

# Evaluation Report

---

‘Increasing uptake of bowel cancer screening in the London borough of Hackney’ (May 2019 – April 2020)

---



Projected funded by



Evaluated by

Lifetime Consulting & Partners Ltd, June 2021

## Project profile

<b>Funder</b>	NHS City and Hackney CCG
<b>Implementing partner</b>	Community African Network
<b>Project Title</b>	“Increasing uptake of bowel cancer screening”
<b>Operational area</b>	London Borough of Hackney
<b>Project Start &amp; End Dates</b>	May 2019 – April 2020
<b>Evaluation date</b>	March – May 2020
<b>Main contact person/s for this project</b>	Janet Murungi (Chairperson) and Oladapo Awosokanre (Coordinator) Community African Network Halkevi Community Centre, 31-33 Dalston Lane, London E8 3DF
<b>Evaluator</b>	David John Musendo (Lead) and Anagha Joshi (Editorial Support) Lifetime Consulting & Partners Ltd, UK 44 Hanworth House London, SE5 OXF Email: <a href="mailto:david@lifetimeconsulting.org">david@lifetimeconsulting.org</a> Mobile: +447775727007 Skype: djnmusendo

@ Cover photo: Representatives of members of the Community African Network. Photo credit: Oladapo Awosokanre

## Acknowledgements

This project was funded by NHS City and Hackney CCG and the evaluation commissioned by Community African Network. Many thanks for funding this project.

We are grateful to the Community African Network for their tremendous support of this report. Specifically, we would like to thank Oladapo Awosokanre and Janet Murungi for the strategic leadership and guidance during the design and execution of this evaluation study. They also kindly provided all the necessary literature and resources that informed this report.

The report would not have been possible without the support of people from both statutory and non-statutory sector agencies, including members of the Community African Network (CAN), volunteers, CCG and others who shared their experiences and perceptions about the project.

Amongst the people who gave us their time, we would mention the following volunteers for their contributions to this evaluation: Carron Adams, Ferrie Kuteesa, Florence Daada, Lukiya Kakembo, Maureen Busulwa, Maureen Obara and Zeynab Diop.

We also thank the following representatives of various organisations who accepted to participate in interviews: Amina Nalubega (Precious Lives), Dani Ilunga (African Art Advice Project), Dr Abdul Pathan (GADHVI Practice), Dr Hailu Hagos (WHEAT Mentor Support Trust) Frances Haste (Hackney CVS), Kirit Suhagiya (Latimer Health Centre) and Thomas Bubi (African support & Project Centre).

Many thanks to the following people who gave technical support to the project from start to the end: Amaia Portelli (City and Hackney GP Confederation), Jackie Brett (Hackney CVS), Jake Chambers (NHS City and Hackney CCG) and Leena Khagram (NHS Bowel Cancer Screening Programme).

David J.N. Musendo and Anagha Joshi

### Evaluators

Lifetime Consulting & Partners

Contact: +447775727007

E-mail: [david@lifetimeconsulting.org](mailto:david@lifetimeconsulting.org)



*Disclaimer: The views and opinions expressed in this report are those of the authors and may not necessarily reflect the official policy or position of Community African Network, Rise Community Acton or their funders.*

## Table of Contents

Project profile .....	i
Acknowledgements .....	i
Table of Contents .....	ii
Tables and figures .....	v
Acronyms .....	v
Executive summary .....	1
1. Introduction .....	4
<i>Purpose of the evaluation</i> .....	6
2. Study methodology.....	7
3. Relevance and appropriateness .....	9
4. Project achievements .....	11
5. Changes brought about by the project .....	18
<i>Who benefitted from the project and how?</i> .....	18
<i>Emerging changes brought about by the project</i> .....	19
6. Sustainability .....	23
7. Project strengths, challenges and lessons.....	25
<i>Enabling factors and facilitators</i> .....	25
<i>Barriers and challenges faced</i> .....	26
<i>Lessons learnt</i> .....	27
8. Conclusion and recommendations .....	29
<i>Summary of findings</i> .....	29
<i>Recommendations</i> .....	30
9. List of appendices .....	31
<i>Annex 1: List of references</i> .....	31
<i>Annex 2: Case studies (compiled by a volunteer)</i> .....	32

## Tables and figures

### List of tables

Table 1: Project targets and achievements .....	2
Table 2: Proposed sample and final study participants in the evaluation.....	7
Table 3: Number of GP screening calls made, achieved and opted out.....	13
Table 4: Workshops facilitated or supported by the project.....	16
Table 5: Summary of participants' perceptions about aspects of the workshop .....	17
Table 6: Who benefitted from this project and how? .....	18
Table 7: Summary of workshop pre- and post-test results .....	20

### List of figures

Figure 1: Project outline: objectives, outcomes and outputs .....	6
Figure 2: Percentage achievement for the project, May 2019 and April 2020.....	11
Figure 3: Number of screen calls made from GP surgeries .....	12
Figure 4: Percentage of clients reporting that they had returned their kits to GPs.....	14
Figure 5: Results of screening call .....	14
Figure 6: Gender of people reached (outreach) .....	15
Figure 7: Age ranges of participants reached through outreach events .....	15
Figure 8: Outreach participants by ethnicity .....	16
Figure 9: What type of information do you require? .....	19

## Acronyms

CAN	Community African Network
CBO	Community Based Organizations
CCG	Clinical Commissioning Groups
FIT	Faecal Immunochemical Test
FOBT	Faecal Occult Blood test
FGD	Focus Group Discussions
KII	Key Informant Interviews
MEL	Monitoring, Evaluation and Learning
MSC	Most Significant Change
SDG	Sustainable Development Goals
ToR	Terms of Reference
UCLH	University College London Hospitals

## Executive summary

This report outlines findings from an end of project evaluation of the “Increasing uptake of bowel cancer screening” project implemented by Community African Network (CAN) between May 2019 and April 2020 in the London borough of Hackney. The project was funded by NHS City and Hackney Clinical Commissioning Groups (CCG) and supported by a technical group of agencies, including eleven members of the CAN and five GP surgeries operating in the borough. The aim of this external evaluation was to assess the performance, approach and success of the project, as well as, the emerging short to medium term impact of the intervention.

### Methodology

This evaluation assessed the achievements of the project against set key performance indicators; explored the emerging changes brought about by the project; examined project sustainability; as well as, drew lessons and recommendations for the future. A mixed-method approach was adopted, drawing quantitative and qualitative data from both primary and secondary sources. The lead evaluator attended and observed three steering group meetings, one outreach session and two training workshops during the course of the project. In addition to reviewing project monitoring data, reports and other useful resources, the evaluator also conducted virtual interviews by phone/Zoom with 7 volunteers, 8 CAN member representatives and 5 partner agencies.

### Project reach

The overall aim of the project was to improve earlier diagnosis of colorectal cancer in the City and Hackney by increasing uptake of colorectal cancer screening among Black ethnic groups, with a focus on people from the Black African and Caribbean community. Overall, the project reached its intended beneficiaries:

- Up to 1,085 people through outreach activities at market stalls at Ridley and Hoxton market, local libraries, GP events, churches, mosques, hairdressers and barbershops. Of the 1,085 people engaged through outreach sessions, 61% (666) were female and 39% (419) were male.
- Exceeding a target of 500 people through community events outreach by an additional 585 people. Data from 617 monitoring forms indicated that out of the population engaged during outreach, 38% were Black African, 29% Black Caribbean, 17% of mixed race and 16% were other ethnic groups.
- In addition to making screening calls to Black African and Black Caribbean people, the project responded positively to requests by GPs to also include non-responders during their calls. After analysis, data from GP screening calls revealed that 32.8% of 302 people contacted through calls were Black Caribbean and 28.8% were Black African. The rest were mixed race (8.8%) or other races (28.8%).
- Up to 78 Black African and Caribbean people took part in targeted and in-depth training workshops on bowel cancer organised and/or facilitated by CAN.
- Furthermore, 1000 language-friendly leaflets were produced in four languages, i.e. French, Somali, Swahili and English. The leaflets were distributed to local people during training and outreach sessions.

## Project achievements

Based on available data and information at the time of this evaluation, it is evident that the “Increasing uptake of bowel cancer screening” project successfully achieved and exceeded its key performance indicators. The evaluators observed that to a large extent, the project took into consideration findings from the evaluation of the project that preceded this project under review. In particular, this project was able to recruit more GP surgeries (5) and volunteers (18) for outreach and screening calls to non-responders. Ultimately, the project collaborated with five GPs in the London borough of Hackney, i.e. Athena, Gadhvi, Healy, Latimer and Nightingale. In total, CAN reached 1,465 Black African and Caribbean people. At GP surgeries, 636 screening calls were made, of which 302 patients were reached. The main achievements of the project are presented in Table 1 below:

Table 1: Project targets and achievements

Indicator	Target	Achieved	% achieved
Engagement of GP practices	4	5	125%
Recruitment and training of volunteer cancer champions	16	18	113%
Develop, produce and distribute language appropriate information materials	1000	1000	100%
Number of individuals engaged through primary care	400	636	159%
Number of individuals engaged through community outreach events	500	1085	217%
Number of individuals engaged with through community workshops	70	78	111%

## Short term changes and emerging impacts

This evaluation observes that one year is rather too short to infer impact. Nonetheless, there is consensus that the project was timely and has benefitted several people and agencies, such as Black and African Caribbean people, particularly those aged 60 and above; community champions; community based organisations; GP surgeries; as well as, the CCG and Hackney CVS. In line with recommendations from the previous evaluation, the project was able to successfully link participating GP surgeries to the bowel cancer hub at Homerton to request for replacement kit. Regrettably, the evaluators could not access bowel cancer screening uptake data from the GPs and CCG to validate the work of CAN due to the lockdown in the UK that had started towards the end of March 2020. Nonetheless, the evaluation believes that the project has successfully resulted in: (1) Increased knowledge and understanding in community members about the bowel cancer screening programme and its benefits; (2) Increased number of Faecal Immunochemical Test (FIT) kits requested for, and completed by, targeted non-respondent bowel cancer screening patients; as well as, (3) Improved uptake of bowel cancer screening in targeted GP practices.

