and ensure that religious belief is not a barrier to screening.
- Lack of ethnicity data in the Screening Hub dataset prevents systematic examination of uptake by ethnicity. It is recommended that this be included in the dataset.
- The project highlighted that it was very difficult for people to get replacement kits and this will hinder screening uptake. It is recommended that this process be more streamlined to facilitate this.
- Interactions by trained volunteers to support GP work has a lot of potential, particularly in integrated models of care and particularly for communities who may not respond to traditional forms of communication. The practical barriers to this need to be well thought through to ensure that potential is realised.

References

1. Public awareness of cancer in the NECLN Sector - Ethnicity Report. STRC, 2010,
2. Ethnic disparities in knowledge of cancer screening programmes in the UK. Robb et al. J Med Screen 2010;17:125-131
3. Breast cancer screening uptake among women from different ethnic groups in London: Jack et al. BMJ Open. 2014. 4(10)
4. Evaluation of a service intervention to improve awareness and uptake of bowel cancer screening in ethnically-diverse areas. Shankleman et al. Br J Cancer, 2014, 1-8
5. Awareness of cancer symptoms and anticipated help seeking among ethnic minority groups in England. Waller et al. Br J Cancer, 2009,101; Suppl 2 S55-9
6. Interventions to increase bowel screening uptake. ACE programme, CRUK 2017 BrInterventions

Appendix 1: Case Study One

A man of African descent said he was diagnosed with prostate cancer 3 days prior to meeting him at Ridley market during the bowel cancer outreach. He recalled that he was sent a Faecal Occult Blood test kit 4 months ago and he didn't do the test. He now knows the importance of these tests.

Appendix 2: Case Study Two

A 62 years old man of African descent was called from Kingsmead Health Centre on 4th October 2018, he recalled meeting the bowel cancer volunteers at Ridley market in September and was shown how to use the kit. At the market he was encouraged to do the screening test. He was convinced and returned his bowel cancer screening kit on a day before the call on 3rd October.

Appendix 3: Case Study Three

A young man of Caribbean descent expressed concerns about being incapable of receiving his colon biopsy results the following week. The biopsy was done when he reported seeing blood in his stool. He repeatedly said that he may not show up at his appointment because he was worried the results would be bad. He shared that he was unable to discuss the process of getting tested or his concerns with his aunt who he lived with, friends or church folks. He mentioned that the psychological support provided by the hospital was insufficient.