

Beating cancer at School

Working with Plashet School on early action to save lives



Acknowledgements

I would like to thank everyone who has contributed to making this project a resounding success; in particular the staff and students of Plashet School who welcomed us in with such enthusiasm and took part with fantastic energy and the Newham public health team who had the faith in us to fund and support this unusual project.

Frances Clarke



Community Links
105 Barking Road
Canning Town
London
E16 4HQ

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Foreword

Save one life, save many lives: one woman's experience.



I am very pleased to introduce the Community Links' Breast Cancer Awareness in Plashet School Report.

It was the aim of this project to save lives through increased awareness and early detection of breast cancer and as you will see when you read the report the project has succeeded in raising awareness and increasing confidence amongst the pupils and their mothers.

In addition we know that the project has saved a life. **My life.**

I am the IT Manager within the school and assisted in the early weeks with the setting up of a breast cancer room on the school intranet. I listened to the main messages of the breast cancer awareness campaign and went home to carry out my first ever breast self-examination, at the age of 47.

I was startled to find that I had a lump in my breast and went quickly to see my doctor who referred me to the hospital for tests. The lump was identified as breast cancer and I was treated during the summer. I was lucky to have caught the cancer early, I had a mastectomy but didn't need to have chemotherapy or radiotherapy as the cancer hadn't had time to spread. I was back at work in the autumn.

This project has saved my life, now find out what else it has done.

Edythe Labinjo, IT Network Manager, Plashet School.

Save one life, save many lives: a community development approach.

I am community development worker and have experienced breast cancer myself. I felt that a community development approach would be ideal to tackle the issue of late detection. I felt that the treatments existed to save women but our knowledge and confidence was lagging behind.

This report is intended not only as an account of how effective the project has been but also includes detail about resources and approaches that we hope will be useful in other communities and help to save more lives.

Frances Clarke, Community Links.

Increasing cancer survival rates in Newham

Cancer survival rates in Newham are amongst the worst in the country. Different factors contribute to this including late presentation, meaning that people with symptoms of cancer leave it very late before seeking help from their GP. This reduces the treatment options available and makes it less likely that people will survive.

We have worked with neighbouring boroughs to develop the “small c” campaign which aims to spread the message that most people survive cancer – if they get treatment early enough.

Newham is the most diverse borough in the country and one of the challenges we face is that universal messages do not reach all our communities equally.

We were therefore very keen to support the Plashet School project to test a different way of sharing health messages within communities. The use of a school setting gave the opportunity to share specific messages between two generations of mums and daughters.

A key to the success of the project was that we allowed key messages to be developed by the participants and gave the girls scope to develop their own skills and knowledge. The project thus built on the enthusiasm of the students and the support of the School staff who allowed the project to cut across the curriculum. This meant that the project developed in directions we couldn't have imagined if we had tried to direct its outputs from the onset – for example in drama, hospital visits and parent evenings.

Once the pilot was launched our role was restricted to largely maintaining an accuracy check on the materials produced by the students – it was key to the overall success that legitimacy of the health messages stemmed from the reputation and authority of the school within its community rather than of more remote health professionals.

As a pilot we were specifically interested in two questions –

- ▶ Could it be done at all?
- ▶ Would it make a difference?

The answer to both seems to be an emphatic “Yes” and I would like to express our thanks to the team at Community Links and all the staff students and parents at Plashet School for working together to produce such an inspiring project.



Tim Baker

Assistant Director of Public Health in Newham

Introduction

Plashet School Breast Cancer Awareness Project

The aim of our project is to increase early detection of breast cancer amongst Asian girls and their mothers and thereby to save lives.

Traditional methods have not succeeded in reaching this group and so we sought to pilot a different approach. The key objectives of our campaign were to encourage Asian girls and women to embed regular self examination as a lifetime habit, to increase awareness of the possible signs and symptoms of breast cancer, to increase confidence to approach a doctor with concerns and to promote the importance of attending breast screening appointments. We sought to reach mothers, with these messages, through their daughters.

We have run similar projects where we have successfully harnessed the unique influence of children, so called “pester power”, to motivate whole families to become involved and change their behaviour. We felt that this approach could be effective in this context.

Inspiration for the project

Community Links was inspired to create this project by King's College and North East London Cancer Network research *“Awareness of breast cancer among women living in inner North East London”*. (July 2010)

The research indicated that Asian women have lower than average:

- ▶ Awareness of symptoms
- ▶ Reported breast checking
- ▶ Confidence to detect breast changes
- ▶ Knowledge of the breast screening programme

The research found that Asian women were more likely to report that they worry about what the doctor might find and that embarrassment and lack of confidence in talking about symptoms may discourage them from seeing the doctor. As a result of these factors early detection amongst Asian women is low.

Link to research:

http://info.cancerresearchuk.org/prod_consump/groups/cr_common/@nre/@hea/documents/generalcontent/cr_052797.pdf

Community Development Approach

A Community Development Approach

...all our work involves enabling people to take more control over their own lives

Community Links promotes community development; we believe that all our work involves enabling people to take more control over their own lives. We seek to build knowledge, skills and confidence which means that, in this setting, individuals can exercise more responsibility for their own health and the health of those around them.

We were aware that the medical treatments available to women with breast cancer had advanced in recent years but that this did not seem to be generally known and that women are not accessing these life saving treatments. Many women still expect breast cancer to be a death sentence involving a mastectomy, chemotherapy and hair loss on the way. We wanted to send out the message that cancer can be successfully treated if caught early and that we don't need to be so frightened of it. These days 9 out of 10 women, with breast cancer, survive if they are diagnosed early.

We chose to approach Plashet School as it is a large girls secondary school with a high proportion of girls from ethnic minorities, particularly from South Asia. The school responded positively to the suggestion, feeling that it would be of great benefit to the girls and their families. The teacher with responsibility for CPSHE and an Assistant Head agreed to partner us on the project. In the School a number of members of staff had experience of breast cancer and one teacher had died as a result several years before.