## Enabling factors and challenges

This report has highlights several factors that could have positively influenced the delivery of this project. Key factors included the presence of a strong team of community volunteers/champions for

the project; as well as, a committed team of staff and an active steering group. The evaluation established that CAN was a strong collaborative partnership with exceptional abilities to reach out Black African and Black Caribbean communities in Hackney. In addition, the recent replacement of the Faecal Occult Blood test (gFOBT) by the Faecal Immunochemical Test (FIT) was considered a positive development to support better acceptance of the bowel cancer screening process. On the other hand, some challenges were noted. Amongst these were delayed start up process to identify participating GPs, resulting in an even shorter project timeframe than planned. Most respondents felt that the project could have done even more if it was run over a longer period of time. The advent of Covid-19 towards the end of the project also compounded the challenges as the project had to end at least a month before its planned time.

### Summary of recommendations

The evaluation concludes that the CAN Bowel Cancer Screening Project effectively achieved its set outcomes. Despite being a one-year project, the service was deemed highly relevant and the results were an improvement from previous efforts. Key recommendations are summarised below:

1. Increase the period in which a project is implemented to at least three years. It is only when they are longer term that the impact is assessed and likewise the prospects of sustainability.
2. The issue of religious and social beliefs could be addressed by working with religious and community leaders so that they could reach out to patients within their reach.
3. For future programmes, consider using other creative media, such as digital and social media, for delivering critical messages about bowel cancer screening. Associated with this is a recommendation to consider creative communication methods, including intergenerational dialogues.
4. CAN to continue supporting its volunteers with capacity to work in local communities on similar projects. The evaluation has particularly commended the project for its ability to recruit professional volunteers at the London School of Hygiene and Tropical Medicine.
5. Consider collecting and collating project monitoring and evaluation data using data collection tablets and other online platforms, such as KoboToolbox to reduce costs on paper and double reporting.
6. Future programmes could consider more capacity building and facilitation for CAN members to access resources and host trainings and workshops for their own communities.
7. GPs should be encouraged to ensure that they continue with bowel cancer screening calls and follow up activities within their existing routine basis.
8. Agencies such as the CAN are encouraged to diversify funding sources in order to continue providing longer term support for Bowel Cancer Screening Project activities.
9. Funding agents, such as the CCG and others, are encouraged to reserve essential funding opportunities for small community groups and networks.

# 1. Introduction

## Contextual setting

The World Health Organization identifies cancer as the second leading cause of death globally. It is estimated that about 1 in 6 deaths is due to cancer.<sup>1</sup> Locally in the UK, cancer also contributes to a significant proportion of mortality and morbidity, much of which is preventable. Around a third of all deaths in the City and Hackney are attributed to cancer, with breast, prostate, lung and colorectal cancers, in particular, contributing substantially to this burden.<sup>2</sup>

Colorectal cancer is the third most common type of cancer in the City and Hackney and, despite the screening programme, most cases of colorectal cancer are diagnosed at later stages (stages 3 and 4) compared to other major cancers. Colorectal cancer screening uptake in the City and Hackney remains significantly below the national rate (annually 43% compared with 59%). Unsurprisingly, one-year colorectal cancer survival is also significantly below national rates.

Concurrently, evidence from across London suggests that Black men, especially men from African and Caribbean communities, are significantly more likely to develop colorectal cancer than men from other ethnic groups. Migrant communities are less likely to attend screening programmes, and recent local evidence has highlighted one reason for this is a lack of information in general, and specifically, lack of information in an appropriate language. Around a third of all deaths in the City and Hackney are attributed to cancer, with breast, prostate, lung and colorectal cancers in particular contributing substantially to this burden.

It is well established that high coverage of cancer screening programmes can lead to earlier diagnosis and improved outcomes.<sup>3</sup> Increasing local uptake of the colorectal screening programme, which is substantially lower in Hackney than the national average, it is therefore a priority for action locally. The 2017 Better Health Briefing 47 which focused on “Cancer and black and minority ethnic communities” particularly highlighted that there is a higher incidence of certain cancers in black and minority ethnic communities and the general incidence of cancer in these communities is rising.<sup>4</sup> In addition, according to Public Health England (2016), after adjustment for age, sex and deprivation status, among Black Caribbean as well as Black African colorectal cancer patients with known stage there were significantly higher proportions of late stage compared with the White British group.<sup>5</sup>

---

<sup>1</sup> WHO (2018), Cancer Key Facts. Available at: <https://www.who.int/news-room/fact-sheets/detail/cancer>. Accessed 02 June 2020.

<sup>2</sup> National Cancer Intelligence Network, “Cancer and equality groups: key metrics 2015,” [Online]. Available: <http://www.ncin.org.uk/view?rid=2991>. [Accessed May 2018].

<sup>3</sup> Koo S, Neilson LJ, Von Wagner C, Rees CJ. The NHS Bowel Cancer Screening Program: current perspectives on strategies for improvement. *Risk Manag Healthc Policy*. 2017;10:177 - 187. Published 2017 Dec 4. doi:10.2147/RMHP.S109116

<sup>4</sup> Qulsom Fazil (2017), 2017 Better Health Briefing 47 which focused on “Cancer and black and minority ethnic communities”. Accessed on 26 May 2020. Available at: <http://raceequalityfoundation.org.uk/wp-content/uploads/2018/07/REF-Better-Health-471-1.pdf>

<sup>5</sup> PHE (2016) National cancer registration and analysis service data briefing. PHE publications gateway number: 2016220

### About the Community African Network (CAN)

CAN is a network of African led organisations working together to address key issues affecting the African community in Hackney. CAN was established in 2016 when 7 local organisations agreed to jointly advocate, campaign and promote issues around health and well-being affecting Africans in Hackney. The Community African Network is managed by a committee including a chair, secretary and treasurer.

The Community African Network has grown organically from 7 to 11 member organisations. Over the years member organisations have built their internal capacity through training, advocacy capabilities through joint outreaches and support from the Hackney Council Voluntary Service (HCVS). Member organisations include:

- African Arts and Advice Centre
- African Community School
- African Support and Project Centre
- Central Africa's Rights & AIDS (CARA) Society
- Hackney Somali Community (Safa Marwa Foundation)
- International Youth Centre
- Nenita Sa Engineering Foundation, NSEF
- Precious Lives
- Rise Community Action
- Undugu Community Association
- WHEAT Mentor Support Trust

### About the Bowel Cancer Screening Project

The overall aim of the project was to improve earlier diagnosis of colorectal cancer in the City and Hackney by increasing uptake of colorectal cancer screening among Black ethnic groups. Therefore project activities were set to increase the awareness of bowel cancer and the uptake of bowel cancer screening for the benefit of older Black African and Afro-Caribbean communities. This was to be achieved through community training and awareness raising activities; targeted outreach; and engaging GP surgeries in City and Hackney.

In order to help increase bowel cancer screening uptake rates in Hackney and City, the Clinical Commissioning Groups (CCG) provided funding worth £37,000 to Rise Community Action (on behalf of the Community African Network). The project was implemented between May 2019 and April 2020. This particular project was built upon an existing volunteer community cancer champions programme: 'Improving awareness of bowel cancer screening and uptake in the older African community in Hackney'.

## Project overview

This particular intervention was an extension of an existing pilot project (2018-19), and was expected to deliver on the following core activities summarised in figure 1 below.

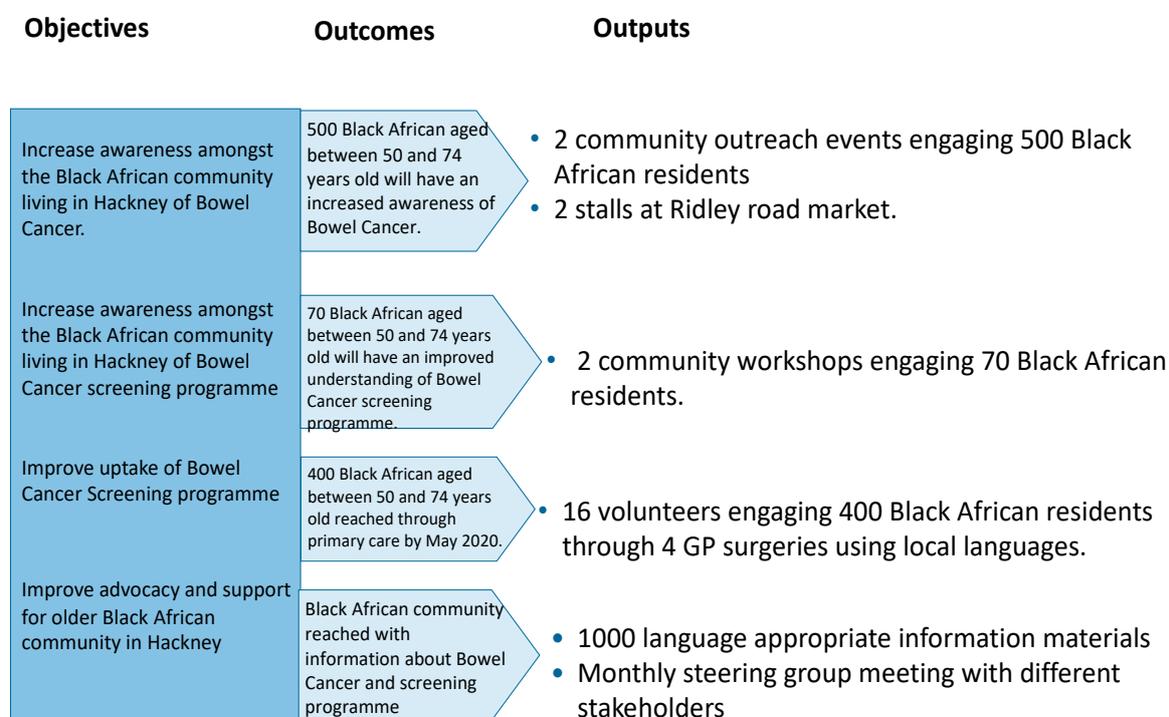


Figure 1: Project outline: objectives, outcomes and outputs

## Purpose of the evaluation

This independent study was commissioned to evaluate the short to medium-term impact of the Bowel cancer screening project activities. The evaluation was expected to focus on: (1) Recording of achievements against the project's key performance indicators; and (2) The production of an evaluation report detailing outputs and impacts of the service after 12 months.

More precisely, the **specific objectives** for the evaluation study were to:

1. Review the achievements of the project against set key performance indicators;
2. Determine the effectiveness of the strategies and activities utilised;
3. Assess the short to medium-term impact of the service after 12 months, including key factors that helped or hindered the delivery of the project;
4. Consider sustainability issues and critical gaps/key needs; and
5. Draw conclusions, lessons and recommendations for future programming.

