



**WE ARE  
MACMILLAN.  
CANCER SUPPORT**

ADVICE



2016

# BEATING CANCER

Early detection of cancer

## **Community Links**

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Canning Town  
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Working in partnership with  
Macmillan Cancer to  
promote early detection

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MACMILLAN.  
CANCER SUPPORT**

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## Foreword

This report documents the Cancer Early Detection work that Community Links has carried out during 2014-16. You will read how we have sought to share life-saving messages in settings from primary schools to pensioners clubs, from busy shopping centres to small local pharmacies. We have developed a range of strategies to reach people who are not receiving mainstream health messages. This work is vital, for one in two people now get cancer during their lives, if we are to survive this we must catch it early, therefore, we must know the main symptoms, we must self-check, we must attend screening and we must go to a GP if we have any concerns. This report details how we have gone about sharing these life-saving messages.

Fifteen years ago I detected breast cancer in the early stages, I was treated and I have been well since then. This can be a much more common story if we embed these cancer messages into our everyday lives, into our schooling and into our care for one another. You will read here, how we have gone about that task.

*Frances Clarke*

### **Frances Clarke**

*Health Projects Manager*

Macmillan Cancer Support recognises early diagnosis as one of the 9 issues that matter most to cancer patients in the UK today, aiming to ensure that all people affected by cancer will be able to say 'I was diagnosed early' by 2030.

East London in particular faces lower cancer survival rates when compared to the national average, likely owing to the late diagnosis of patient's cancer. This can be attributed in part to the public's low awareness of cancer symptoms and delays in presenting to their GPs, and for this reason, Community Links with its long history of projects aimed at addressing low awareness of cancer symptoms in local residents was seen as an ideal partner for Macmillan to work with. Investment was provided to fund a project aimed at running a number of interventions to target those most at risk, by raising awareness amongst influential community members and training local volunteers to act as early detection advocates to name but a few.

With cuts in NHS spending towards local cancer awareness initiatives like this, it is more important than ever for health and social care leaders- with support from voluntary sector organisations like Macmillan & Community Links - to take a shared approach to the early diagnosis agenda. A special thanks goes to Frances Clarke, without whom this work would not be possible.

### **Daniel Callanan**

*Macmillan Quality Lead, North East London*

# Main Recommendations

## Act early

Early Action is vital. One in two people get cancer; treating breast, lung and bowel cancer costs the NHS £4.5 billion a year, with a much greater emotional cost. Yet if caught early survival rates can be as high as 9 out of 10. The Early Action Taskforce showcased Community Links' Detecting Cancer Early programmes, pointing to their contribution to saving human and financial costs as well as developing resilient individuals and thriving communities. Maximising the impact of the project and its cost effectiveness with the involvement of volunteers, students, cancer survivors and health champions requires a core resource, without which it is unsustainable.

**Recommendation 1; each of the four east London local authorities and CCGs should recognise the value of early action and fund a cancer early diagnosis project, enabling a cost effective, joined up and preventative approach. Convene Early Detection Groups**

## Convene Early Detection Groups

The Newham Cancer Early Detection Group, convened by the lead councillor for health promotion and comprising of a cross-sector partnership between Newham Council, Macmillan, Cancer Research UK, Newham CCG and the NHS, was highly effective. The involvement of council officers from a range of departments enabled creative solutions to be developed and implemented within current services and early diagnosis information to be shared across a range of programmes. Council involvement also enabled a range of extensive media channels to be used to share the early detection messages widely.

**Recommendation 2; CCGs and Councils in other areas should establish Cancer Early Detection Group groups and CCGs and Councils in east London should consider establishing a joint east London Cancer Early Detection Group. Designate Lead Councillor Role**

## Designate Lead Councillor Role

The Mayor of Newham appointed a lead councillor to promote the early detection of cancer in the Borough, with an initial focus on increasing the take-up of bowel screening.

**Recommendation 3; Local authorities should identify a lead councillor role with responsibility for the promotion of early diagnosis of cancer, as Newham have done. Create new local neighbourhood partnerships**

## Create new local neighbourhood partnerships

Exploring and developing new partnerships in different sectors was very important, particularly when embedded in local neighbourhoods and offering the opportunity to communicate effectively and directly to local people. This is especially important in deprived areas. Our project utilised innovative methods of information transmission, for example children and young people have been proven to be very effective conduits of information to their families. Schools and sixth forms have been open to this engagement. This channel is not currently being systematically utilised by the NHS, and there is no long-term engagement strategy.

**Recommendation 4; Engagement with schools should be included in the new Sustainability and Transformation Plans.**

**Recommendation 5; Department of Education should include early detection of cancer in the CPSHE National Curriculum.**

Pharmacies also proved willing to engage in promoting early diagnosis, even without financial incentives, and they too enabled the targeting of local areas and deprived communities.

**Recommendation 6; Public Health England should deliver regular and focussed cancer screening promotion campaigns within pharmacies in areas of low take up.**

## Other recommendations

### Identify teachable moments and making every contact count

We have sought to think creatively about those moments when people may be more open to receiving early detection information. There are a huge range of opportunities from being in the queue to see a teacher at parent's evening, to receiving the all clear after diagnostic tests. This builds upon the 'make every contact count' approach but it is a call to consider the possibility of increased impact in particular settings and beyond medical professionals.

**Recommendation 7; Commissioners and service deliverers should seek to identify teachable moments in diagnostic and treatment pathways and in broader interactions with service users.**

Similarly, we have sought to identify moments when people in deprived areas can be reached and brought into the cancer national screening programmes. This is particularly important as evidence suggests that once a person has taken part in one screening they are likely to continue to take part in future years, and they are more likely to take part in the other programmes. We have adopted a locally targeted model, but action could also be carried out at a regional level.