The school advised that we involve the 540 pupils in years 9 and 10, who would be aged between 13 and 15. 99% of these girls were members of ethnic minorities and 86% were of South Asian origin.



Delivery

The first step was to identify and recruit appropriately skilled volunteers. We prioritised ex-pupils of Plashet School, cancer survivors and those with related knowledge such as medical students and bio-medical scientists. Through our networks and those of the school we quickly built a strong team, most of whom were in their early twenties, were ex-pupils and were of South Asian origin. We also involved a worker at a local cancer support project, CYANA (Cancer You Are Not Alone).

As a team we would go onto create and use a blend of interactive and face-to-face strategies to raise awareness amongst the girls and via the girls to their mums. But, we began the project by assessing the girls' and mums' breast cancer awareness using the Breast Cancer Awareness Measure. This was the same questionnaire used by the NELC Network which had inspired our project.

The nine page questionnaire was completed within each of the 18 classes in Years 9 and 10, during tutor group lessons. This assessment would be repeated after one year in order to provide a measure of the impact of the project. The girls filled-in the questionnaires during tutor period time and then took copies home to their mums to complete. We also attended a parents evening and filled in questionnaires with mums while they waited to see teachers.

We worked on this phase for six weeks, making assembly presentations and visiting classes to remind and cajole the girls into returning their mums' forms. In the end 631 participants (403 girls and 210 women) completed this baseline questionnaire*.

Questionnaires inform classroom lessons

The results showed that few girls and mums knew the possible signs and symptoms of breast cancer unprompted; significant numbers rarely or never checked their breast; the majority lacked confidence to notice a change in the breast; not everyone realised the importance of going to the doctor quickly with concerns and knowledge of the breast screening service was low.

We used the information from the questionnaires to inform an educational presentation which was delivered within PSHE lessons for each of the 18 classes.

The volunteer team considered how to create an appropriate presentation for the 13 to 15 year old girls. We decided to use drawings of women showing the possible signs and symptoms rather than photos or films of real women. We included photographs of mammogram machines and the units they are based in, we showed drawings of breast self examination. Drawings were considered less embarrassing than real bodies and were equally informative.

The presentations were made by young ex-pupils, just a few years older than the children in the classes. These young women were backed up by older women who were cancer survivors. We have found that this type of peer led learning is both engaging and powerful for the audience.



Nida Thamannah ex pupil and Bio-Medical Science Student urged the girls to not let embarrassment prevent them from giving their mothers life saving information.

Those leading the presentations provided information about signs and symptoms, sought to build confidence to carry out self examinations and to notice changes in breasts. We discussed the barriers to seeking medical help and endeavoured to develop the confidence to seek help if a possible symptom is identified. We also explained the purpose of mammograms and how important it was for mums, aunties, grannies to attend their appointments.

The classroom presentation included Youtube clips from famous pop star cancer survivors, photos of Doctor Who and finished with the uplifting and highly popular 'Just Stand Up' song, performed by pop, R&B, rock and country stars such as Beyonce, Fergie, Leona Lewis, Miley Sirus, Carrie Underwood, Rihanna, Mariah Carey, Ciara, Melissa Etheridge, Mary J Blige, LeAnn Rimes, Natasha Bedingfield and Keyshia - a dozen of the most famous women stars. The co-creation of this presentation with the young volunteers ensured that it was relevant, accessible, popular and entertaining for the pupils.

To see 'Just Stand Up' visit:
www.youtube.com/watch?v=SRXxpKj-9sY

The volunteer group had created an interesting, engaging and not too embarrassing PowerPoint presentation and the response from the girls was very positive. The classroom sessions also involved interactive card games which we had created to reinforce the awareness of possible symptoms. We used model breasts of various designs, some made from material - the **Breastology Bag**- and some from soft plastic to encourage discussion and overcome embarrassment.



Intranet

We created a breast cancer awareness room on the Plashet School intranet (Fronter). In this room we put information about all of our breast cancer messages and we provided profiles of our volunteers who were leading the presentations in the classes. Members of the volunteers' group added photographs, links to films and a variety of useful information for girls and mums. We encouraged the girls to show this information to their mums if they had computers at home. We also used Fronter as a means of sending messages to the pupils about our activities and meetings.

Later we created a facebook page which served a similar purpose to the Fronter site. We used this page to profile our activities and to spread our health messages. With facebook and Fronter it was vital to keep uploading new interesting images – photos, films, copies of articles in local papers, TV coverage, all preferably involving the girls themselves. The girls did look at the sites to see themselves and their friends and at the same time were given more of the breast cancer information.

Young Lifesavers Group

The next step was to involve the pupils in leading the project. At an assembly we asked the girls to volunteer to become Young Lifesavers. Their role would be to identify ways to cement the learning for their fellow pupils and to consider how to overcome the barriers involved in sharing our messages with mums and other women family members. The girls were motivated by wishing to help their mums and by wanting to get useful experience and insights into a range of roles and occupations in advance of applications to college or work. The girls completed application forms with great enthusiasm and we accepted all 92 into this group.

Local NHS staff provided training in breast cancer awareness for the group and we held regular meetings to identify ways of communicating our messages and plan our activities. A main area of our work with the Young Lifesavers was to co-create resources in a range of mediums in order to reach out to women relatives.

'small c' campaign

The 'small c' campaign was launched shortly after the Young Lifesavers Group was formed. The initiative is a partnership between NHS East London and the City, NHS Waltham Forest, Barts and The London NHS Trust and the North East London Cancer Network. Other partners are Barts Cancer Centre, Homerton, Newham and Whipps Cross University Hospitals, as well as local GPs, pharmacists and community groups.