## 2. Study methodology

### Study design

This evaluation utilised both quantitative and qualitative data collection methods to evaluate the relevance, effectiveness, short term impacts and prospective sustainability of the bowel cancer screening awareness project in Hackney and City. Demographic and other project monitoring data were collected from the project's paper monitoring tools and project reports. A mixed methods approach was chosen in order to assess the short to medium impact of the campaign, as well as to identify the strengths and weaknesses of the project.

Qualitative interviews, using semi-structure questionnaires, were conducted by telephone, Zoom or Skype with partner agencies (both statutory and non-statutory), as well as, GP practice representatives, CAN partner representatives, volunteers and other agencies. At the same time, quantitative data was gathered and analysed, with a focus on data describing GP practice screening calling and uptake rates, in conjunction with outreach campaigns and training workshops. In addition, the evaluator used notes from steering group meetings and interviews as well as observation notes collected during project implementation.

### Study participants

In the face of Covid-19 and a national lockdown from the end of March 2020, any prospects for face-to-face meetings were made impossible. Therefore, purposive sampling procedures had to be used to identify and enrol people who would participate in this evaluation. Purposeful sampling is widely used in qualitative research for the identification and selection of a small number of information-rich cases with in depth information and knowledge of a phenomenon of interest (Palinkas et al., 2015). Thus, only those people who had directly engaged with the Bowel Cancer screening project through meetings and engagement; training and workshops; outreach and steering meetings were considered.

A database with 33 potential participants was considered to derive the final sample size. E-mails, mobile text messages and an online questionnaire were sent to all eligible participants. About 61% (n=20) of the targeted participants were reached and responded to the questions that were sent to them in advance of each interview.

Table 2: Proposed sample and final study participants in the evaluation

Category of participants	Target	Achieved	Percent
Project volunteers / champion	11	7	64%
CAN staff and member representatives and management	12	8	67%
Partner agencies, including funders, statutory sector and GP Practices	10	5	50%
<b>Total</b>	<b>33</b>	<b>20</b>	<b>61%</b>

## Data collection

The evaluation was conducted by Lifetime Consulting and Partners. Classified as a service evaluation, no research ethics approvals were deemed necessary for this study. Nonetheless, the process of conducting the evaluation was designed to ensure appropriate research standards were maintained, including seeking verbal informed consent all study participants, ensuring their rights, anonymity and confidentiality. Data collection took place between April and May 2020, with approximately 30 minutes spent on each interview. The main activities carried out for data collection were as follows:

- *Desk review:* Various project documents, such as project monitoring forms, quarterly reports, previous evaluation reports were reviewed to complement findings from observations and interviews. For a closer analysis of data, the evaluators used a sample of data and monitoring forms for a group of 636 screening calls; 617 people reached through outreach and 28 responses from workshop evaluations.
- *Key informant interviews:* A total of 16 virtual interviews were conducted with staff from statutory and non-statutory sectors, including community volunteers and CAN staff.
- *Online semi-structured questionnaire:* Two people opted to fill an online semi-structured questionnaire rather than participate in a telephone interview. This was due to their time availability and was sufficient to provide needed data.
- *Observations:* Throughout the life of this project, the Evaluators participated in three steering group meetings, two outreach sessions and two workshops.

## Data synthesis and reporting

Project monitoring data were entered into a mobile software, ODK, before analysis of the achievements made by the project. SPSS Version 23.0.0 was utilised for quantitative data analysis, results were presented as descriptive statistics (frequencies, mean and range) and summarized in appropriate graphs. Qualitative data from the interviews was analysed using thematic analysis procedures to map-out emerging themes and findings were triangulated with quantitative data before making conclusions during reporting.

## Study limitations

Considering that the evaluation was conducted between April and May 2020, which was at the peak of the Covid-19 pandemic in the UK, all planned face-to-face interviews and focus group discussions were cancelled. To mitigate this, the evaluator made phone calls to interview various people who were aware of the project as either supporters or participants. In addition, the evaluator used notes from observation visits made during the course of the project as he had participated in various activities, such as steering group meetings, outreach sessions and training workshops. Furthermore, GP uptake data from other GPs could not be accessed to further validate the records of CAN and report on actual outcomes due to the closure of key offices. Therefore, the evaluation focused on data available from project records and recommend that future programmes should consider collecting data as part of the project's ongoing monitoring and record keeping.

### 3. Relevance and appropriateness

The need for a project to address the challenges of health and in particular uptake of bowel cancer screening amongst Black and Minority Ethnic groups is widely acknowledged and accepted. This section highlights the extent to which the Bowel Cancer Screening project and the strategies used were relevant for the context and appropriate for the purpose of the project.

#### **The relevance of the Bowel Cancer Project**

Evidence across London suggests that people from Afro-Caribbean backgrounds, especially men, are significantly more likely to develop colorectal cancer than people from other ethnic groups. The Bowel Cancer screening project was found highly relevant, with the initial project developed primarily to target individuals aged 60 to 74 from Black African and Caribbean ethnic groups who were eligible for colorectal screening. According to people consulted during this evaluation, these communities are faced with a myriad of challenges that affect their willingness to participate in bowel cancer screening in the City and Hackney.

Previous research has identified several challenges that affect uptake of bowel cancer services, such as a lack of awareness and knowledge at individual and community levels; cultural and religious beliefs, language barrier; low levels of willingness to participate in bowel cancer screening; contesting priorities on GP practices, as well as, poor involvement of community organisations to help reach out to 'hard-to-reach' communities. In particular, the return rates for tests kits was generally low. Some of the reasons for low uptake included:

- Some older people not finding it necessary to complete the test when they don't have any symptoms of bowel cancer
- Concerns and fears that the bowel cancer screening test is hard, unlikable or unhygienic
- A lack of awareness and understanding of the benefits of testing and their eligibility to participate.
- Patients also reported not having received bowel screening kits; not giving priority to screening; they had not understood the importance and either threw away or misplaced the kit; as well as, just not getting around to doing it.

Most evaluation participants noted that some parts of City and Hackney are more socially and economically deprived than the average for London. GPs supported local data findings that show bowel cancer screening uptake was well below the national average, particularly in BME communities who are less likely to attend screening programmes. In recognition of the above-mentioned issues and other underlying challenges in the City and Hackney, most evaluation participants felt that it was prudent that CCG specifically considered the Community African Network to implement this project and recognised the network was well placed to promote higher screening outcomes in the targeted areas. The combined efforts of the Community African Network provided them with a competitive ability to reach out to local communities, most of whom they were engaged with in other means.

## Main project strategies

Addressing key bowel cancer screening related challenges, needs and opportunities identified in the City and Hackney, this project was aimed at reaching out to Black African and Caribbean communities in Hackney. In order to achieve its aims, the “Increasing uptake of bowel cancer screening” project implemented several strategies for achieving its expected results. The main project strategies that were used by this project included:

- Volunteer recruitment and training to act in a peer advocate roles through GP practices and during community outreach. Up to 18 volunteers were recruited and took part in this project, of which 16 were female and 2 were male.
- Development, production and distribution of language appropriate information materials in four languages, i.e. English, French, Somali and Swahili. The project also sourced for additional information resources to help raise awareness of bowel cancer screening, and to encourage patient participation in the borough.
- Call screening to follow up on non-responders: Based on evidence suggesting that GP involvement can increase the uptake of bowel cancer screening, the project worked closely with GP practices to follow up on non-responders. Specifically, the project assigned volunteers across the five GPs to make phone calls to remind patients about screening, a strategy that has, in the past, been found to be more successful than written reminders alone.<sup>6</sup>
- Community workshops with local communities were conducted, which are considered effective strategies to increase knowledge and understanding about bowel cancer, especially on risk factors, the screening process, symptoms of bowel cancer, as well as, how to return bowel cancer screening kits to GPs.
- Individual and community outreach activities were commended by various people in this evaluation. Our consultations with various respondents confirmed that whilst mass media communication strategies can help promote health education, there is strength in interpersonal communication channels as they can be highly influential in persuading people to change health-related behaviors.<sup>7</sup>

From the evaluators’ perspective, the project was well placed in being implemented by CAN, a given their efforts to address a whole range of health challenges facing Africans and other BME communities in Hackney. The network has a track record of working with African communities to deliver health messages and help change behaviour. Through a network of trained community champions and volunteers, CAN has demonstrable capacity to engage with the Black African and Black Caribbean communities in places where people congregate, enabling sympathetic, culturally relevant dialogue and discussion about knowledge, barriers and support.

---

<sup>6</sup> Basch C, Wolf R.L., Brouse C.H, Shmukler C, Neugut A, DeCarlo L.T, et al. Telephone Outreach to Increase Colorectal Cancer Screening in an Urban Minority Population. *American Journal of Public Health*. 96 (12) 2246-2253 (2006).

<sup>7</sup> Yanovitzky I, Blitz CL: Effect of media coverage and physician advice on utilization of breast cancer screening by women 40 years and older. *Journal of health communication*. 2000, 5: 117-134.

## 4. Project achievements

The CAN Bowel Cancer Project was funded by the NHS City and Hackney Clinical Commissioning Group (CCG), an NHS organisation led by local GPs, who are best placed to assess, understand and meet the health needs of their patients, ensuring effective and accessible healthcare for all.<sup>8</sup>

### Achievements against targeted key performance indicators

Overall, the project achieved and/or excelled in all its targets. By the end of April 2020, CAN had reached 1,465 people from Black African and Caribbean communities across City and Hackney through outreach events, workshops and GP patient engagements. Of these people, 1,085 were reached through outreach activities and 78 participated in workshops organised and/or facilitated by the project. In addition, 636 GP screening calls were made and 302 patients from 5 GP surgeries were directly contacted. Figure 2 below presents an overall summary of the project's output achievements.