**Recommendation 8; The London Mayor should require Transport for London to make a link between the claiming of the 60+ oyster card and the completion of the first bowel test kit that people will receive at 60.**

### Diverse teams

We found that mainstream health messages were not reaching our diverse communities, therefore making it important to involve a diverse range of people to deliver the cancer screening messages in a wide range of culturally appropriate settings. We found that information is best received when delivered by people who look and sound like us. There are many opportunities to increase diversity, particularly if volunteering is seen in a broad way; volunteers can be students in need of relevant work experience, they can be sixth formers sharing messages with family and friends, they can be cancer survivors sharing experience and knowledge, they can be carers and they can be local leaders.

**Recommendation 9; Commissioners and service deliverers should develop diverse teams and ensure that staff represent the communities with which they wish to engage.**

### Evaluation

We used variations of the Cancer Awareness Measure to evaluate the impact of our work and we created our own monitoring form to collect demographic and qualitative information, as you will see in this report.

**Recommendation 10; to commissioners: Establish a standard evaluation process and a consensus on the outcomes to be sought and on the methods of measurement.**

## Context and Issues

The problem we are addressing in this programme of activities is the late diagnosis of cancer which results from late presentation. We have focussed on those factors that contribute to late presentation: low public awareness, negative beliefs about cancer, later presentation to a GP, low uptake of screening leading to late/emergency presentation to GP and hospital services. Late presentation of cancer in Newham is evidenced by low survival rates. Newham has the worst one-year survival rate for cancer in England (ONS, 2013).

The programme we have developed is needed because Newham is a socio-economically deprived area: 25th from bottom in deprivation rankings (Department for Communities and Local Government, 2015), it is highly ethnically diverse: 83.3% of the population are from BME (Black and ethnic minority) groups (Office for National Statistics, 2011). Furthermore, the population is transient and experiences a high degree of population churn: 2007:12,000 people moved here from outside the UK; with an average stay of 14 months (Mayhew, 2009).

These factors combine to present particular challenges to healthcare and to screening programmes. This is illustrated by the low take-up of bowel screening: 38% of Newham people aged 60-74 had been screened for bowel cancer during the 30-month period prior to March 2015, compared to 48% for London and 57% for England (Public Health England, 2015).

In addition to these overall figures, some ethnic groups, particularly Asians, have lower than average take-up as evidenced in a pilot study of bowel screening (Szczepura, et al. 2003).

Our response to these particular challenges has been to seek to address the specific issues which deter local people from detecting cancer in the early stages. The issues we have focussed on include lack of awareness of the signs and symptoms of the main cancers (breast, lung and bowel), reluctance or lack of awareness of the value of participating in the national screening programmes, low levels of breast self-examination and reluctance or lack of awareness of the need to see a GP quickly with any concerns.

We are concerned that national awareness campaigns do not reach all communities equally. We need a programme of activity that communicates messages more effectively and directly to local people in order to overcome barriers. As Community Links has been rooted in the community for almost 40 years, we have the experience and skills needed to develop a range of appropriate strategies. In some cases we have sought out the target groups and approached them directly, in others we have delivered information through intermediaries such as local leaders, local professionals, carers, medical students and younger family members.

We describe a three pronged approach: firstly, working through schools and colleges, secondly working with health and social care partners, and thirdly reaching target groups in community settings.

**NEWHAM HAS  
THE WORST  
ONE-YEAR  
SURVIVAL RATE  
FOR CANCER IN  
ENGLAND**

# 1. Schools Programme

Firstly, we have focussed on involving younger family members to reach our target groups. Through these cross generational approaches we simultaneously give children and young people health information that will be valuable to them whilst also seeking to reach their adult family members. We carried out an education programme within a range of local primary schools, secondary schools and sixth forms. The interventions varied in each setting.

Schools offer a captive audience; helpful not only in relation to the delivery of our health messages but also in monitoring our impact over time. The interventions varied in each setting.

## Primary Schools

We delivered lessons in six local primary schools, focussing on the early diagnosis of lung cancer and the dangers of smoking, including shisha. Community Links' sessional workers, volunteers and trained medical students from Queen Mary's/St Bart's delivered presentations on lung cancer and smoking to year four and year five classes (aged 8-10). The presentations were designed for these young audiences and were highly interactive and engaging. As part of the medical students' programme they created resources to use with the young children that would explain how the lungs work and how smoking damages them, for example, they used balloons with honey inside to illustrate the impact of tar. They also created resources, such as, chatterboxes to communicate information in an interactive and fun way.

The children were extremely receptive, asking insightful questions – particularly if a member of their family was a smoker. Many of the young children already knew what shisha and e-cigarettes were and were intrigued to learn more. Targeting children during primary school and educating them about shisha, e-cigarettes and smoking is critical to their outlook on smoking during their teenage years. This is especially important in east London where shisha is popular amongst teenagers and young adults. We stress the importance of not starting smoking, explaining that people who start at a young age are at an increased risk of lung cancer and are more likely to become life-long smokers. If young people do not smoke by the time they are 19 years, they will probably never start (84% of smokers start by the age of 19.3 years).

We ask the children to share this health information with their families and we provide them with resources to take home.

### Outputs

*28 classes involving 819 children took part in this programme (appendix A).*

## Secondary Schools

In Plashet Secondary School for girls we ran breast cancer awareness lessons for pupils aged between 13 and 16. Lessons were delivered by a diverse team of local women, some of whom had recently attended this school and some of whom were cancer survivors. A range of interactive and face-to-face strategies were used to communicate cancer awareness messages to the girls and through them to their mums.