The 'small c' perfectly coincides with our approach, that cancer if caught in the early stages, when it is small and less difficult to treat is much more likely to be survived. The idea of the 'small c' campaign is to bring cancer down to size, to try to overcome the huge fear that people feel when they think of it. This fear can immobilise people and prevent them from taking action, prevent them from seeking help.

The Young Lifesavers' Group took home materials created by the 'small c' campaign and asked their mothers to answer some questions about their effectiveness. Mums were given samples of leaflets, oyster card holders, nail files and mirror stickers. These resources were designed to raise awareness of the signs and symptoms of breast cancer, to promote self examination and to remind women to carry them out regularly. This proved to be an effective way of enabling the girls to discuss the breast cancer messages with their mums and to get valuable feedback at the same time.

 www.smallc.org.uk

A separate report details Community Links work on the "small c" campaign raising awareness of cancer and promoting early detection in a number of settings across the London Borough of Newham:

 www.community-links.org/uploads/documents/Small_c

Talking to your mums!

- How confident do you feel about talking about breasts with your mums?
- How do you think your mums will feel?
- How can we encourage mums to be TLC?
(Touch, Look and Check in with GP)

Any one of these symptoms could be a warning sign of breast cancer.



Lump – may not be seen, but might be felt



Skin texture
e.g. dimpling/puckering



Appearance or
direction of nipple



Nipple discharge



Rash or crusting



Trip to St Bartholomew's Hospital

The Young Lifesavers' Group told us that experiences always help things to stick in people's mind and they recommended experiences such as trips. And so to help raise awareness and to help the messages to stick in people's minds we organised a trip for the Young Lifesavers to the breast screening unit at St Bartholomew's Hospital



St Bart's Hospital staff took 53 girls through all of the processes involved in breast screening: Mammography, Breast MRI and Ultrasound/biopsy. The girls were shown the mammogram machines by a trained nurse who explained the process in detail and stressed the importance of attending appointments for the mothers, aunts and grandmothers of the girls.

The girls saw the most up to date equipment and were given wonderful opportunities such as practising ultrasound scans themselves on chicken breasts stuffed with olives.

It was a terrific opportunity to see state of the art equipment, to have a go themselves and to learn about all the processes involved in diagnosing breast cancer.

The girls were also given a session with a breast cancer nurse who checked their knowledge of signs and symptoms and stressed that it is vital for all women to check themselves regularly and to know what is normal for them. Throughout the day the girls were reminded to take this information home to their mums.



It was a big day for the Young Lifesavers and they were right to think that an experience of this sort would stick with them for years to come. They now knew what a mammogram machine looked like and what it did. They knew what a breast screening unit was like and what happens there and they also had a wonderful insight into the work of radiologists and breast cancer nurses. Many came away with thoughts of careers in the NHS.

 www.community-links.org/linksuk/?m=201110

The Central and East London Breast Screening Service (CELBS) featured the trip on their re-launched website, promoting the take up of breast screening in the local community.

 www.celbreastscreening.org.uk/areas/newham

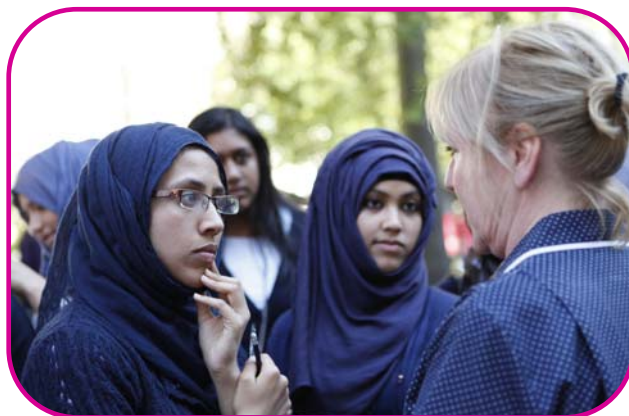


Sharing the Trip

A young woman film maker volunteered to accompany us on the trip to St Barts and she recorded each of the sessions that took place. This enabled us to share the experience with the girls in Years 9 and 10 who had not been able to take part in the trip. A small group of Young Lifesavers spoke about the day and showed the film in assemblies.

A short film by Jaha Brown details the visit to St Barts. The film is now available online

 www.vimeo.com/jaha



Communicating with mums

Information was taken home to families in a variety of ways including articles written for the School newsletter. However, a lack of information in Asian languages was identified by the Young Lifesavers as a barrier to communication with some of their mums. The girls identified that it could be very embarrassing and difficult to translate some of the symptoms into their mother's language. Symptoms such as 'puckering and dimpling' proved very awkward. Girls and staff responded by creating podcasts in Asian languages which were made available on the school internet site and facebook. We went on to make contact with other National Awareness and Early Detection Initiative (NAEDI) projects who had translated materials into Asian languages and made short multi-lingual films and we made use of those:

 www.detectcancerearly.org

At our regular meetings the girls decided that the most effective way to communicate with mums would be at an after school event – an evening of entertainment and information. They felt that activities put on by children and young people are often the best way to get their parents along.

This suggestion was welcomed with enthusiasm by School staff who decided to theme the whole day as a Pink Day for breast cancer awareness. Girls were allowed to wear a pink item of clothing if they paid 50p to a cancer charity. Staff baked and sold cakes and lessons began with a breast cancer fact of the day.

"We are supporting this project because it will be of benefit to our pupils and to their wider families. We are getting the whole school involved by organising a 'Pink Day' where we will raise both awareness and money for breast cancer services."

Mrs Nasir, Headteacher.



Mums' and Girls' Night



The evening event was billed as 'women and girls only' in order to create a safe and less embarrassing environment for girls and particularly for mums and other women relatives. Male members of staff provided background support for the project while respecting it as a 'women only' event. Staff and pupils enjoyed the inherent feminism of the event. In preparation for the evening event the girls studying GCSE drama developed a play and the choir learnt the 'Just Stand Up' song.