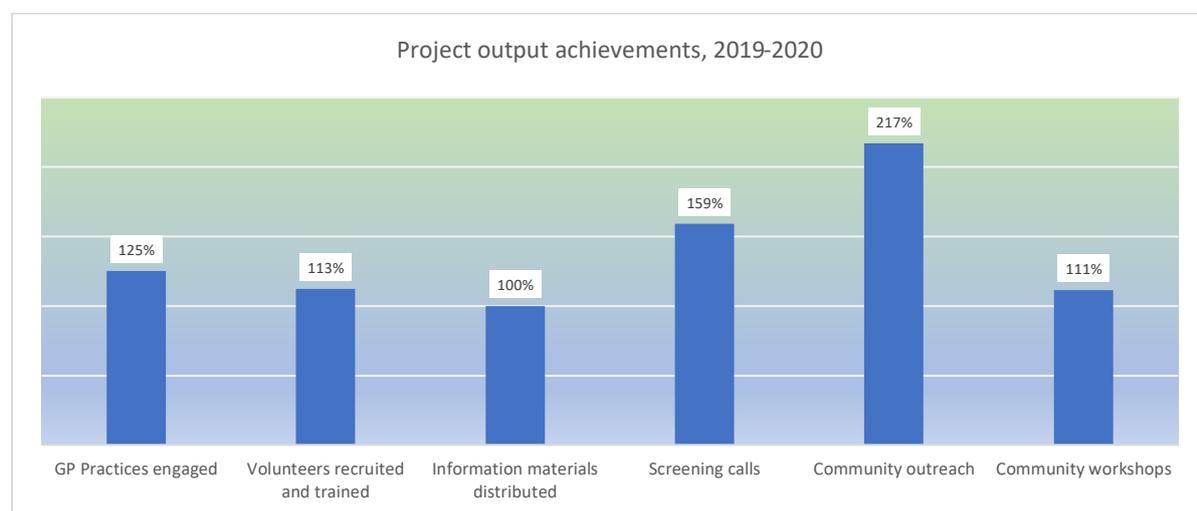


Figure 2: Percentage achievement for the project, May 2019 and April 2020

### Engagement of GP Surgeries

The project supported the proactive promotion of bowel cancer screening to eligible groups of people through GP engagement and collaboration with CAN's community volunteers. Community volunteers, also referred to as champions, received training on good practices in following up non-responders and were provided with calling space in each of the participating GPs. Despite a slow start of the project, the project ultimately engaged five out of a target of four GPs who accepted to provide their clients data and space for volunteers to make calls. The greatest breakthrough in getting GP acceptance of the project was after a presentation by the Project Coordinator at a GP's consortium meeting, supported by CCG. As shown in Figure 3, Nightingale GP surgery had the greatest number of calls made

<sup>8</sup> NHS City and Hackney Clinical Commissioning Group. Available at: <http://www.cityandhackneycgg.nhs.uk/>

(150) and Gadhvi had the least, i.e. 52. Generally, these numbers were proportionate to the number of registered patients at each GP practice.

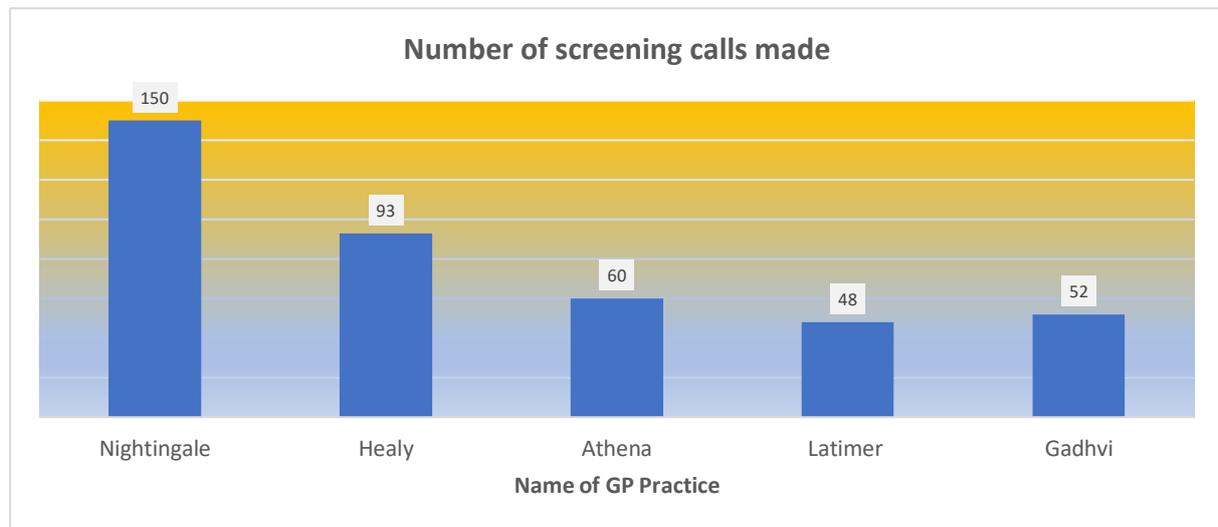


Figure 3: Number of screen calls made from GP surgeries

### Volunteer engagement, support and supervision

The CAN Bowel Cancer Project recruited and trained 18 community volunteers as champions for the project, of which 17 were female and one was male. Most of the volunteers had been part of the previous project on bowel cancer awareness and were mainly drawn from network members of CAN, as well as, students from London School of Hygiene and Tropical Medicine. Notably, concerns around the low involvement of men as community champions were highlighted during this evaluation. It was observed that women from Black and minority ethnic groups are more likely to take up volunteering roles, compared to their male counterparts.

Discussions with various evaluation respondents indicated that the project had successfully offered training to local champions (volunteers) and provided other non-financial incentives to retain their interest and commitment to the project. Volunteers acknowledged that activities such as daily debriefs after sessions with the project team leaders were motivational. Direct support through volunteer celebration days, training, vouchers, and in-person support from the project staff were also critical in the achievement of the project's successes to date.

While this project demonstrates good practice in volunteer engagement, some respondents felt a need for greater engagement of men as volunteers in outreach sessions. They argued that including men in volunteering could help increase project accessibility and acceptability. Others suggested that the project could aim to recruit younger men, including students, as volunteers.

## Production and dissemination of information resources

Patient information leaflets have been a legal requirement in the UK since 1999. Lessons learned from the pilot phase highlighted a lack of bowel cancer information in general, as well as, a specific lack of language appropriate information resources. The current project produced 1000 leaflets with bowel cancer messages and these were made available in four languages, i.e. English, French, Somali and Swahili. This ensured optimal reach to people who had language difficulties.

*“The materials that were provided were of great value. I had printed copies and leaflets as well as brochures to explain the screening process. I can say that the information was simplified and it was made easy for me to take and share with other people. I also got a file and in each GP practice I had a computer and a phone.”*  
(Volunteer, female, working in GP Practices)

For future programmes, project staff would recommend the use of other creative media in passing on messages about bowel cancer, such as the use of digital media. Given the ever-changing technological environment, there is scope to reach a wide range of people in a more cost-effective and efficient manner. It may also be helpful to create and send relevant information links and where possible, resources such as demonstration videos and other prompts.

## Call screening from GP Surgeries

Trained volunteers were trained to carry out screening calls to patients who were reported as not having returned their kit four weeks after invitation. Using a clearly outlined script, volunteers would follow-up these patients and offer advice and further information about bowel cancer screening. By the end of the project, 302 clients were reached, out of a total of 636 calls made by volunteers. Aged between 60 and 74, the average age of call respondents was 65.5 and just above half (53%) were male.

Table 3: Number of GP screening calls made, achieved and opted out

Name of GP surgery	Number of calls made	Patients reached through calls		Patients opting out	
		Number	Percent	Number	Percent
Healy	93	53	57%	0	0%
Athena	60	31	52%	0	0%
Latimer	104	48	46%	4	8%
Nightingale	327	150	46%	34	23%
Gadhvi	52	19	37%	5	26%
<b>Overall</b>	<b>636</b>	<b>301</b>	<b>47%</b>	<b>43</b>	<b>11%</b>

As shown in Table 3, the highest proportion of clients reached were called from Healy GP surgery (57%) followed by Athena (52%). None of the clients from these two GP facilities opted out of the programme. Whilst Nightingale had the highest number of patients that were reached i.e. 150 (46%), there was also a high percentage of clients who opted out of the programme, i.e. 34 (23%).

### Responses from screening call participants

Nearly one in six call respondents, i.e. 17% (50 of 302), reported that they had already returned their kits to their GPs at the time when they were called by CAN volunteers. Nightingale GP Surgery had a larger proportion of people (23%) reporting that they had returned their kits to their practice, compared to the other practices. None of the respondents from Athena had returned kits.

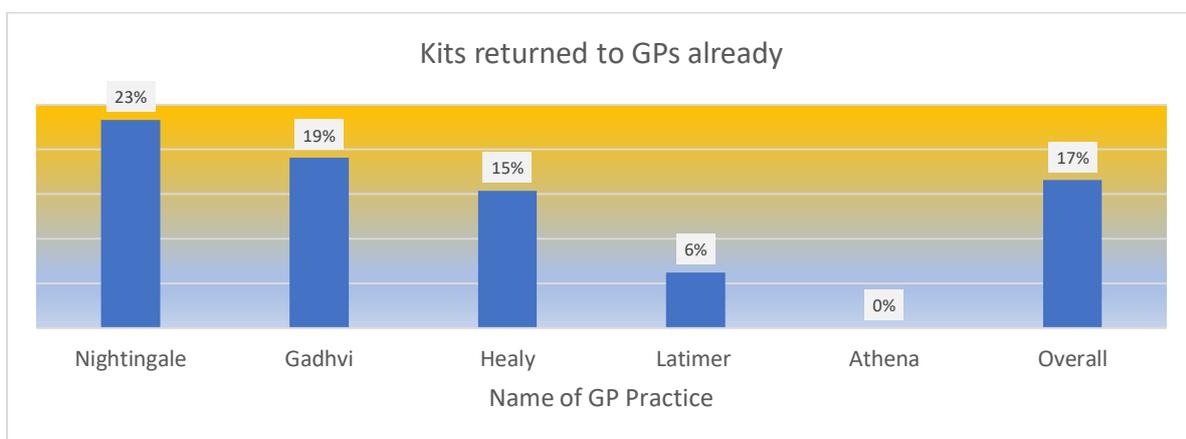


Figure 4: Percentage of clients reporting that they had returned their kits to GPs

Available data showed a significant willingness of patients to participate in the programme, as indicated by slightly over half the number of people that received calls (57%) requesting for test kits to be sent to them. At Athena, almost all (90%) requested for a replacement kit; followed by Healy (79%) and Latimer (75%). On the other hand, about a tenth (11%) of the respondents also said that they would return their kits.