Chatterboxes were created in primary schools to educate children on how the lungs work and to explain how smoking damages them

**WE DELIVERED  
BREAST CANCER  
AWARENESS  
LESSONS IN 27  
CLASSES AND  
MADE ASSEMBLY  
PRESENTATIONS  
ON LUNG CANCER  
AND SHISHA  
SMOKING**

We encouraged the girls to share these messages with their women relatives. Girls took home resources describing self-examination, breast screening and signs and symptoms to share with their mums. We knew from pupil focus groups that the girls felt that they were often the only people who were likely to share this information with their mothers.

## Outputs

1,229 students took part in this programme (see appendix A). We delivered breast cancer awareness lessons to students in year 10 (aged 14-15) and lung cancer awareness for years 8 (aged 12-13) and 9 (aged 13-14). In total we delivered lessons in 27 classes. We also made assembly presentations on lung cancer and shisha smoking.

## Outcomes

In this school we were able to carry out an analysis of our impact using the Cancer Awareness Measure; this is a detailed survey instrument created by Cancer Research UK and Kings College. We used the Breast Cancer Awareness Measure (B-CAM) and the Lung Cancer Awareness Measure (L-CAM) to assess the impact of this programme on knowledge levels and behaviour.

### Findings from the Breast CAMs in Plashet School

493 students completed the B-CAMs

- ▶ Before the session 5% of students could identify three or more possible signs and symptoms unprompted, this rose to 80% after the session.
- ▶ Before the session 17% of students could identify three or more possible signs and symptoms prompted, this rose to 95% after the session.
- ▶ Before the session over 50% of students were not at all confident that they would recognise possible symptoms this fell to 1% after the session with 83% feeling fairly or very confident.
- ▶ Before the session 72% rarely or never checked their breasts, after the session 64% said they would check at least once a month.
- ▶ Before the session 20% said they would wait a year to contact a GP with any concerns, after the intervention no-one would wait that long and 83.5% said they would go within a week
- ▶ Knowledge of the NHS breast screening programme was low pre-intervention, with just 27% knowing of its existence. Post-intervention this had more than tripled to 97%.
- ▶ Knowledge of the age of the first and last invitation to this screening programme pre-intervention was also low, but following the intervention this had also improved with 83% and 76% respectively identifying the correct age.



### Findings from the Lung CAMs in Plashet School

495 students completed the L-CAMs

- ▶ Before the session none of the students could identify three or more possible signs and symptoms unprompted, this rose to 84% after the session.
- ▶ Before the intervention 37% of students could identify three or more possible signs and symptoms prompted, this rose to 96% after the session.
- ▶ Before the intervention almost half felt not at all confident to recognise possible symptoms, afterwards 93.5% felt fairly or very confident and no-one felt not at all confident
- ▶ Before the session 20% would wait a year or never contact a GP about symptoms and after the intervention 71% would make contact within a week.
- ▶ Before the intervention over 90% recognised that smoking was a risk factor for lung cancer with 69% recognising second hand smoke. After the intervention 100% recognised smoking and 96% recognised second hand smoke as risk factors.

In most cases we administered the CAMs at the end of the lesson but in two classes we instead returned after two months to see if the knowledge had been retained.

## Findings from the Breast CAMs: Returning After Two Months

29 students completed the B-CAMs

- ▶ Before the session none of the students could identify three or more possible signs and symptoms unprompted, after two months 71% could identify three or more.
- ▶ Before the session 34% of students could identify three or more possible signs and symptoms prompted and after two months all could identify three or more.
- ▶ Before the session over half of the students were not confident that they would recognise possible symptoms, after two months 52% were fairly or very confident.
- ▶ Before the session 66% rarely or never checked their breasts, after two months 67% were checking at least monthly.
- ▶ Before the session 41% would have waited at least a year to contact a GP with any concerns, after two months 71% would wait no longer than a week.
- ▶ Knowledge of the NHS breast screening programme was low pre-intervention, with just 38% knowing of its existence, after two months 96% remained aware.
- ▶ Knowledge of the age of first and last invitation to this screening programme pre-intervention was also low, but after two months 63% and 88% respectively could identify the correct age.

## Findings from the Lung CAMs: Returning After Two Months

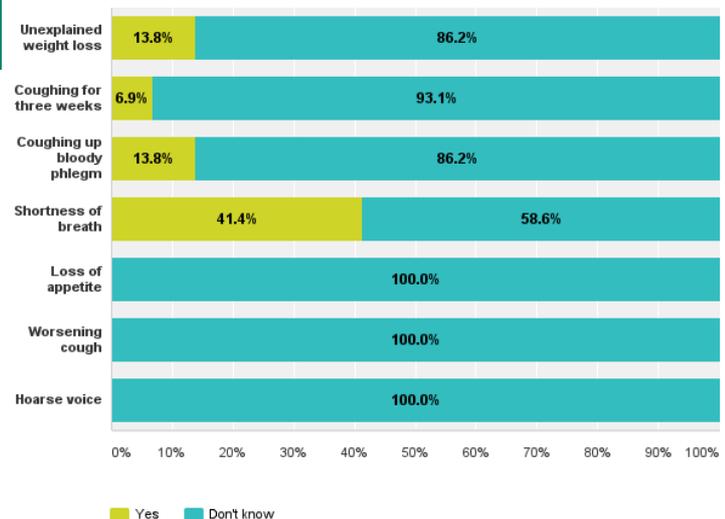
29 students completed the L-CAMs

- ▶ Before the session none of the students could identify three or more possible signs and symptoms unprompted, after two months 78% could identify three or more.
- ▶ Before the session 52% students could identify three or more possible signs and symptoms prompted, after two months 100% could identify three or more.
- ▶ Before the session almost half of the students were not at all confident to recognise possible symptoms, after two months 96.5% felt fairly or very confident.
- ▶ Before the session almost a quarter said they would wait longer than three months to contact a GP with any concerns, after two months 71% said they would visit in less than a week.
- ▶ Before the session 99% students identified smoking and 96% identified passive smoking as risk factors, after two months the levels were 100% and 96% respectively.

