



1. Introduction

Why the need for an Intervention: A Bit of Background

Breast cancer is the most common cancer observed in women with an estimated one million new cases diagnosed throughout the world each year (Cancer Research UK, 2009). In the UK the incidence of breast cancer has increased by 50% over the past two decades (Cancer Research UK, 2009). The latest figures show that 48,000 new cases were diagnosed in the UK in 2008 with women residing in the UK having a 1 in 8 chance of developing breast cancer over their life time (Cancer Research UK, 2009).

Whilst the incidence and prevalence of breast cancer continues to increase, overall survival rates have improved (Cancer Research UK, 2009). However, there is evidence that this improvement in survival has not benefited all communities for example black British women. Black British women are less likely to develop breast cancer than white women with studies showing a 10-40% lower incidence rate than their white counterparts (NCIN, 2009). Despite the lower incidence black women have higher mortality rates (NCIN, 2009; Bowen, 2009 and Wild, 2006).

It has been shown that the increased mortality in black women is due to the fact that black women are more likely to be diagnosed with breast cancer when the disease is at a late stage and prognosis is poor (Blackman, 2006; Lannin, 1998 and Eley, 1994). Therefore the key to improving the poor mortality is to develop strategies for earlier diagnosis. Earlier diagnosis can be achieved by ensuring that black women have a greater awareness of the signs and symptoms of breast cancer and by improving the uptake of breast cancer screening in this population. Patient Navigation is an intervention that can improve both sign and symptom awareness and breast cancer screening uptake.

What is Patient Navigation?

Patient Navigation is a public health intervention that was developed by the US surgeon Dr. Harold P. Freeman to address the inequalities that exist in cancer care (Freeman 2006). The main aim of Patient Navigation is to eliminate the barriers to timely diagnosis and treatment and it was conceived after observing that one of the most deprived areas in New York,

Harlem, had profound disparities in terms of survival rates and the uptake of health care services. In addition, the majority of residents in Harlem who had cancer were diagnosed with late stage disease. To address this Dr. Freeman developed a health care model that aimed to span the entire health care continuum. This model provides a proactive approach to ensuring early public engagement with health care services and provides a comprehensive support system that prevents delays and improves the patient experience. This is achieved by assigning Patient Navigators to patients to guide them through the health care system; act as advocates; assist in locating relevant resources; raise awareness and ensure that any barriers to accessing health services are overcome. In this way the factors preventing disadvantaged communities from being diagnosed and treated in a timely manner are eliminated. The Patient Navigation model is divided into four components:

- Outreach Navigation
- Diagnostic Navigation
- Treatment Navigation
- Financial Navigation

Outreach Navigation aims to not only engage with the community to raise awareness about cancer but it mostly endeavours to promote cancer screening. It aims to be proactive by enabling screening appointments to be made whilst Patient Navigators are on location in the community through a live booking system. Through Outreach Navigation, Patient Navigators form a one-to-one relationship with members of the public and when an appointment is made on location they follow-up with the individual and guide them through the cancer screening process. They ensure that any questions the individual has about cancer screening is answered, any barriers to attending their screening appointments are identified and addressed, and ensures that screening test results are given to the patient as quickly as possible. If an abnormal finding is observed during the cancer screening process the individual is then moved rapidly on to the next step in the Navigation process, Diagnostic Navigation

Diagnostic Navigation begins when a patient has been informed of an abnormal finding following their cancer screen. The aim of this step is to ensure that the patient goes from abnormal finding to a confirmed diagnosis in the shortest possible time. At this stage patients will be undergoing further examinations and the Patient Navigator will provide assistance at every step, attending appointments to provide support and ensuring patients have a clear understanding of the diagnostic plan being recommended by the physician. In addition, if any additional services are required such as counselling, transportation or childcare assistance the Patient Navigator will provide information and assist in these areas. If a confirmed diagnosis of cancer is made the patient then moves on to Treatment Navigation.