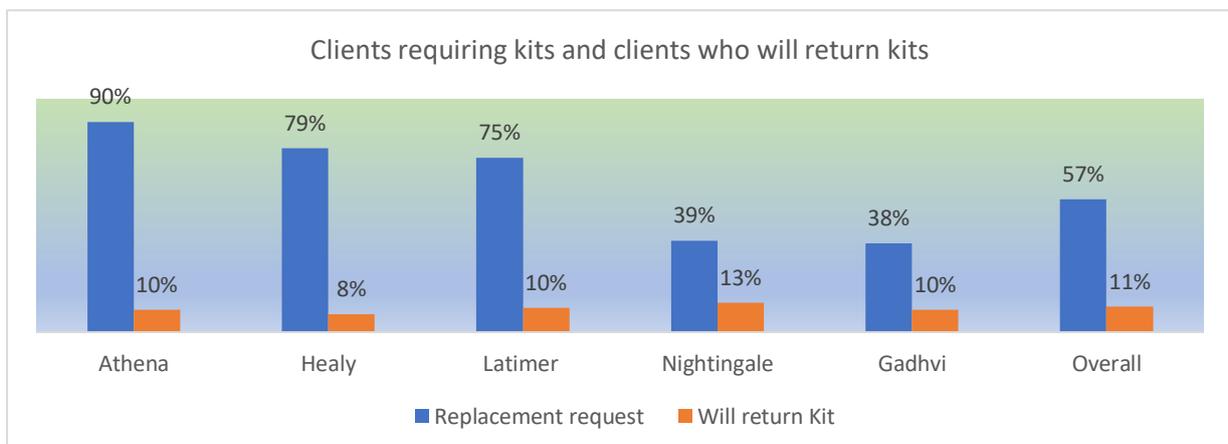


Figure 5: Results of screening call

## Community outreach events

The project reached up to 1,085 people through outreach activities at market stalls at Ridley and Hoxton market, local libraries, GP events, churches, mosques, hairdressers and barbershops. Of these, 61% (666) were female and the remaining 39% (419) were male. Generally, women were found more receptive to outreach, compared with men. The project was successful in exceeding its target of 500 people by 117%, by reaching out to an additional 585 people.

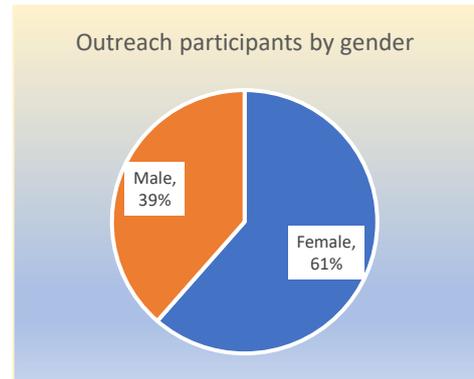


Figure 6: Gender of people reached (outreach)

### Characteristics of the outreach participants

A total of 617 outreach monitoring forms were made available to the evaluator and they were assessed. The age ranges of the participants are presented in figure 7, indicating that more than half the number of people reached were aged 60 and above, i.e. 39% between 60-79 and 18% aged 80 and above. According to project staff, having a wide range of ages engaged during community outreach had its benefits. Outreach sessions were open and having people of all ages presented opportunities to talk to younger people who would pass on bowel cancer screening messages to their family members who are eligible for screening.

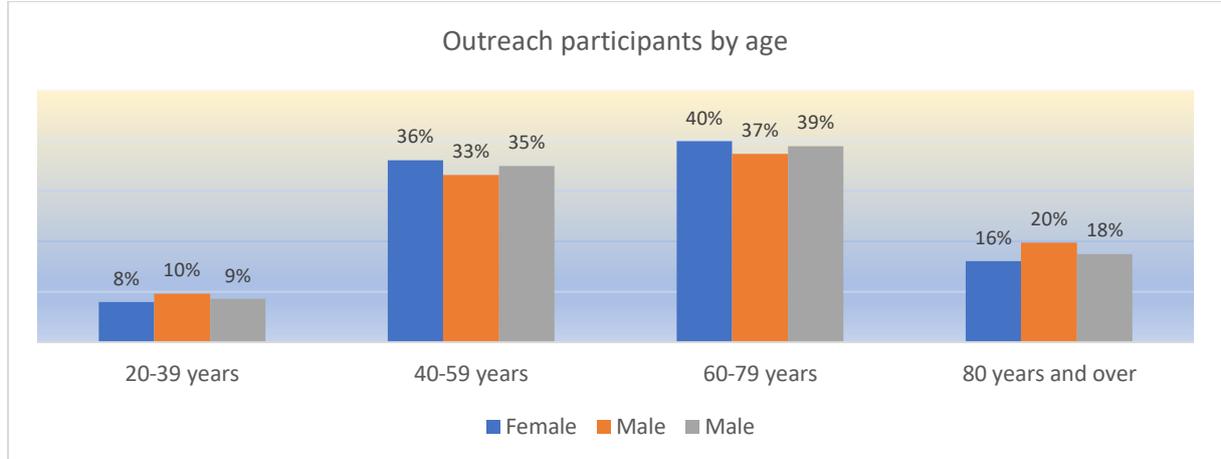


Figure 7: Age ranges of participants reached through outreach events

Further analysis of data available from a sample of 617 outreach monitoring forms revealed that of the population reached, 38% were Black African, 29% Black Caribbean, 17% of mixed race and 16% were other ethnic groups. The graph with these data in figure 8 below shows that a proportionate representation of male and female participants across the different ethnic groups were engaged.

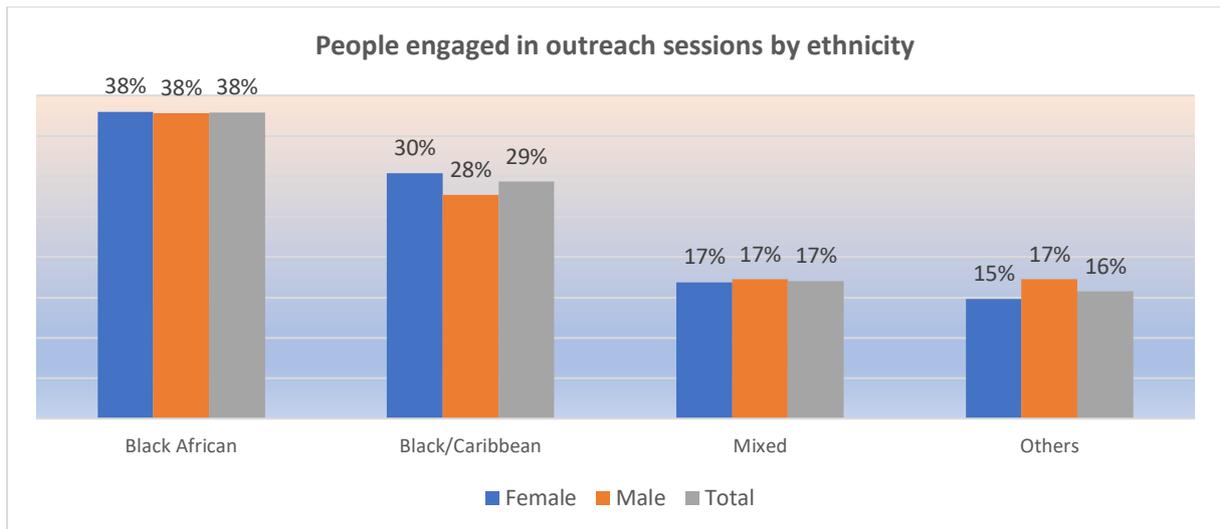


Figure 8: Outreach participants by ethnicity

### Intention to take the test

Despite a positive response during outreach, results from the project’s monitoring forms reveal that the process of changing one’s attitude towards screening could require longer engagement than a short contact made in public places. For instance, out of 83 people aged 60 and above who had never taken a test, only 39% (n=32/83) responded that they would consider taking a test after the outreach session. On the contrary, nearly half (48%) were unsure and 13% would not take the screening at all. Closer analysis shows that of the proportion of women who had never tested, only approximately 40% (n=22/43) were willing to test, and similarly, low levels found in their male counterparts (33%, n=10/30).

### Community workshops

In addition to general community awareness efforts, the project facilitated three workshops to engage local communities to increase awareness and encourage the return of colorectal screening kits. The project worked with other partner agencies, such as the Macmillan Cancer Support’s Community Connectors Programme; Social Action for Health and Cancer Research UK. Community workshops were coordinated by network partners affiliated to CAN to ensure greater reach to communities that are often underserved.

Table 4: Workshops facilitated or supported by the project

Nature of workshop	Participants
Macmillan Cancer - Community Connectors Programme	21
SAfH volunteer Training – facilitated by Cancer Research UK (2 workshops)	13
Somali Culture and Health Day – BC Workshop	44
<b>Total</b>	<b>78</b>

### Feedback from workshop evaluation forms

Results from a sample of 28 training activity evaluation forms revealed that overall, the training workshops facilitated by the project were well received by the participants. Out of the 28 people who filled the evaluation forms, three quarters (75%) were female.

A large majority of the workshop participants, i.e. 70%, identified “basic information about bowel cancer” as the best part of the workshop, followed by “the facilitation team and methods” (26%). From a sample of 28 workshop participants, the following countries were included in the report, i.e. from Bermuda, Congo / DRC, Jamaica, Kenya, Nigeria, Somali, South Africa, Sudan, Uganda, United Kingdom and Zimbabwe.

*“We received sufficient training about bowel cancer. It was relevant as we were learning something new. The trainers also pointed us to what to expect in the community.” (Project volunteer)*

In Table 5, a summary of workshop participants’ views about various aspects of workshop, showing higher ratings of ‘excellent’ or ‘good.’ The knowledge of the facilitators of the subject were commended as excellent by a large proportion of participants, i.e. by 82%; and followed by the contents of the workshop (68%).

Table 5: Summary of participants' perceptions about aspects of the workshop

Evaluation component	Excellent	Good	Moderate	Poor
Facilitators' knowledge of subject	82%	18%	-	-
Workshop content	68%	32%	-	-
Venue	57%	43%	-	-
Workshop publicity	57%	39%	-	4%
Time keeping	39%	54%	-	7%

When asked what needs to be improved in the future, the participants highlighted a need for more information and resources (47%), better time management (41%) and improvements in planning and logistics (12%).