**66% OF STUDENTS RARELY OR NEVER CHECKED THEIR BREASTS, HOWEVER TWO MONTHS AFTER THE INTERVENTION 67% WERE CHECKING AT LEAST MONTHLY**

### Q1 Unprompted Symptom Recognition (pre-intervention)

Answered: 29 Skipped: 0



The results from the B-CAMS indicate that the levels of knowledge of signs and symptoms and of the NHS screening programme were maintained after two months. Behaviour change was also sustained, with commitment to regular self-examination and going to a GP quickly with possible symptoms, remaining at high levels. These results are consistent with those that we found in a pilot study (Community Links, 2012), in which the second CAM was completed at the end of the academic year, several months after the intervention. However, confidence to detect possible symptoms has fallen over the two months, from 83% being fairly or very confident at the end of the lesson to 52% after two months. This is a small sample from which we cannot generalise. However, this may indicate that confidence in relation to breast cancer symptoms can decline faster than knowledge or behaviour.

The results for lung cancer are all maintained over the two month period, including confidence to identify possible symptoms. This may indicate that participants feel more confident to detect symptoms that do not involve self-checking. We focus on 'know what is normal for you' in order to normalise and demystify identifying symptoms and to boost confidence. This is particularly important when self-checking and we do encourage women to look for as well as feel for any changes and we stress the value of a mirror in the bathroom. It will be important to ensure that this is effectively covered in future interventions.

## Sixth forms

We ran awareness programmes in St. Angela's, St. Bonaventure's and Newham Sixth Form College. We involved young members of our team to deliver a peer-to-peer approach in an effort to build rapport and make easier the discussions about the effects of smoking including shisha and e-cigarettes. Carbon monoxide monitors were especially effective in drawing attention to the health risks of smoking.

Sixth formers were encouraged to share this health information with their families and to be aware of invitations for cancer screening appointments and the arrival of bowel testing kits for their family members. This was particularly stressed where family members do not read English and may not open their own post.

### Direct involvement of parents and carers

An important complement to this work with children and young people is the direct interaction with parents and carers. We took part in parents' evenings and events in order to speak directly to parents about the programmes that we were running in the schools and to reinforce our cancer messages. We involved pupils in sharing these messages. These are particularly effective settings because the parents have time to take part in discussions, they are captive audiences as they wait to be seen and they are receptive to hearing about the activities that their children are involved in.

#### Outputs:

*303 people participated in this programme (Appendix A2).*

**OUR FINDINGS INDICATE THAT CONFIDENCE IN RELATION TO BREAST CANCER SYMPTOMS CAN DECLINE FASTER THAN KNOWLEDGE OR BEHAVIOUR**

#### Outputs:

*This programme involved 863 sixth formers in six classroom sessions, one lunch-time open-access discussion and one assembly (Appendix A)*



## 2. Cancer Early Detection Group

### Local bowel screening campaign

We focussed on harnessing the involvement of professionals by establishing The Cancer Early Detection Group which was convened by the Lead Councillor for Health Promotion. This brought together council officers from a range of departments: Adult Social Care, Strategic Commissioning and Community, The Language Shop, Public Health and Communications plus staff from Macmillan Cancer, Cancer Research UK, Newham CCG and the NHS to consider and implement a range of interventions to promote the early detection of bowel cancer.

Bowel cancer was identified as a key issue because of the poor survival rates for bowel cancer locally: Newham's bowel cancer one-year survival rate of 69% is the second worst in England (CRUK, 2014). Bowel screening rates were very low with 38% coverage compared to 57% for England. Studies also indicate even lower take-up for Asian groups, particularly Muslims (Public Health England, 2015).

An aim of this programme was to seek to normalise conversations about bowel cancer and bowel cancer screening. Resources were created which would promote the message that bowel cancer could affect anyone and that everyone over 60 should take part in screening, whatever their ethnicity.

Business size cards, postcards, posters and badges promoting and explaining the test kit and providing information about how to order a kit, if necessary, were created. The graphics showed what the kit looks like in order to increase recognition of the test kit when it arrives in the post. The artwork was able to be used in a range of different settings including poster sites and local media.

Articles and adverts appeared in the Newham Magazine which is delivered to 120,000 homes. Articles featured groups whose take-up is particularly low. This partnership sought to address the needs of some of the most vulnerable groups. For example, a proportion of those invited to participate in bowel cancer screening also receive domiciliary care, residential care and other community services, provided through adult social care. An initial presentation was delivered to contracted providers for these services to raise awareness of bowel cancer and bowel cancer screening, in order to enable staff to actively prompt and support individuals to participate in screening. In addition, training was provided for volunteer carers, to also enable them to prompt and support individuals to participate in screening. Training for staff in care agencies and residential homes is ongoing.

Newham Council's Language Shop staff participated in the Cancer Early Detection Group and identified that deaf people were often confronted with barriers in how information is provided and were at a significant disadvantage in relation to taking part in screening. They provided advice and guidance on the resources that were developed and on the resources available to deaf people including the NHS BSL DVD. They facilitated Community Links' provision of training for local Deaf Forums and older deaf people's groups.

**NEWHAM'S BOWEL  
CANCER ONE-YEAR  
SURVIVAL RATE OF  
69% IS THE SECOND  
WORST IN ENGLAND  
(CRUK, 2014)**

In another initiative designed to reach the most vulnerable, Newham Council (LBN) identified isolated older people in their 70s who were living alone, on low incomes. These individuals received a Christmas food hamper. We organised to piggyback on this initiative and to include information in the hampers which explained the importance of taking part in bowel screening and which provided the telephone number to re-order a kit.