So, one Wednesday evening in November over 250 students and their parents packed into the school hall, watched a play, a 60 strong choir singing the cancer song, and a series of presentations about the early signs of breast cancer. The Young Lifesavers had made cakes and decorated the hall, stage and tables in a vibrant pink.



The turnout was terrific, particularly when compared with our afternoon tea and advice session for mums, at the start of the project, which had attracted only three mums.

Written information in a range of Asian languages was on each table along with pink squash and pink cakes. In the background Asian language short films were playing describing breast cancer symptoms and offering advice.

The girls brought a fresh and irreverent approach to cancer awareness, their play showed cancer cells attacking women who refused to recognise the signs of breast cancer and seek help from the doctor.

Khadijah Sannan (16) was the Director of the play:

"My team and I had to think of ways we could highlight the importance of the awareness of breast cancer. So we thought of having three characters all having breast cancer and seeing how their lives worked out. We wanted to show the mums that it is important for them to recognise the signs and symptoms of breast cancer. We added humour – so our message wouldn't be boring and get lost. It was great fun, we had the most amazing feedback from the mums which made us really happy. I'm glad they learnt something from it, just as we did."

Drama star **Aliya Amin** (16) agreed:

"Participating in the event and helping inform the women of such life changing and important issues really felt so amazing and rewarding. Knowing that we could save a life with the information we were passing on put a smile on all our faces."



Plashet School Drama group:

on the way to a theatre production of *Legally Blond* as a reward from School for all their hard work in preparing the breast cancer play

Two of our volunteers, older pupils now at university, led the health awareness presentations in the Hall. They showed the PowerPoint that had been used in CPSHE classes and gave a detailed description of the possible signs of breast cancer and explained why it is important to carry out regular breast self examination and vital to go to the doctor if you are worried in any way.

They also explained that if you receive an invite for a mammogram appointment you should always go. *"Mammograms can detect cancer even before we can see or feel anything"* explained volunteer **Thamannah Miah**.

We have found that communication is more effective if the audience recognise the messenger as someone like themselves – someone from the same community. Recognition builds trust, which enables meaningful discussions about health issues to take place. This recognition combined with the volunteers' unembarrassed and matter of fact approach to talking about women's bodies was very powerful.

Their dynamism in encouraging women to be confident to go to the doctor with concerns was very effective and prompted much discussion and laughter. This approach helped to normalise the discussion of cancer and enable the sharing of vital awareness information.

The evening was a huge and enjoyable success, drawing praise from parents, students, and NHS staff. It contrasted powerfully with the first event for mothers at the start of the project when three women attended and two of those had to be press ganged.

The Young Lifesavers as social researchers.

We trained the Young Lifesavers to complete the B-CAM Questionnaire with their fellow students, mums and other women relatives. The Lifesavers completed forms at the Mums' and Girls' Night, visiting each of the tables as mums enjoyed the event.

Media

In order to share the messages with a wider community we took a proactive approach to channelling our messages through the local media. The local newspaper, the **Newham Recorder**, agreed to partner our breast cancer campaign, included an extensive launch report and regular ongoing articles.

London wide television coverage was gained during the launch of the 'small c' campaign. This showed a breast cancer lesson taking place at Plashet School. We also targeted the Bengali and east London media and several detailed multi-lingual articles were featured sharing the information about signs and symptoms, self exams, confidence to go to doctor and breast screening appointments. In addition we used the Community Links blog and facebook channels to share our work.

Newham Council

The Newham Magazine, produced by Newham Council and distributed to all Newham households also carried our cancer awareness messages and information about signs and symptoms.



What do you do if you notice something?

- Act quickly!
 - See a doctor
- (a REAL one!!!)



community links



Newham's Mayor, **Sir Robin Wales**, supported the project by attending a celebration breakfast, talking with the Young Lifesavers about their work and with **Edythe Labinjo** about her lifesaving experience of self examination. The Mayor also shared with them his personal experience of a close friend who has the illness.

This breakfast with the Mayor and a photo in the local press was offered as a much sought after prize for the form class which brought back the most questionnaires from their mums.



Findings

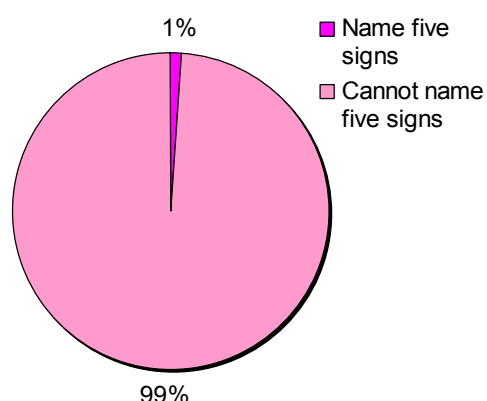
B-CAM Questionnaire Results

In the first round 613 B-CAM questionnaires were completed by 403 girls and 210 women. The second round of B-CAM questionnaires were completed at the end of the first year of the project. 624 questionnaires were completed by 432 girls and 192 mothers and other women relatives.

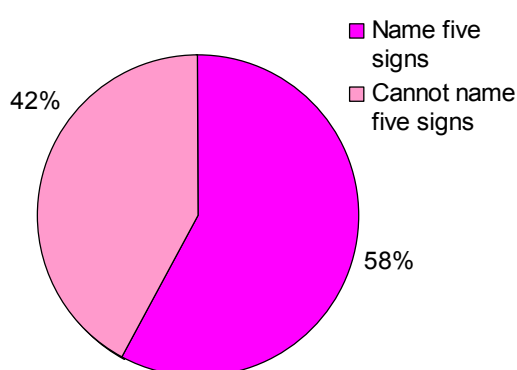
Naming the possible signs and symptoms of breast cancer without prompting.

At the end of the project 57.7% of girls could name five and more symptoms **unprompted** compared to 1% at the start.