## 5. Changes brought about by the project

Bowel Cancer Screening Project has made outstanding progress towards achieving its expected results and influencing changes towards increased bowel cancer screening in the City and Hackney. In almost all instances, targets were excelled. Although it is too early to make claims about the long term impact of the Bowel Cancer Screening Project, there are indications that the project could positively influence changes towards improved health outcomes in the future.

### Who benefitted from the project and how?

A total of 1,465 people of Black African and Caribbean communities were reached through the project, of which three quarters (74%, n=1,085) were through community outreach sessions, a fifth (21%, n=302) through call screening at GP surgeries, and the remaining 5% (n=78) through training workshops. While these groups of people were the primary beneficiaries of this project, participants in this evaluation reported that other people / agencies also benefitted from this initiative, as shown in table 6.

Table 6: Who benefitted from this project and how?

Who benefitted?	How did they benefit?
Black and African Caribbean people, particularly those aged 60 and above	<ul style="list-style-type: none"> <li>Improved awareness and knowledge about bowel cancer and the screening process.</li> <li>Reduced fear and improved confidence to participate in the national bowel cancer programme.</li> </ul>
Community champions / volunteers	<ul style="list-style-type: none"> <li>Gained knowledge about bowel cancer and new skills for community outreach and engagement.</li> <li>A sense of fulfilment in serving members of their community.</li> <li>Personal development and other substantial positive benefits for the volunteers themselves.</li> </ul>
Community organisations (members of CAN)	<ul style="list-style-type: none"> <li>Technical and financial resources to further their work with local community members on cancer related issues.</li> <li>Gained experience, skills and expertise in this work.</li> <li>Improved collaboration between network members.</li> </ul>
GP surgeries	<ul style="list-style-type: none"> <li>Additional support for their staff to reach out to non-responders and thereby increase uptake of screening services.</li> <li>Increased opportunities to follow up on their patients and update their records.</li> <li>Contribution towards the reduction of inequalities that exist in relation to cancer incidence and in cancer screening uptake.</li> <li>Greater appreciation and ownership of the national bowel cancer screening activities.</li> </ul>

Who benefitted?	How did they benefit?
The CCG and Hackney CVS	<ul style="list-style-type: none"> <li>• Greater publicity, awareness and localisation of the bowel cancer screening programme.</li> <li>• Increased support from a network of community organisations to reach out to people that are often regarded as 'hard-to-reach'.</li> <li>• Although the project was short-term, there is a likelihood that in the long term, the project would ultimately help improve colorectal cancer survival and reduce overall mortality and morbidity.</li> </ul>

### Emerging changes brought about by the project

An evaluation of a one-year project would be unrealistic to assess any impacts. It is, however, sensible for us to consider the potential benefits of this project, as gathered from project monitoring data, reports, as well as, feedback from project participants, volunteers and other key informants. Given the successes of the project, emerging changes were observed in the areas of knowledge, uptake of bowel cancer screening and ultimately improvements in the number of patients returning bowel cancer screening kits to their GPs. Most importantly, the evaluators observed that the project was well implemented, addressing some of the recommendations from the previous evaluation, especially in terms of recruiting more volunteers, reaching out to more GPs and improving access to replacement kits in collaboration with the Homerton cancer hub.

### Increased knowledge and understanding about bowel cancer screening

People reached by this project had an expressed need for information related to bowel cancer. During outreach sessions, three quarters of the people spoken to, i.e. 77% (n=474/618) reported that they needed to learn something about bowel cancer. These people were also articulate about the nature of information that they needed, most of which was covered in the outreach sessions conducted by project volunteers. Themes that arose from people reached in the program, when asked what more information they required in regards to bowel cancer, are presented in figure 9.

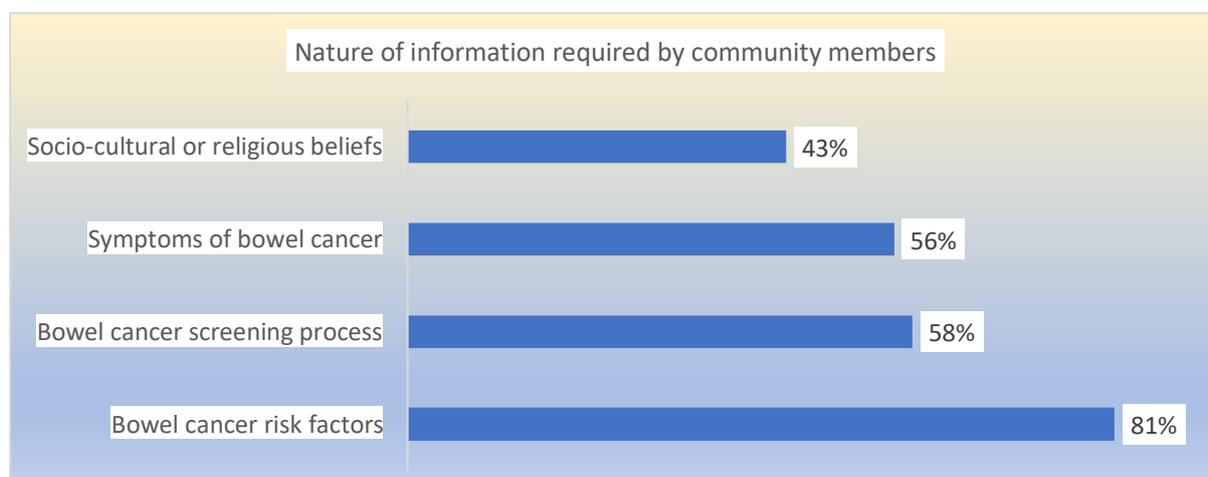


Figure 9: What type of information do you require?

Most of the volunteers expressed gratification at the positive feedback they received from the people whom they spoke with when making screening calls, especially for the advice that they offered on a subject that is often shunned by many people. Older people were especially thankful to have someone call them and inform them of the benefits of the screening. Volunteers stressed that they would continue to receive a new kit every 2 years until they would have reached 75. With their gained knowledge and understanding, a large proportion consequently felt more confident in completing their screening test and sending the kit back to the GP after the call.

*Bowel cancer screening process is one of our priority issues of concern in our area. Our practice has always had a low bowel cancer screening practice was extremely low .... We didn't have the capacity until the project came to our rescue" (Key informant, GP surgery representative)*

The evaluator accessed pre and post-test evaluation forms from a sample of 28 respondents who participated in at least one of the project facilitated workshops. Overall, there was a positive increment in self-reported elements of the evaluation template (see Table 7). It is important to note that 64% of the people who filled the evaluation forms had been to at least one bowel cancer workshop. Generally, the people who were trained appeared to have had good background knowledge about bowel cancer, explaining a high score at baseline. There was an average incremental effect from 88% before the workshops to 96% after the workshop. The most significant change was the percentage of training participants who became aware of how to get a screening kit, i.e. 93% compared to a baseline of 82%.

Table 7: Summary of workshop pre- and post-test results

Knowledge question	Pre-workshop	Post workshop
Aware of the symptoms of bowel cancer	93%	100%
Knows what to do if you have symptoms of bowel cancer	89%	93%
Knows how to get a bowel cancer screening kit	82%	93%
Cultural or religious reasons why you don't want to undergo bowel cancer screening?	86%	96%
<b>Overall</b>	<b>88%</b>	<b>96%</b>

### Improved uptake of bowel cancer screening in targeted GP practices

One of the main ideas of this project was to proactively encourage non-responders aged 60 to 74 to actively participate in the national bowel cancer screening programme. The focus of this project had a specific interest and focus on neighbourhoods and GP practices with a higher population of Black Africans and Black Caribbean, where the response to the screening programme was lower than other areas.

Volunteers spoke with non-responders and provided essential bowel cancer information, explaining the importance of returning their kits to GPs. The benefits of participating in the programme were also highlighted, in particular, to identify and treat bowel cancer at an earlier stage; and ultimately to reduce deaths from bowel cancer.

As a result of this work, participating GPs had an opportunity to check and update their bowel cancer screening records, including contact details for their clients. As they observed an increase in the number of clients requesting for kits and returning their kits. A greater sense of appreciation, interest and ownership of the bowel cancer screening programme was acknowledged amongst participating GPs.

#### **Increased numbers of Faecal Immunochemical Test (FIT) kits completed by targeted non-respondent bowel cancer screening patients**

An integral part of this evaluation was to establish the short to medium term impact of the activities undertaken by the project. In line with recommendations from the previous evaluation, the project was able to successfully link participating GP surgeries to the bowel cancer hub at Homerton to request for replacement kit.

*“This campaign was important because I believe that more people are now aware of bowel cancer, the risks and the benefits of early diagnosis. The increase screening uptake will help in early intervention which could be beneficial to both the participants and the National Health Service in the U.K.” (Project Volunteer, Female).*

At the time of writing this report, data about the people who ultimately took the test was not available. This was mainly due to Covid-19, and non-availability of data since the evaluation was done during the UK lockdown between March and May 2020. Acknowledging the challenge of not getting latest uptake data from the GPs and CCG to validate the work of CAN, we recommend that this be considered for future projects.

*NB No other data were available from NHS regarding bowel cancer uptake due to the Covid-19 situation.*

### Case story: Personal experience of a volunteer in the project

I worked with CAN as a volunteer on the bowel cancer screening project within the black community in Hackney. What motivated me to volunteer in this project was the idea of giving back to the community by providing information that could be useful in early interventions of bowel cancer therefore saving lives.

The training materials and the information provided were straightforward and useful in carrying out the task. I mostly worked with GP surgeries in Hackney area particularly Healy, Latimer and Athena G.P. surgeries. My day involved calling over 60 year old patients and discuss with them about the bowel cancer screening program, including risks and benefits of participating in the screening program.

Some of the patients were hesitant about participating in the screening and I encouraged them by listening to their concerns and assuring them. I also explained to them the easy ways to collect the samples. I urged some of the patients who could not read the sample collection instruction to visit their G.P surgeries and request a nurse to assist them with sample collection. I made follow up calls to ensure that patients had returned their screening kits. I had a personal target of 30 calls per day, but I mostly made between 35 and 45 calls every day.

I looked forward to my volunteer days which were Tuesdays and Thursdays between 3pm and 6pm. I enjoyed talking to patients and the joys that I felt in some of the patient's voices. It was very fulfilling to encourage the patients as most of them were happy to have received my call. The most exciting moments were when I got feedback from the G.P surgeries that the screening uptake was improving and that more patients were requesting for the bowel screening kits.