Treatment Navigation aims to ensure that patients diagnosed with cancer are treated as quickly as possible to ensure the best possible outcome. Treatment Navigators form a bridge of understanding and support between the patient and treatment team. They ensure that the patient understands their treatment options and the reasoning behind the doctor taking a particular course of action. They guide the patient through the entire treatment process making sure they have access to all the relevant support services.

Financial Navigation tackles the financial barriers that may hinder the rapid diagnosis and treatment of cancer. Where any financial difficulties exist it is the role of the Financial Navigator to address these. They take on the responsibility of any administrative tasks required for benefits, insurance and other financial claims relieving the patient of these tasks.

This four component Patient Navigation model was extremely successful in Harlem. Following its introduction the five year survival rate for breast cancer at the Harlem Hospital Cancer Control Centre increased from 39% to 70% (Oluwole, 2003). Additionally, the percentage of patients diagnosed at an early stage increased from 6% to 41% whilst the percentage of late stage presentations decreased from 49% to 21% (Oluwole, 2003). The success of this intervention led to the passing of the Patient Navigation Outreach and Chronic Disease Prevention Act in 2005, and the widespread implementation of Patient Navigation throughout the USA.

Why Patient Navigation ?

Having observed the success of the Patient Navigation program in the US at increasing cancer screening uptake and reducing the percentage of late stage diagnoses it was felt that an adaption of the program may be successful in reducing the inequalities that exist in the UK with respect to breast cancer and African Caribbean women because the populations in New York and London are similar; both are black populations with many living in deprived areas of their respective cities. As the populations are similar it was felt that it would be beneficial to use similar approaches to address very similar problems.

The success of the US program was due to its personalised and proactive nature which allowed for the specific barriers to accessing health services to be effectively addressed. It made a significant effort at building personal relationships between Navigators and patients where understanding the patient was at the core of the relationship. Another key aspect of the relationship was ensuring that the Navigator and the patient worked together to ensure good health which created a different dynamic to the traditional patient support programs that were more top down. Additionally, part of the strategy was to ensure that patients understood every aspect of their journey and what options were available to them

empowering them with knowledge of their disease beyond what mainstream programs were able to offer. This made patients feel more equipped to make informed choices about their health care. Furthermore, the program made allowances for Patient Navigators to go to significant lengths to address specific barriers that patients might have be they personal, financial, or work related. The environment was such that patients felt comfortable to discuss these barriers without fear of judgement or any negative consequences. The development of this relationship where the Navigator showed genuine concern and put the patient first created a level of trust that facilitated the retention of the patient and prevented any loss to follow-up. Finally, one of the most important success factors was that Patient Navigators were from the same cultural background, spoke the same language, if English was not a first language, and hence were able to effectively communicate with, relate to and understand the patient. In the UK many national interventions aimed at engaging with ethnic minorities are rarely successful due to a lack of cultural understanding and a lack of a personalised approach that meets the needs of the individual hence it was felt that this approach would be worth exploring. Therefore a pilot project was established focusing on the South East London, specifically the boroughs of Southwark and Lewisham.

Why Southwark and Lewisham?

Southwark and Lewisham have a low coverage and uptake rate for breast screening; significantly lower than the national average. The screening uptake in Southwark is 62% and in Lewisham it is 66% whilst the national average is 77%. These boroughs also have a large ethnic minority population and evidence has shown that screening rates in the UK for black and minority ethnic (BME) groups are lower than for white women. For example one study conducted by Peterson (2007) showed that in Southwark the breast screening uptake for African born Africans was 40%, for English born Africans was 41%, Celtic born Africans was 42%, Celtic born Caribbeans was 52% and English born Caribbeans was 57%. These uptake rate are low especially in the African groups. These boroughs would thus benefit from an intervention that specifically targets BME groups and hence the reason for focusing the Patient Navigation pilot in this geographic area. The main aim of the pilot is to increase the uptake of breast screening services by African Caribbean women. Therefore the focus for this pilot was on Outreach Navigation; that is engaging with the African Caribbean community in these areas to proactively encourage breast screening attendance.