Girls at start of project

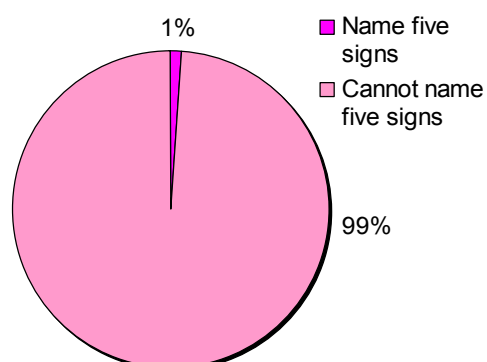


Girls at end of project

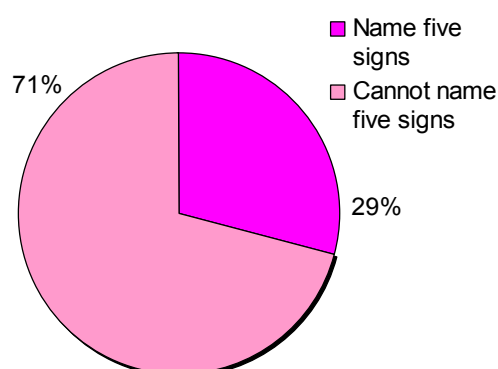


After the project 29.2% of women could name five and more symptoms unprompted compared to 1% at the start.

Women: start of project



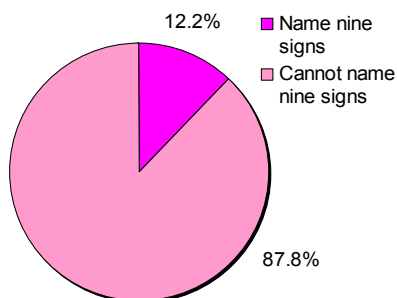
Women: end of project



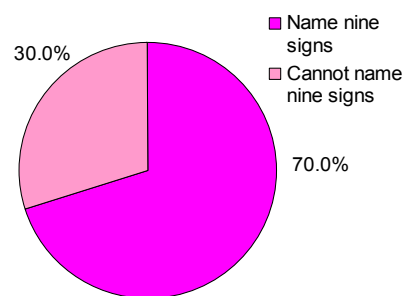
Naming possible signs and symptoms with prompting.

The questionnaire includes a list of 11 signs and symptoms and asks which could indicate cancer; 70% of girls and 77% of women can now name **nine or more** possible signs and symptoms with prompting. This is an increase from 12.2% for girls and 23.3% for women; 97% of girls and 93% of women can now name five and over possible symptoms with prompting.

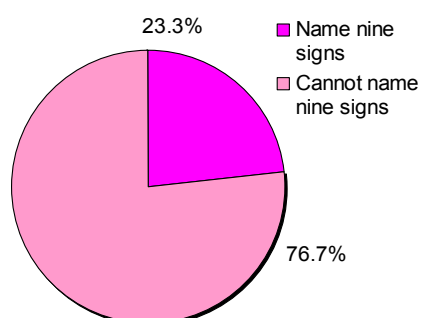
Girls: start of project



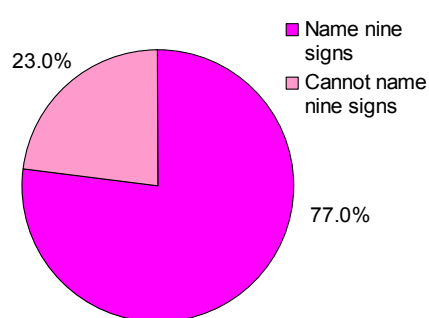
Girls: end of project



Women: start of project



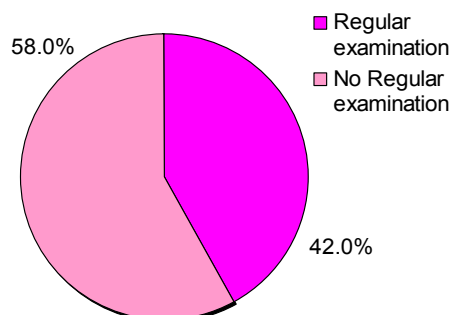
Women: end of project



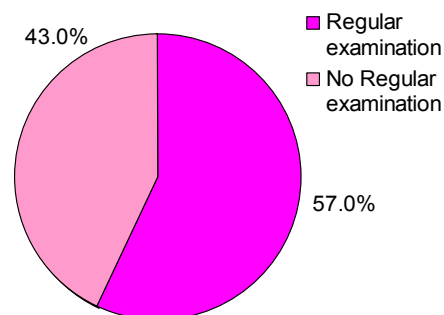
Frequency of breast self examination

The questionnaires showed that the percentage of girls who check regularly, at least every six months, had risen from 42% to 57%.

**Girls: self examination
start of project**

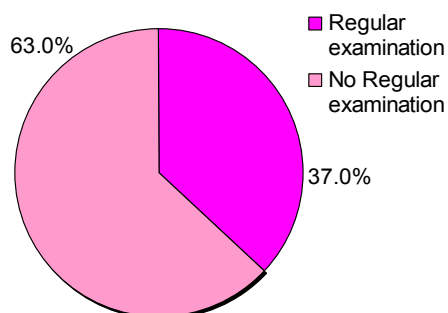


**Girls: self examination
end of project**

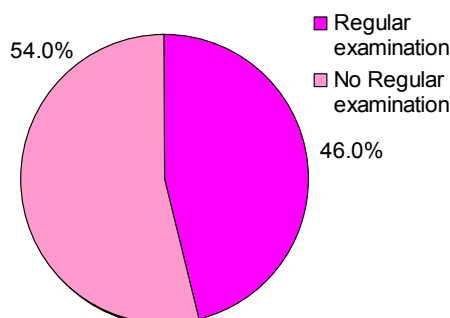


The questionnaires showed that mums who check regularly, at least every six months, had risen from 37% to 46%.