Majority of the patients did not send back their screening kits because they did not understand the importance of the screening. The reason being that the screening kits are sent through post with written information that was too long and therefore people could not be bothered to read it. In addition, some patients expressed cultural and religious reasons as to why they did not wish to participate in the bowel cancer screening program.

The most challenging part of the process was getting up to date patient information. Several phone numbers were not going through and some of the patients had moved from the listed residence. There was also the challenge of missing information and contact details.

What I learnt from this experience was that some people just need a little education and explanation on why they need regular health screening. I also learnt that religion and beliefs greatly influence people's decisions and views on modern medicine. This experience enabled me to be a better listener and I strengthened my patience and tolerance.

## 6. Sustainability

This study examined the extent to which Bowel Cancer Screening Project promoted activities that are sustainable over time. Although the project has produced results, the question of sustainability remains a challenge.

### Prospects of sustainability after the project has ended

In general, Bowel Cancer Screening Project placed a strong emphasis on raising awareness and improving knowledge about bowel cancer at the individual and community level. It can be argued that the knowledge gained by the people who were reached will last longer than the project itself. This was also true for the volunteers who were trained and had their knowledge enhanced, pledging that they will continue spreading the message to their families, friends and other contacts.

One of the key strengths of this project was that it was implemented through a network of community organisations, most of who felt that they have had their capacity enhanced and that as they continue implementing their other work, they will maintain a role in passing on bowel cancer screening messages - even after the project has ended.

Besides community knowledge and capacities built, this project was not delivered in isolation. Rather, there was a strong emphasis on working in close collaboration with GPs, who also appreciated their role in continuing the bowel cancer screening programme as an integral part of their work.

As a network of organisations, CAN members expressed their willingness and commitment to continue searching for funding from CCG and other sources. Although there were no promises of project continuation at the time of this evaluation, the trustees and staff of CAN stressed that they had already begun work on developing project proposals to secure more funding.

### Challenges to sustainability

Despite the prospects of sustainability highlighted above, nearly all the participants in this evaluation expressed deep concerns about the end of this project without assurance of further funding. The work of the volunteers had already stopped by the end of the project and the part time project staff working on the project were in their final reporting stage. Key concerns relating to sustainability that were raised are captured below:

The CAN Bowel Cancer Project was implemented for a short space of time. Appreciating the benefits of a long term investment in a project, it is less likely that one year would have been sufficient to build stronger prospects of sustainability of a project over time. Most people were concerned that the project will ultimately lose the momentum that it had gained if it stops at this point.

*“It is sad to see something like this project come to an end this soon. Based on my knowledge of the work and the community, there is definitely a need for ongoing education for the general community as there is limited knowledge” (Project volunteer, Female)*

*“It is a real challenge to think that the funding has stopped. So, how can we retain that energy which has been building? (Representative, Community African Network)*

*Sustainability is a problem .... That is one of the trickiest issues for this project. There is severe frustration that community groups receive funds and do good work, but then the funding stops. There is a sense of people saying we could do something more. (Key informant, Statutory sector)*

NHS City and Hackney CCG is made up of 42 GP practices which are grouped into six consortia groups.<sup>9</sup> However, this project was implemented in only five GP practices, which is just about 12 percent of the total. Notably, demand for similar services is still very high across the borough. One representative of GP practices that were interviewed felt that more GP services need to be engaged.

*“A surprising thing is that we have 42 practises in City and Hackney – yet only five GP practices were involved. Was that due to the budget? I hope there is more funding for this type of work in the near future” (GP Practice representative, City & Hackney)*

*“It is very bad news that the project has come to an end. We were hoping that it could be made to reach out to other GP practices that have not been involved and even more that it would have been extended to also address other forms of cancers as well” (Representative, Community African Network)*

---

<sup>9</sup> NHS City and Hackney CCG. “Member GP Practices” Accessed on 29 May 2020 and available at <http://www.cityandhackneyccg.nhs.uk/about-us/member-gp-practices.htm>

## 7. Project strengths, challenges and lessons

The evaluators assessed the main factors affecting the delivery of the project and identified several factors that either supported or could have hindered the achievements of the project. Overall, the design of Bowel Cancer Screening Project was deemed suitable and appropriate for the set targets and short-term outcomes. Below were some of the main strengths and challenges of the project.

### Enabling factors and facilitators

1. **The project recruited a strong team of community volunteers / champions:** the critical role played by the volunteers was demonstrated through the achievements recorded in this report. The project would not have been any successful without the zeal and commitment shown during outreach activities, often on the streets and in market places. Most OF THE outreach volunteers were survivors of cancer themselves and over 60- passion of the subject The recruitment of professional volunteers studying at the London School of Hygiene and Tropical Medicine also brought a remarkable slant to the project, especially by further enhancing the project's engagement work with GPs.

*"It was a good experience. I felt kind of needed and helpful. I enjoyed working with the GP Practices. It was nice to speak to people on the phone" (CAN Project Volunteer)*

*"The engagement of community volunteers in reaching out to people who are least accessing services can be a useful model that works. It is good for communities" (key informant, Partners)*

2. **The staff engaged in the project were committed and supportive:** A part time Project Coordinator was appointed to coordinate the project and be the main contact point in providing training for the volunteers and support to the GPs. There were very many positive comments that were mentioned about the Project Coordinator during this evaluation. He was also supported by a supportive team of board members. Volunteers and members of the steering committee were extremely grateful for the high level of professionalism and support offered. From the evaluator's perspective and observations, such compliments were genuine and evidenced throughout the delivery of the project.

*"We had an amazing Project Coordinator, even though he was only a part time worker. I was impressed by the way when a problem came up, he would immediately work. Understanding the work of the volunteers" (Key informant, CAN Member staff)*

3. **The project was supported by an active steering group that met regularly:** The overall service delivery for this project was overseen by a Steering Group, composed of CAN members as well as representatives from the funders and statutory sector. At least four meetings were held to ensure that high quality standards were maintained and key performance indicators achieved.

*"We had a very good partnership that was well supported through an active steering group. As we met regularly, we received all the information about the project on time and there was maximum participation by CAN Members and our partners, including the funders" (Key informant, CAN member).*

4. **The project was implemented by a strong network of community organisations:** The delivery partner for this project, CAN, was made up of eleven agencies working to improve health and wellness amongst their communities. These organisations provided volunteers, participated in steering group meetings and most importantly, invited their members to events, such as workshops. It is recommended that funders should consider networks such as CAN as they are well placed to promote higher screening outcomes in the targeted areas. They also present opportunities to cascade the information to their own organisations.
5. **Great support from GP surgeries who accepted to take part in the project:** All the five participating GPs cooperated with the project and willingly provided contact details for patients that were on record as not having sent back their screening kits to their GPs in the three months preceding the calls. CAN volunteers, with very close support from the Project Coordinator, made use of the telephone scripts that they were provided with to follow up on these patients. All actions were recorded using the project's monitoring forms with anonymised data returns submitted to the Project Coordinator soon after the call screening session.

*"I am glad to say that GP workers were very helpful, despite having very busy schedules" (CAN Project volunteer)*

6. **The replacement of gFOBT to FIT as the primary screening testing instrument:** The original guaiac Faecal Occult Blood test (gFOBT) was replaced by the Faecal Immunochemical Test (FIT) as the primary screening test in England, Scotland and Wales, and will be introduced in Northern Ireland in 2020. The FIT test is reported to be easier to complete as it only requires one stool sample rather than the two samples from three separate stools required for guaiac. Key informants involved in this evaluation felt that this could have contributed to greater uptake of these service.

### Barriers and challenges faced

Notwithstanding the remarkable progress made by Bowel Cancer Screening Project, several challenges were noted in this project:

1. **Slow project startup of the project and implementation breaks:** Due to delays in GP acceptance, the project faced delays of nearly three months. Therefore, instead of starting in May 2019, most activities 2019, especially with GPs only started in September 2019. In addition, there were some major implementation breaks, particularly in December during the Christmas season and in March with the unprecedented emergence of the coronavirus pandemic.
2. **The duration of the project was too short for impact:** Although this project was built on the successes and lessons from a previous project, this intervention was for only one year. Due to a delayed inception and then lockdowns due to Covid-19, the amount of time for the project was eventually reduced to approximately nine months. Every second individual interviewed during this evaluation agreed that the potential impact and prospect of sustainability will be affected by the short duration of the project, especially in the absence of further funding.
3. **There was a lot of paper work involved in data reporting:** A few volunteers and project staff acknowledged that whilst the project was well equipped with all essential data collection and reporting templates, there was a lot of manual reporting that was taking place. The use of online platforms for

reporting could be considered in the future.

4. **Poor response and acceptance of bowel cancer screening at individual and community level(rephrase so as not to contradict our success as if project was a failure to may be use socio-cultural/religious beliefs or lack of awareness or denial):** Several evaluation respondents highlighted challenges related to lack of knowledge, negative attitudes, as well as, socio-cultural reasons that resulted in people in unwilling to participate in the programme. During outreach sessions, many people expressed that they found the subject of bowel cancer screening embarrassing and not culturally acceptable. While some people had misconceptions about bowel cancer, others did not feel it was relevant to them and to some, it was considered an unfriendly topic- with some even scared of the results if they were to reveal they had bowel cancer.

*“Uptake of services is affected by socio-cultural and religious issues that do not actively promote health seeking behaviours, including early testing practices. Our people wait until they are ill to consider testing and screening” (Staff, CAN member representative)*

5. **Lack of available patient data from GP practices:** As shown in this report, just above half of the calls that were made, i.e. 53%, were either unreachable or not picked up. In some instances, contact numbers had changed which would require for GP practices to work hard to ensure that they have up-to-date data for their clients. Present data also indicated that nearly one in five persons that were called, i.e. 17%(50 of 301), had already returned their kits by the time these follow up calls were being made.
6. **The emergence of Covid-19 towards the end of the project made affected a number of aspects toward the end of the project.** This included: volunteer engagement with patients through GP surgeries ceased by end of February 2020; collecting uptake data from participating GP surgeries was a huge challenge due to lockdown from March; cancellation of steering group meetings; and the end of the project evaluation was delayed because of coronavirus.

## Lessons learnt

This section outlines key lessons learnt from the implementation of Bowel Cancer Screening Project. Key lessons were based on what worked and what did not in the implementation of the project.