### Outputs:

- ▶ 2,900 vulnerable older people received a hamper containing bowel screening information.
- ▶ Five deaf clubs involving 194 people took part in the bowel screening promotion programme.
- ▶ Forty locations for outdoor advertising ('6 sheet' bus shelter adverts) x 6 weeks.
- ▶ Newham Magazine: full-page advert on inside cover, 2 x half-page adverts, double page editorial.
- ▶ Single-page editorial in collaboration with CCG.
- ▶ Internal Communications: featured twice in Ask Grainne, weekly e-newsletter targeting 650 social care professionals; featured twice in the 'Provider Newsletter', a monthly email to all 600 providers of services commissioned by adult social care.
- ▶ CCG Communications: campaign featured twice in the 'Practice Newsletter' distributed to all GPs and Practice Managers.
- ▶ Information on IAG website.
- ▶ Intranet promotion for staff.
- ▶ Poster (JPEG) featured on screens in 3 community neighbourhood centres.
- ▶ Mentions on social media sites including Twitter and Facebook.

**AS A RESULT OF  
OUR PARTNERSHIP  
WORK, THREE  
ADDITIONAL  
QUESTIONS WERE  
INCLUDED IN THE  
HEALTH CHECK  
TEMPLATE**

## Annual health checks

The Cancer Early Detection Group included officers who were responsible for the commissioning of NHS health checks which are offered to those aged 40-74, every 5 years. In July 2015 the London borough of Newham Adults' Commissioning team awarded NHS Health Check contracts to GP providers across the borough.

As a result of our partnership work, three additional questions were included in the Health Check template, questions about whether the patient had taken part in national bowel, breast and cervical screening programmes. If the patient had not taken part in the relevant programmes, they were encouraged to do so and given information about how to request an appointment (breast and cervical) or how to request another test kit (bowel).

This element of the NHS Health check was implemented gradually during 15/16, and was complemented by additional training sessions for Health Care Assistants. The training was delivered in partnership with Community Links to ensure practice staff were fully aware of the importance of cancer screening and confident in signposting residents appropriately.

Completion of these additional prompts is monitored by the Council on a quarterly basis through reports taken from GP data systems (EMIS Web).



**IF FOUND EARLY BOWEL CANCER CAN BE TREATED AND CURED.**

The NHS Bowel Cancer Screening Programme offers free screening every two years to all men and women aged 60 - 74 who are registered with a GP. You will automatically receive a screening kit in the post.

If you're aged 75 or over, or if you've lost yours, then call 0800 707 6060 to request a free bowel cancer screening kit.

For more information visit [www.cancerscreening.nhs.uk](http://www.cancerscreening.nhs.uk)

## Outputs:

- ▶ 11,000 NHS Health checks a year: by including these additional prompts into the national programme we created an opportunity to remind a significant number of residents of the importance of accessing national cancer screening programmes.
- ▶ 75 Health Care Assistants trained in bowel cancer awareness and screening.

## Involving Pharmacies

When considering the challenges that could be involved in completing the bowel testing kit, it was felt to be important that recipients should be able to access support and advice locally. It was identified that pharmacies could meet this need as they are very local, within walking distance of 99% of the population in deprived areas (Todd et al., 2014), have long opening hours, don't require appointments and are familiar to local people. In addition pharmacies did have experience of promoting early detection as they had played an active role for several years in the 'small c' campaign ([www.smallc.org.uk](http://www.smallc.org.uk)). We approached the North East London Local Pharmacy Committee (NELPC) to seek their support.

The NELPC agreed that the bowel screening resources we were creating could include the advice that people could talk to their local pharmacist, as well as their GP, if they needed support in completing the test kit. We discussed the training that we would offer pharmacy staff and the NELPC advised us not to organise formal sessions as staff were too busy. The NELPC advised instead that we make available a training video which they would circulate to pharmacies as part of the introduction to our project.

On the basis of this advice we felt that it would be necessary to be very flexible in our dealings with pharmacies. We decided that the best approach would be to visit pharmacies in order to follow up the email from the NELPC, and we visited 51 pharmacies over the coming months.

In these visits we explained our project, delivered the specifically created resources (posters, cards and badges) and offered training. We knew that external training would be a problem and so we offered training on the spot or at a date convenient to the pharmacy, on their premises.

We asked pharmacy staff to initiate conversations with people who would be eligible for screening. They were asked to check whether the over 60s had received their test kit, to explain how to do the kit and to provide a screening promotion card with information about how to request a screening kit if the person had not received one. Pharmacists were asked to ensure that every prescription bag for a person over 60 would contain a card which explained bowel screening and how to reorder a kit.

Pharmacies were provided with monitoring forms to record the number of people they spoke to and the actions they took. The monitoring forms were collected fortnightly by Community Links staff and more resources were provided if needed. We also provided information in Bengali and Urdu which was requested by several pharmacies.

**WE PROVIDED  
INFORMATION  
IN BENGALI AND  
URDU WHICH  
WAS REQUESTED  
BY SEVERAL  
PHARMACIES**



We did not financially incentivise the involvement of pharmacists in this programme but instead, through our visits, we stressed the health benefits of taking part in screening and offered opportunities for promotion in the local press. For instance, we involved respected local leaders such as Stephen Timms (MP), who had recently received a bowel kit, in local media stories with participating pharmacies.

The strengths of the programme included the availability of resources which were delivered directly to the pharmacies and replaced at regular intervals, training offered on-site at a time of the pharmacy's choosing, development of understanding of the capacity of pharmacies and of supportive relationships between Community Links and the pharmacies.