**Mums: self examination
start of project**



**Mums: self examination
end of project**



The percentage who were fairly or very confident to notice a change in the breast rose from 32% to 46% for girls and from 46% to 53% for mums

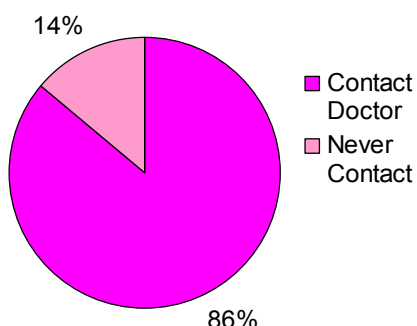
How quickly they would contact a doctor if they found a change in their breast

The figures for contacting in less than two weeks rose from 72% to 80% for girls. This figure has stayed stable for women at 85%.

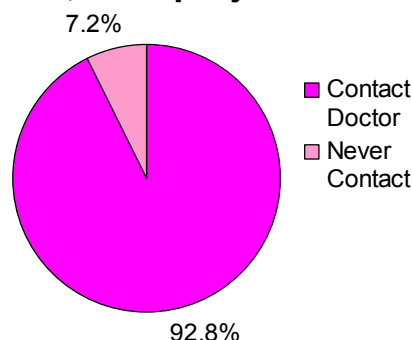
At 90% the figures for contacting within six weeks have remained stable.

Originally 14% of girls said they would never contact the doctor if they found a change in their breast, this has reduced to 7.2%. For mums it has dropped to 1.6% from 5%.

**Contacting a Doctor:
Girls, before project**



**Contacting a Doctor:
Girls, after project**



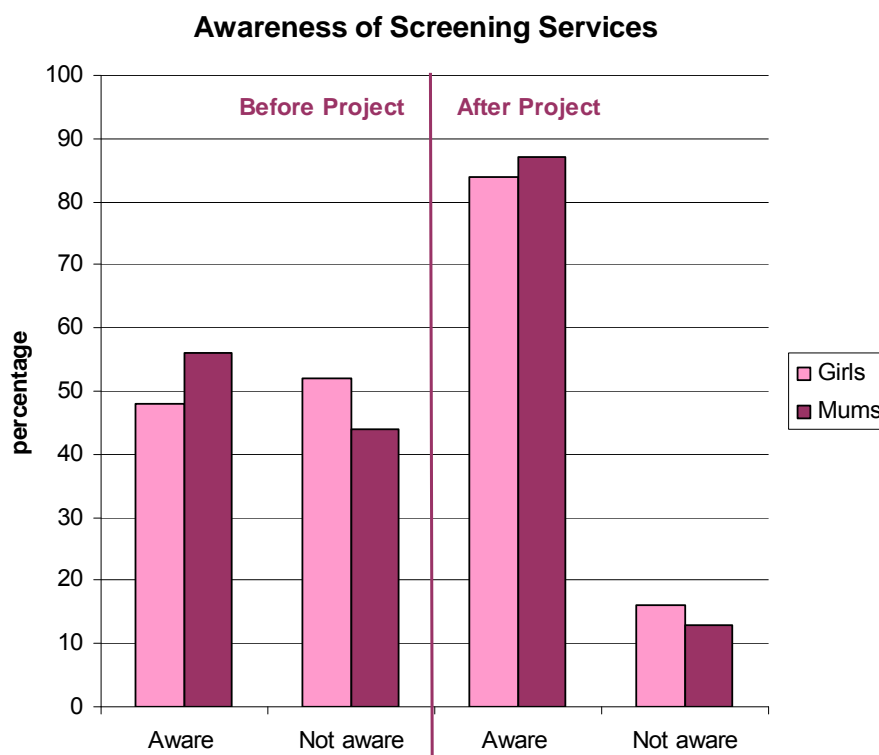
The questionnaires asked how many women will develop breast cancer in their lifetime – 1 in 3, 1 in 9, 1 in 100, 1 in 1000?

After the project 54.9% of girls and 58.9% of women knew it was 1 in 9 compared to 46.7% girls and 35.2% women.

(This was the closest correct answer, although the figure has now risen to 1 in 8).

Knowledge of breast screening was tested in three questions:

Did they know there was a screening service? At the start of the project 48% of girls did know there was a screening service – this rose to 84%. Knowledge amongst mums rose from 56% to 87%.



Did they know the age at which women are first invited for breast screening?

At the outset 6% of girls did know and this rose to 38%; 23% of Mums did know and this rose to 40%.

Did they know the age at which women are last invited for breast screening?

At the beginning of the project 10 % of girls did know and this rose to 43%. At the beginning of the project 13% of women did know and this rose to 32%.

Do the questionnaire findings indicate that we achieved our key objectives?

1. To encourage Asian girls and women to embed regular self examination as a lifetime habit.

Girls and mothers showed an increased commitment to self examine at least monthly – 47% for girls and 46% for mums and other women relatives. This represents a rise of 11% points for girls and 9% points for mums. In addition the percentage who were fairly or very confident to notice a change in the breast rose to 46% for girls and 53% for mums, a rise of 14% points for girls and 7% points for mums.

2. To increase awareness of the possible signs and symptoms of breast cancer.

Girls and mothers successfully learnt about the signs and symptoms of breast cancer. 70% of girls and 77% of women can now name nine or more possible signs and symptoms with prompting. This is an increase from 12.2% for girls and 23.3% for women. 97% of girls and 93% of women can now name five and over possible symptoms with prompting.

3. To increase confidence to approach a doctor with concerns.

The questionnaire asked how quickly the respondent would contact a doctor if they found a change in the breast. Girls showed an increased willingness to contact their GP quickly if they had concerns and the figure for contacting in less than two weeks rose to 80%. The figure stayed stable for women at 85%.

The number of people who said they would never go to the doctor if they found a change in the breast fell from 14% of girls to 7.2% and for mums it has dropped from 5% to 1.6%

4. To promote the importance of attending breast screening appointments.

Girls and mothers demonstrated an increased awareness of the breast screening service - 84% of girls and 87% of mums now knew there was a service, a rise of 36% points and 31% points.