1. Volunteers / champions are a key source of provision in the community and their role must be acknowledged. During this project, volunteers made immense contributions towards raising community awareness on bowel cancer screening and in particular, reaching out to people that would be hardly reached through mainstream interventions. Besides being cost efficient as a resource, volunteers are also committed to working hard.
2. Understanding barriers to participation in bowel cancer screening programmes and identifying potential solutions to overcome these barriers are key to reducing inequalities across the bowel screening programmes.
3. Local community organisations and networks, such as CAN, offer great opportunities to the statutory sector to fill the gaps which most agencies would struggle to reach. These ‘smaller agencies’ are a stimulus for social action, and have the ability to inspire local people to take initial steps and become active in responding to needs in their communities. It is therefore useful to consider investing more

resources in these agencies and help them to improve their undertakings as well as inspiring them to scale up their work. The success obtained by engaging CAN showcases the potential benefits and opportunity of engaging agencies that would complement statutory services, given the flexibility offered by community groups to meet specific needs of the groups that they serve.

4. Bowel cancers screening services would achieve greater impact if sufficient resources, both time and money, are invested into commissioned projects. This project has demonstrated great potential. Nonetheless, limiting it to just one year makes it very difficult to determine both the long term impact and sustainability of the project.
5. Telephone engagement through GP practices with individuals who have received but not returned colorectal screening kits is an effective method to improve uptake. Practices should follow-up these patients and offer advice and further information about the importance of their participation in the bowel cancer screening programme. Follow-up must be carried out by appropriately trained members of staff or volunteers.
6. A multi-stakeholder approach increases the prospects of project acceptability, efficiency, effectiveness and sustainability. CAN has demonstrated the immense benefits of working with a number of community organisations and the statutory sector, in a bid to achieve impact toward a particular cause. Besides the benefits of various connections with different black and minority ethnic groups brought about by CAN, the ability to work closely with GP surgeries further endorsed and gave more credence to the work of these organisations. It is therefore more likely that such partnerships results in a considerably positive impact on bowel cancer screening levels and detection rates.

## 8. Conclusion and recommendations

### Summary of findings

This evaluation concludes that the CAN Bowel Cancer Screening Project has made positive strides towards improving earlier diagnosis of colorectal cancer in the City and Hackney by increasing uptake of colorectal cancer screening among Black ethnic groups, with a focus on men. This has been mainly achieved through targeting at least 1,465 people from Black African and Caribbean communities across City and Hackney through outreach events, workshops and GP patient engagements.

In terms of its planned outputs and outcomes, this project can be described as having been successful in achieving its objectives. Such positive results generate a firm basis for continuous funding and support for community project efforts, such as through CAN, to further pursue non-responders and raise awareness with targeted communities on the importance of bowel cancer screening.

Having several trained and available volunteers available for work was an added advantage to the project. This evaluation shows that building volunteer capacity, through training and ongoing support, is one of the most effective strategies to deliver low cost interventions through a handful of volunteers. Most people at community level tend to positively identify with volunteers from their own communities, who often speak their language, and understand the challenges they face.

The CAN bowel cancer screening project demonstrates the need to enhance community interest and motivation in addressing local and national challenges through projects such as this. Most evaluation participants that we spoke to during this evaluation reported that the project was of benefit to all the people who were involved in it. Besides benefitting the community at large, the project positively contributed towards the organisation's own individual and corporate priorities. The community interest is still present and funders ought to consider this approach further.

Despite their busy schedules, participating GPs have shown increasing interest in reaching out and following up to non-responders. Getting the full involvement of GP surgeries in bowel cancer screening is likely to result in greater ownership of the intervention and ultimately result in positive health outcomes at local level and across the nation.

Evaluation findings suggest combining strategies such as volunteer engagement, community outreach; and, GP partnership/follow up screening calls could effectively increase the uptake of bowel cancer screening initiatives. Being a one-year project, it is too early to ascertain the long term impact of the project. However, results from this evaluation indicate the project's positive influence on intentions toward screening and an increase in the number of people aged 60 and above taking up bowel cancer activities.

## Recommendations

- 1) The amount of time allocated to a project has a strong association on the achievement and sustainability of the results. Future projects ought to increase the period in which the project is implemented, possibly to a minimum of three years for a project. It is only when they are longer term that the impact is assessed and likewise the prospects of sustainability.
- 2) The problem of lack of bowel cancer screening information could be addressed by simplifying the explanation attached to the screening kit with diagrams that are easy to visualise. Initial calls could also be made to the patients right before the kits are sent out to their homes. This could alert and offer them opportunities to ask questions. It could also help them commit to sending back the samples.
- 3) To ensure timely replacement of screening kits, volunteers could forward the list of patients who need replacement kits directly to the screening centre at the end of a call day. At the beginning of the next phase of the project, phone records could be updated and sorted out based on ethnicity.
- 4) The issue of religious and social beliefs could be addressed by working with religious and community leaders so that they could reach out to these patients. Attempts were made to do this in the project but it was not regarded as a primary task for this work.
- 5) CAN to continue supporting its volunteers (new and existing) with capacity to work in local communities on similar projects. The evaluation has particularly commended the project for its ability to recruit professional volunteers at the London School of Hygiene and Tropical Medicine.
- 6) For future programmes, the use of other creative media should be considered, such as digital and social media, for delivering critical messages about bowel cancer screening. Taking advantage of the ever changing technological environment increases the scope to reach a wide range of people in a more cost-effective and efficient manner through these media. The project would also benefit in making use of existing links, such as demonstration videos and other prompts for messaging purposes.
- 7) Consider collecting and collating project monitoring and evaluation data using data collection tablets and other online platforms, such as *KoboToolbox*. This is likely to reduce costs on paper and double work in data entry, as well as, avoid mistakes and missing data in the future.
- 8) For capacity building purposes, future programmes could consider more capacity building and facilitation for CAN members to access resources and host trainings and workshops for their own communities. This is a model that was preferred by other CAN members, rather than to always invite participants to central workshop place.
- 9) GPs that are encouraged to ensure that they continue carrying out bowel cancer screening calls and follow up activities within their existing routine basis. In addition, they ought to ensure that GP practice records are updated and kept in secure electronic patient records. We also encourage that specific training on bowel cancer screening should also be made for GP staff, some of whom may not have learnt about the process at all.
- 10) Agencies such as the Community African Network are encouraged to diversify funding sources in order to continue providing longer term support for Bowel Cancer Screening Project activities.
- 11) There is a clear demand, need and scope for funders to invest more resources into projects such as those implemented by the Community African Network. Funding agents such as the CCG and others are encouraged to reserve essential funding opportunities for small community groups and networks.

## 9. List of appendices

### Annex 1: List of references

- 1) Basch C, Wolf R.L., Brouse C.H, Shmukler C, Neugut A, DeCarlo L.T, et al. Telephone Outreach to Increase Colorectal Cancer Screening in an Urban Minority Population. *American Journal of Public Health*. 96 (12) 2246-2253 (2006).
- 2) Koo S, Neilson LJ, Von Wagner C, Rees CJ. The NHS Bowel Cancer Screening Program: current perspectives on strategies for improvement. *Risk Manag Healthc Policy*. 2017;10:177 - 187. Published 2017 Dec 4. doi:10.2147/RMHP.S109116
- 3) National Cancer Intelligence Network, "Cancer and equality groups: key metrics 2015," [Online]. Available: <http://www.ncin.org.uk/view?rid=2991>. [Accessed May 2018].
- 4) NHS City and Hackney Clinical Commissioning Group. Available at: <http://www.cityandhackneyccg.nhs.uk/>
- 5) NHS City and Hackney CCG. "Member GP Practices" Accessed on 29 May 2020 and available at <http://www.cityandhackneyccg.nhs.uk/about-us/member-gp-practices.htm>
- 6) Taskila T, Wilson S, Damery S et al. Factors affecting attitudes toward colorectal cancer screening in the primary care population. *Br J Cancer*. 2009;21;101(2):250-5.
- 7) Yanovitzky I, Blitz CL: Effect of media coverage and physician advice on utilization of breast cancer screening by women 40 years and older. *Journal of health communication*. 2000, 5: 117-134.
- 8) WHO (2018), Cancer Key Facts. Available at: <https://www.who.int/news-room/fact-sheets/detail/cancer>. Accessed 02 June 2020.
- 9) Weller, DP and Campbell C. Uptake in cancer screening programmes: a priority in cancer control. *Br J Cancer*. 2009;101(Suppl 2):S55–S59.

## Annex 2: Case studies (compiled by a volunteer)

### Case study 1: Challenges brought about by religious beliefs

One of the female patients in her 60's informed the volunteer that her faith was sufficient to keep her healthy. At first the patient did not want to listen to any information about bowel cancer. The volunteer asked her for a few minutes and explained to her everything she needed to know about the symptoms of bowel cancer, the at-risk groups and the benefits of the screening and early detection. The volunteer asked her whether she had any questions which she did have, and the volunteer addressed them. The volunteer explained to the patient that one could be religious and still participate in modern medicine. The volunteer gave the patient an example that she wouldn't decide to stay at home and not work to earn a living because of the belief that God is the provider.

The volunteer encouraged the patient by explaining to her that taking care of one's body by having health check-ups would not interfere with one's faith. The volunteer urged the patient to rethink her decision and told her that she was free to participate in the future if she needed more time to think about it. Even though the patient still opted out of the screening program, the volunteer and the patient ended up having a great conversation and the patient could probably opt back into the screening program in the future.

### Case study 2: The story of an unsatisfied patient

When asked why she had not returned her screening kit, one of the patients informed the volunteer that it was because one of the nurses at the G.P practice had been rude to her. The patient sounded upset and requested to opt out of the screening program. The volunteer managed to calm her down by asking her to relax. The volunteer then assured the patient that she would listen to her explanation on what had transpired during her last G.P visit. After listening to her, the volunteer clearly informed the patient that she was not in a position to intervene in her case. However, she told her that she would forward her case/complain to the person in charge.

The volunteer apologised on behalf of the G.P surgery for the unfortunate incident. The volunteer urged the patient to participate in the screening and explained to her that it was for her own benefit. She eventually agreed to participate and requested for a screening kit replacement. After the call, the volunteer informed the manager of the patients complain. The volunteer was later informed that the matter was resolved and that the patient returned her screening kit.