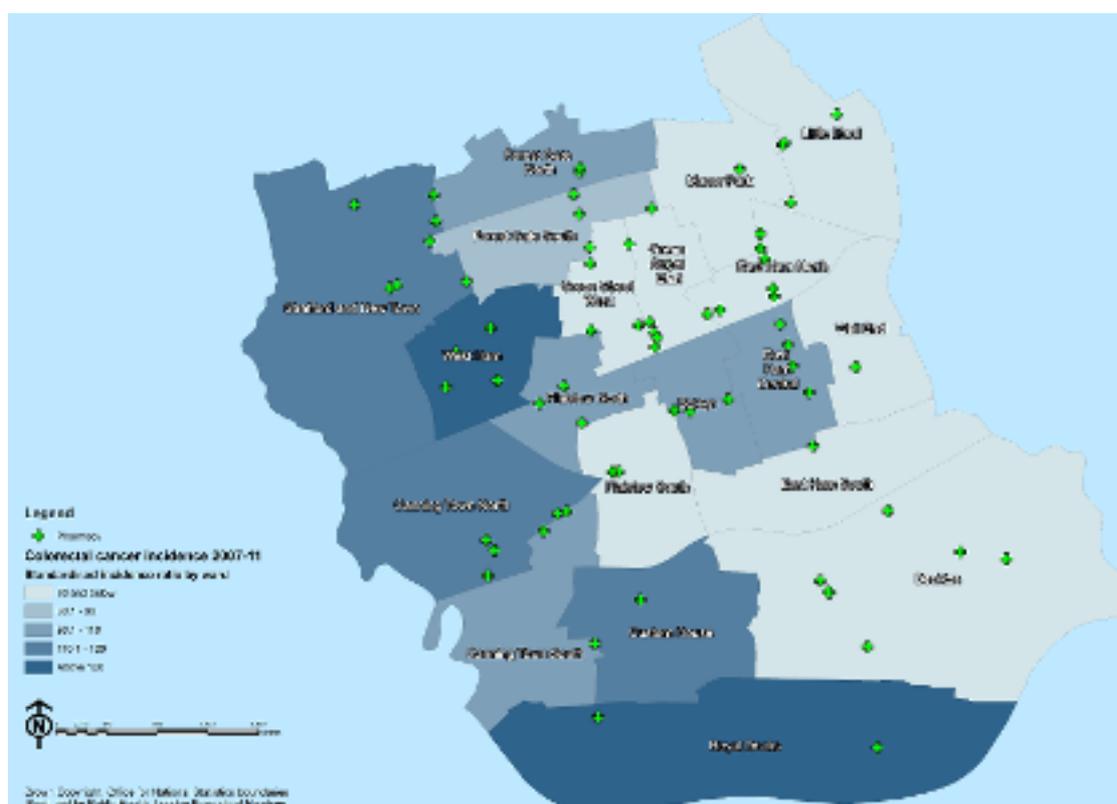
We experienced challenges in being able to speak to the pharmacists, on several occasions locums were present who did not feel able to take the decision to participate in the programme. Also, in some cases, we were aware that information was not cascaded to all counter staff, several of whom worked part-time, and it could take a number of visits to ensure that relevant people were adequately informed.

We also learnt that the resources that were provided to the pharmacists should ideally include a sample bowel testing kit that they could use to help explain the process.

### Outputs:

Community Links visited 51 pharmacies to offer information, resources and/or training for staff, 48 pharmacies agreed to participate. Pharmacists recorded having had discussions with and providing information materials about bowel screening and the signs and symptoms of bowel cancer to 330 people. Several pharmacies reported that they were too busy to complete the monitoring forms although they did initiate discussions with customers. In addition Pharmacists occasionally called The London Bowel Hub on behalf of eligible patients to order a kit for those who had not received it in the post.

See appendix B for list of participating pharmacies and their actions.



This data informed the planning of Community Links' bowel screening promotion programme with Newham pharmacies.  
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## 3. Reaching Target Groups in Community Settings

### Community Groups and events

Because of concern that national awareness campaigns do not reach all communities equally, and because of the challenges of reaching people in our diverse and constantly changing community, we sought to deliver a programme of activity that communicates messages directly to local people. We adopted the approach of going to where people are, rather than expecting them to come to us, as that provided access to large numbers of people.

Community settings offer an ideal opportunity for us to discuss our key messages. We participated in a broad range of events from small groups to large well attended events. At large events our approach is to involve a diverse team of sessional workers and volunteers who mingle with people in queues and busy areas. We use a variety of resources to attract attention to our messages and at the Mayor's Show, which attracts 50,000 people each year, we used the inflatable bowel to draw people in.

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We ran outreach sessions in busy shopping areas, basing ourselves in Boots and Wilkinson's stores. We developed relationships with store and shopping centre managers who also allowed us to engage with people in the busy shopping malls and around the Stratford Tube Station.

Our symptom checker cards, for breast, lung and bowel cancer, are eagerly accepted and they are rarely dropped on the ground. People express their appreciation for these simple cards which carry the knowledge that could one day save the life of the person being spoken to or of someone they care about. These cards can also help to boost confidence and aid communication when they are shown to GPs.

While sharing our health information we also tackle misconceptions, for example, you must complete the bowel kit in one day; cancer always causes a lot of pain; painless symptoms are not concerning; cancer is always caused by additives and chemicals in our diet and people who follow an organic or "natural" diet could never get cancer.

Where appropriate we sought to integrate our training into ongoing group activities. For instance, we offered training within English classes for speakers of other languages (ESOL), thus enabling participants to learn some basic information about signs and symptoms while also practising their English language skills.