Girls and mothers also showed an increased awareness of the age at which women are first invited for breast screening this rose to 38% for girls and 40% for mums, a rise of 32% points and 17% points.

Girls and mothers showed increased awareness of the age at which women are last invited for breast screening, this rose to 43% of girls and 32% of women, a rise of 33% points and 19% points.

Discussion of findings

We were only able to provide questionnaires in English and so there could have been errors if the information was translated by girls for mothers.

There are some possibilities of bias in the questionnaire process. In relation to the question about the factors that might dissuade a person from going to the doctor if they had a symptom of breast cancer. The respondent is being asked about a situation in which they are assuming that they have a problem whereas in reality they would be unsure. This inherent bias could have affected the results.

The questionnaires were designed to be completed by an interviewer; most of ours were completed by the girls and mothers independently either at school or at home.

There are a number of possible consequences of this, one of which is that in a number of cases the first page of the questionnaire was left blank. This could have been because the respondent did not see the question on the first page, which asked people to list the possible signs and symptoms of breast cancer unprompted. This could have resulted in an under-reporting of knowledge of signs and symptoms, unprompted.

The questions about possible signs and symptoms of breast cancer, with prompting, may also involve some bias as it is counter-intuitive for school pupils to answer a multiple choice question by giving the same answer in all of the categories.

Conclusions



We sought to make girls more aware of their breast health and to embed habits of self examination. We endeavoured to reach mothers through their daughters, to promote breast cancer awareness and to influence behaviour in relation to self-examination and breast screening.

We have seen that the girls' own knowledge and confidence has increased significantly and that they have simultaneously motivated their mums and other women family members to change their attitudes and behaviour. We have found that the girls can deliver breast cancer awareness information to their mothers and motivate them to be more actively aware of their own breast health and more confident to go to the doctor should a change occur.

Once again we have found that children are a great route to adults and can share knowledge and influence behaviour.

Why was the project successful?

Is it that the project was special and managed to do the extraordinary by reaching a 'hard to reach' group? Or is it that the group was not so 'hard to reach' but instead needed a focussed and appropriate approach?

"It is vital to target the group that you are working with physically, geographically and socially. A school is ideal for this."

Tim Baker, NHS(NHLC).

We believe that cancer awareness is vital learning for life and a school is an ideal location from which to disseminate this knowledge. Schools reach everyone, children expect to learn at school and adults also respect the learning environment. A school is an ideal institution in which to enhance the existing sense of community with a responsibility for health.

Children are a channel of communication for parents and in this case, where some mums do not speak or read English, they may be the only channel. We explored with the Young Lifesavers where their mums would get information about breast cancer and those whose mums did not speak English felt that no-one else would be providing this. Universal health messages were not reaching this group of women.

The School staff welcomed the project and supported it during the year. For some staff the project did involve tedious and repetitive work in getting the girls to complete their questionnaires and remember to bring back those of their mums. The project sought to reduce this burden on the teachers by visiting classes frequently, with Young Lifesavers, to remind and collect forms. Year Heads played an active part in reminding girls in assemblies and rewards were offered as incentives.

Messages delivered by peers are the most plausible and can have a great impact. The involvement of slightly older peer volunteers in making the initial presentations to the girls within assemblies and classrooms enabled us to create relevant resources which succeeded in exciting the pupils and motivating them to be involved.

High levels of pupil involvement as Young Lifesavers added to the excitement which was maintained by a range of events, outings, media coverage and on-line messaging. Facebook and Fronter, the school intranet, enabled us to share our photos and press coverage regularly while at the same time reinforcing our awareness messages. The project succeeded in creating a presence in the School and in normalizing the discussion of breast cancer.

Our volunteer team proved to be strong and reliable as well as highly relevant to the audience. It is very worthwhile to spend time building a good varied team, different experiences and skills allows the group to share and grow during the project. Our university students had excellent social media skills and an extraordinary ability to motivate the girls, while our older women had excellent face to face communication skills and were able to provide insights into their experiences of cancer survival. Everyone had something to learn and something to teach.

It was essential to meet with members of the local media to discuss the purpose of the project and to elicit their active involvement. As a result we received ongoing support in the form of articles covering our progress and the opportunity to regularly share information about the signs and symptoms with readers. They also agreed to include website details for the 'small c' campaign and contact details for Community Links' project so that anyone wishing to get more information about breast cancer or to volunteer could get in touch. This enabled a range of potential partners to get in touch and help to build the project further.

This was a pilot project and we did not go into it with fixed ideas. We carried out the first B-CAM to clarify which issues needed addressing and we were highly inclusive in developing the programme. The input of the Young Lifesavers and of staff helped to determine the direction. Resources were co-created and activities developed in response to input: the 'Just Stand Up' song was so popular in the classroom presentations that many girls wanted to perform it and went onto do so for their mums; as many Young Lifesavers were drama students it seemed natural to them that they would produce a play; outings are popular with schoolchildren so the trip to St Bart's was born. In addition to finding fun ways to develop the project the Young Lifesavers also identified and tackled difficult tasks: recording breast cancer awareness information in a number of Asian languages.

The project would not have existed without the partnership between Community Links and the local NHS. It would not have succeeded without the knowledge and insights of both partners. Community Links, an organisation embedded in the local community, brought over 30 years experience of reaching into local communities. The local NHS public health team brought extensive and specialist knowledge of the challenges facing early detection. Together we have shown that with serious thought and effort we can build projects that reach out and empower local people to take responsibility for their health.

Notes

- In the first round, 18 respondents did not give their names and in the second round 25 did not, these questionnaires were not analysed.