We have been pleased by the willingness of community group members to share their experiences of cancer. Those who attended mammograms or completed the bowel kit often had practical tips to share. This peer-to-peer advice seemed to be very motivating and likely to encourage increased take-up amongst group members. For example, a member of the Newham Chinese Association had seen bowel screening promotion cards in pharmacies and this had prompted her to complete the FOB test, having ignored the kit when it arrived in the post. After the test she was called for a colonoscopy, no cancer was found, but some polyps were removed. She explained the testing process to other group members and urged them to complete and return the kit.

We encouraged members of community and faith groups to take responsibility for supporting each other by sharing this cancer awareness.

**1,487 PEOPLE WERE  
REACHED THROUGH  
OUR WORK WITH  
FAITH AND  
COMMUNITY  
CENTRES**



### Outputs:

- ▶ 1,487 people were reached through our work with faith and community centres (see appendix C).
- ▶ 2,430 people were reached through our work at community events (see appendix C2).
- ▶ 3,103 people were reached through our work in shopping centres (see appendix C3).

## Outcomes:

Lung and Breast CAMs were completed in community groups to assess impact on knowledge and behaviour. We completed CAMs with a range of community groups although it was not possible to obtain reliable feedback in some settings. For instance, the CAM could not be effectively used in the Deaf Forums due to the communication barriers. Such groups remain a priority for our interventions and we received feedback that our resources and our approach in the presentations was effective - we provided direct information via the use of interpreters and the presentations included detailed Q&A sessions.



## Findings from Breast CAMs in Community Groups

*88 people completed the B-CAMs*

- ▶ Before the intervention no-one could identify three or more possible signs and symptoms unprompted this rose to 62% after the session.  
Before the intervention 33% could identify three or more possible signs and symptoms prompted, this rose to 96% after the session.
- ▶ Before the session 37% were not at all confident to recognise possible symptoms with very small numbers being fairly or very confident, after the intervention 73% were fairly or very confident.
- ▶ Prior to the intervention 37% reported not checking their breasts at all and 37% reported checking only once every 6 months. After the intervention 63% would check at least once a month and 24% at least weekly.
- ▶ Before the intervention the majority of participants would take longer than a week to contact a GP about a possible symptom, following the intervention 78% would make contact within three days and none would not contact the GP at all.
- ▶ Before the intervention half of the participants knew there was an NHS breast screening programme. Post-intervention all participants were aware.
- ▶ Before the intervention knowledge of the age of first and last invitation to this screening programme was also low, with 61% not knowing. Following the intervention, 100% knew of the programme.

## Findings from the Lung CAMs in Community Groups

*109 people completed the L-CAMs*

- ▶ Before the session 5% of people could identify three or more possible signs and symptoms unprompted, this rose to 99% after the session.
- ▶ Before the session 57% could identify three or more possible signs and symptoms prompted, this rose to 99% after the session.
- ▶ Before the intervention 64% of participants were not at all or not very confident to recognise possible symptoms. After the intervention 92% were either very or fairly confident, with only 7.5% now not very confident.
- ▶ Before the intervention 33% would contact a GP about a possible symptom within three days, after the intervention this rose to 65%.
- ▶ Before the intervention, 78% were aware that smoking, and 78% were aware that passive smoking, would increase the risk of lung cancer. After the intervention this rose to 99% and 98% respectively.

## Involving Hospitals and GP Practices

We identified that local hospitals would be an appropriate location for the sharing of our messages with our target groups. Large numbers of people are involved in waiting in clinics or in visiting their relatives and friends. Clinics, such as hearing aid repairs and outpatient and communal areas, offer opportunities to talk to many people. We engaged with cancer survivors who were keen to know of the symptoms of further cancers and of the details of the cancer screening programmes. We engaged with people visiting relatives and friends who were also keen to receive this information. We became aware that for some people these were teachable moments: moments in their lives when they were very receptive to this potentially life-saving information.

An additional benefit of working in these hospitals was the presence of Macmillan Cancer information and advice services which would enable those people who had follow-up questions to receive ongoing support.

### Outputs:

*We reached 1,047 people within hospitals and GP practices (Appendix D)*

### Training for Local Health Advocates

Because of the challenges of reaching people directly in our diverse community we have sought to train local people who can continue to independently share the health messages: to promote knowledge of signs and symptoms as well as confidence to undertake self-examination and screening and to go to the GP with any concerns. We have trained a variety of groups including Newham Council Health Link Workers, local councillors, medical students (Queen Mary's), public health masters and undergraduate students (UEL); care and residential workers, volunteer carers, sixth form students, health care assistants and nurses.

We also offer these trained local people the opportunity to deliver our health messages in a variety of locations including community centres, general practices, hospitals, faith centres, shopping centres and supermarkets, libraries and pensioners' clubs. In this way we extend our team and we found that having a diverse team is a huge asset, as health messages are more effectively delivered if the person delivering the message has the appropriate sociocultural knowledge and language skills.

### Outputs:

*We have trained 250 people as health advocates over two years (Appendix E)*

**WE ENGAGED  
WITH CANCER  
SURVIVORS WHO  
WERE KEEN TO  
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FURTHER  
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THE DETAILS OF  
THE CANCER  
SCREENING  
PROGRAMMES**



# Long Term Achievements

## Increased knowledge and behaviour change amongst participants

We encouraged behaviour change such as carrying out regular breast self-examination and taking part in screening programmes. We sought to empower people to know their own bodies and be confident when dealing with their GPs. We encouraged people to take increased responsibility for their own health by being aware of possible symptoms and by attending screening. We measured the impact of our interventions on knowledge, skills, confidence and behaviour through the CAMs. We found from the analysis of the CAMs that within schools and community settings participants did demonstrate increased knowledge and did indicate positive behaviour change.

## Resources embedded in the community - trained volunteer health advocates

The outcomes for the many individuals that we worked with include not only increased awareness for themselves but also an increased responsibility for sharing these health messages with those they care about. We found this approach to be particularly effective when talking to young people in sixth form colleges, where we urged them to share the information with their older relatives – parents, grandparents, uncles and aunties. This is a particularly important intervention in households where the older person may not read English and may not open their own post. We have also once again found that health messages are powerful when delivered by peers, this is particularly true when considering lung cancer and smoking.

Those people who were trained as local health advocates have been tasked to continue to share their knowledge, a range of trained local leaders will continue to be a resource for their communities. Medical students involved in the programme will be able to draw on their increased awareness of early detection when they begin to practise. Feedback from the medical students was overwhelmingly positive. The students acknowledged how much they had learnt and are now increasingly aware of the significance of health promotion and its relevance to medicine. Volunteer and professional care workers have been equipped to provide ongoing support in completing the bowel testing kit. And Newham council's contract with care providers now allows staff to accompany people to breast screening appointments under the tasks within the specification.

## Increased knowledge and active concern amongst related local education, health and social care professionals

Through this programme we developed wide-ranging partnerships within the wider health and social care economy. Through the Cancer Early Detection Group we brought together professionals from health and social care to identify and target recipients of Adult Services and other vulnerable groups in order to promote early detection. We designed and delivered initiatives, such as the additional questions in Health Checks and associated training for Health Care Assistants which would not have taken place otherwise and which will continue. LBN intends to continue to monitor the progress of this scheme in 16/17, working closely with GPs, Newham Clinical Commissioning Group (NCCG) and Community Links, to improve uptake of the service and ensure the programme works to improve the health of Newham residents.

Within the pharmacy programme we saw that pharmacists became more aware and knowledgeable about the bowel screening programme and they actively communicated bowel cancer awareness to local people. Awareness was also raised amongst local people that pharmacists can support them in participating in screening; and we tested a partnership approach that encourages us to consider further work. It was clear that many pharmacies valued the opportunity to develop their interactive/supportive role and that even without financial incentivisation they were willing to participate in the programme and in monitoring.

We have developed a programme with a range of resources to use in schools and sixth forms, resources which are adapted for different age groups and settings. Schools and colleges have co-operated enthusiastically in the development and delivery of programmes involving students and their parents. We have found that children and young people can effectively share messages with their family members and that in some cases, particularly where some do not read or speak English, they may be the only people who can.

Schools have also shown appreciation for the additional benefits for their pupils, such as, increased confidence and communication skills and work experience which can be demonstrated in job and university applications.

Community Links adopts an early action approach to tackling society's problems. We believe it is vital to support people to develop the knowledge, skills and confidence to take responsibility for their health and the health of those around them – family, friends and neighbours. In this programme we have evidenced the development of knowledge, skills and confidence in a range of settings including schools, colleges and community groups and with a variety of partners in the fields of education, health and social care. I wish to thank all the participants and colleagues who have helped to make this such a successful programme reaching over 11,000 people (see appendix F).

**WE BELIEVE IT IS VITAL  
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AND THE HEALTH OF  
THOSE AROUND THEM  
– FAMILY, FRIENDS AND  
NEIGHBOURS**

I have been a volunteer with Community Links for six years. I went to school locally and began to volunteer while in the St. Angela's and St. Bonaventure's Sixth Form. During these six years I have worked on a range of cancer awareness programmes, I have shared messages with my peers in sixth form, I have delivered lessons to younger children, I have taken part in outreach events in many community locations, I have worked with mosques and most recently with local pharmacies. After leaving sixth form I began a pharmacy degree at Kings College. I was very enthusiastic to take part in the Community Links bowel screening promotion campaign which involved visiting local pharmacies to deliver a range of resources and offer training to staff. Many of these pharmacies were keen to promote bowel screening which has a very low take-up in this Borough. I shall take this valuable experience with me as I begin to practice as a pharmacist.

**Taariq Miah**

## References

1. Community Links (2012) Beating Cancer at School. Available at: <http://www.community-links.org/our-national-work/publications/beating-cancer-at-schoolworking-with-plasnet-school-on-early-action-to-save/>
2. CRUK (2014) Available at: [http://www.cancerresearchuk.org/cancer-info/cancerstats/local-cancer-statistics/?location-name-1=NHS Newham CCG&location-1=08M](http://www.cancerresearchuk.org/cancer-info/cancerstats/local-cancer-statistics/?location-name-1=NHS%20Newham%20CCG&location-1=08M) Accessed: 22nd August 2016.
3. Department for Communities and Local Government (2015) Available at: <https://www.gov.uk/government/statistics/english-indices-of-deprivation-2015>  
Mayhew, H. (2009) The London Borough of Newham: Counting the confirmed and unconfirmed population.
4. Office for National Statistics (2011) Available at: <http://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/ethnicity/articles/ethnicityandnationalidentityinenglandandwales/2012-12-11>
5. Office for National Statistics ONS, 2014 Available at: <http://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/indexofcancersurvivalforclinicalcommissioninggroupsinengland/adultsdiagnosed19982013andfollowedupto2014#all-cancers-combined-survival-index> Accessed: 22 August 2016
6. Public Health England (2015) Cancer screening coverage –bowel cancer 2.20iii. Available at: <http://www.phoutcomes.info/public-health-outcomes-framework>.
7. Szczepura A, J.M., Orbell S, Gumber A, O'Sullivan I, Clay D & Owen D,, Ethnicity: UK Colorectal Cancer Screening Pilot. 2003: Warwick University.
8. Todd A., Copeland A. and Husband, A. (2014) The Positive Pharmacy Care Law: An Area-Level Analysis of the Relationship Between Community Pharmacy Distribution, Urbanity and Social Deprivation in England, BMJ Open.

# BEATING CANCER

Early detection of cancer



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