Community Links Breast Cancer Awareness

Project 10 Top Tips

Work with community organisations

Build partnerships between community organisations and the NHS. Organisations such as Community Links are embedded in the local community, with extensive experience of community development initiatives. These partnerships can build projects that reach out and empower local people to take responsibility for their health.

Make it personal

When making presentations explain that 1 in 8 women will have breast cancer in their lives. What will that mean for the people in this room? Look around and think about it.

Be embarrassed – have fun

Talking about breasts and self examination is embarrassing, enjoy it and have a laugh. Embarrassment is not boring, it will be remembered.

Find creative ways to reach communities

How can we reach more women? Try podcasts in home languages, letters sent through schools, take part in school parents' evenings, involve children and teachers in creating songs and plays for their families.

Share personal experiences of cancer

Involve people with personal experience of cancer who can share these experiences and how they feel. Look for people who detected cancer early who can give examples of less extensive/invasive treatments.

Involving peers in delivering messages is powerful

Young people and adults listen more to people who they can relate to. If working with children try to involve those just a few years older in presenting the information.

Locally rooted teams

You will be much more effective if the people you use to build your message are recognisable as having come from the audience themselves. Involve people with appropriate socio-cultural knowledge and language skills.

Empower young people to share with families, to be life savers

Young people will take seriously their responsibility to share health messages with their families. By working with children you can motivate whole families.

Use varied resources

When making presentations use a variety of resources such as Youtube songs, podcasts, models, games, websites. Don't be boring, people learn and remember in different ways. Be interactive; be funny.

Keep media involved

Work in partnership with the local papers and Council magazines – and look for opportunities to feature in the national press, radio and TV – in order to share health messages more widely.

Appendix

Most Commonly Known Symptoms by Levels of Knowledge

When cross-comparing the number of symptoms that respondents are able to correctly identify with the list of symptoms itself, we found that:

Those who could identify 4 or less symptoms correctly while being prompted could most commonly identify (in order of frequency):

- ▶ Lump or thickening in your breast
- ▶ Pain in one of your breasts or armpit
- ▶ Discharge or bleeding from your nipple
- ▶ Lump or thickening under your armpit

Those who could identify between 5-8 symptoms correctly could also identify (in order of frequency):

- ▶ Puckering or dimpling of your breast skin
- ▶ Change in the shape of the breast
- ▶ Redness of the breast skin
- ▶ Change in the position of the nipple

Those who could identify more than 9 symptoms correctly would name the rest of the symptoms in this order of frequency:

- ▶ Change in the size of the breast or nipple
- ▶ Nipple rash
- ▶ Pulling in of the nipple

Those who could identify four or less symptoms correctly unprompted could most commonly identify, in this order of frequency:

- ▶ Lump or thickening in your breast
- ▶ Pain in one of your breasts or armpit
- ▶ Discharge or bleeding from your nipple
- ▶ Nipple rash

Those who could identify between 5-8 symptoms correctly could also identify in this order of frequency:

- ▶ Redness of the breast skin
- ▶ Change in the position of the nipple
- ▶ Change in the shape of the breast
- ▶ Puckering or dimpling of your breast skin
- ▶ Change in size of breast or nipple

Those who could identify more than nine symptoms correctly would name the rest of the symptoms in this order of frequency:

- ▶ Pulling in of the nipple
- ▶ Lump or thickening in armpit

Information and Resources

Community Links

105 Barking Road
London
E16 4HQ

Contacts:

Frances Clarke	frances.clarke@community-links.org
Zoraida Colorado	zoraida.colorado@community-links.org
Website	www.community-links.org

NHS North East London and the City

75-77 Worship Street
London
EC2A 2DU

Contacts:

Tim Baker	Assistant Director,	tim.baker@elc.nhs.uk
Sarojini Ariyanayagam	Health Improvement Manager	sarojini.Ariyanayagam@elc.nhs.uk

Plashet School

Plashet Grove
East Ham
London
E6 1DG

Contacts:

Sarah Heath	Curriculum Manager for Humanities	sarah.heath@plashet.newham.sch.uk
Marion Tuplin	Assistant Head	marion.tuplin@plashet.newham.sch.uk

Newham Recorder

Recorder House
539 High Road
Ilford
IG1 1UD
www.newhamrecorder.co.uk

Small c campaign

www.smallc.org

Detect Cancer Early

www.detectcancerearly.org

HEALTH EDCO®

Bringing Health Education to Life

BREAST cancer Awareness

Please visit our website at www.HEALTHEDCO.co.uk or
call us to receive a copy of our latest catalogue

BSE Model Kit

This kit includes our best-selling beige and brown breast models with palpable and non-palpable lumps that simulate easy- and hard-to-find breast tumours. Models feel like actual breast tissue. Kit includes protective slipcovers, carrying case, booklet, and penlight to illuminate non-palpable lumps.



Breastology Bag

Perfect for promoting early detection of breast cancer through breast self-exam, the Breastology Bag is great for individuals or groups. Six soft-sculpture breasts, which come in a handy bag, can be used to learn the basics of breast anatomy and how to feel for breast changes as well understanding the differences between normal, fibrocystic, and harmful lumps. Instructions are printed on the back of each model.

TELEPHONE ORDERS: (+44) 0845 180 0505

Visit our website at www.HEALTHEDCO.co.uk

Beating cancer at School

*Working with Plashet School
on early action to save lives*

Cancer survival rates in Newham are amongst the worst in the country. This report details a project working in an east London school to test a different way of sharing health messages within communities. The use of a school setting gave the opportunity to share specific messages between two generations of mums and daughters. The community development approach aimed to tackle the issue of late detection. Treatments are available to save women if cancer is detected early.

This report is intended not only as an account of how effective the project has been but also includes detail about resources and approaches that we hope will be useful in other communities and help to save more lives.

This report is part of a series reporting the work of Community Links in promoting early action on cancer; see also Breast Screening Take-up project report and “small c campaign” reports.

Community Links
105 Barking Road
London
E16 4HQ

www.community-links.org



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