What are we doing for our Patient Navigation intervention and the aims and objectives of the project

Our Patient Navigation pilot is an adaption of the Dr. Harold P. Freeman's Outreach Navigation component to make it relevant in a UK setting where there is a national breast

screening programme that invites all women over the age of 50 for breast cancer screening. The existence of a national breast screening programme means that there is a record of who should be screened and who has not attended their screening appointment making it easier to target specific people who might benefit from Patient Navigation.

The project was implemented by Betterdays Cancer Care and Cancer Black Care in collaboration with NHS Southwark and it had two main focus areas:

- Identifying and engaging with women who had been invited for breast cancer screening but who had not attended their appointment; and
- Community outreach work to raise awareness of breast cancer related issues and to proactively promote breast cancer screening.

The aims of these activities were to:

- Ensure that new screening appointments were made for women who had not attended their initial appointment
- Ensure that women did actually attend their new screening appointments.
- To identify and address the barriers that prevent African Caribbean women from engaging with the health service
- To raise awareness of all aspects of breast cancer within the African Caribbean community
- To raise awareness of the importance of breast cancer screening within the African Caribbean community

2. Method

Screening Uptake

662 African Caribbean women residing in Southwark and 336 African Caribbean women residing in Lewisham who had not attended their mammography appointments were made known to Navigators by NHS Southwark and NHS Lewisham who then attempted to make contact with them. Once contact was established Patient Navigators endeavoured to establish the reason for not attending, act as facilitators in addressing any barriers to attendance, answer questions about cancer screening and offer support in making appointments. If Patient Navigators were unable to make contact via phone then a letter was sent to ladies and where possible this was followed up with a text message. Furthermore additional attempts were made to contact women who did not respond to the letters sent by the Patient Navigators.

Once women attended their appointment and were given the all clear they were told they would be invited for another mammogram in three years when their next mammogram was due. If there was an abnormal finding following their screening appointment the NHS secondary services then took over responsibility for the well-being of the Patient.

Community Outreach

In addition to engaging directly with individual women, Patient Navigators also implemented a programme of breast health education and community awareness. This programme involved providing breast health awareness sessions with groups of African Caribbean women in Lewisham and Southwark. These sessions included general breast cancer awareness to provide context and covered the importance of screening. Following the presentation women of screening age were given the opportunity to speak to Patient Navigators about their own personal situation. Whilst at these session Navigators also encouraged attendees to:

- if they have been invited for screening to attend their appointment; and
- make an appointment for screening if they had recently missed their appointments

In addition, women were given the option to contact Navigators after the event should they want any additional information or support.

3. Results

As mentioned previously the Patient Navigation Pilot focused on two major areas, Screening and Community Outreach. The results from these two areas are summarised in the following sections.

3.1 Screening

Screening Uptake - SE15

637 women residing in the SE15 area were referred to Patient Navigators. These women had not attended their breast screening appointments between March and June 2010. Navigators attempted to contact women in order to identify and address any barriers to attending breast screening appointments and to make new appointments. Table 1 summarises the current status of the 637 women

Status	No. of Clients	Percentage of Clients
Pending (Unable to contact)	202	31.7%
Appointments	250	39.3%
Already screened/ had already made an appointment to be screened	57	8.9%
Travelling	39	6.1%
Declined	37	5.8%
Moved/Wrong Address	31	4.9%
Live Abroad	13	2.0%
On-going medical issue therefore unable to attend screening	3	0.47%
Died	3	0.47%
Will speak to her GP	1	0.16%
Wrong DOB (too young for screening)	1	0.16%
Total	637	100%

Table 1: Current Status of African Caribbean Women Residing in SE15 who were Referred to Patient Navigators

Appointments

Table 1 shows that of the 637 women Patient Navigators were able to make appointments for 250 women. Of these 250, 93 appointments were made as a result of women contacting Navigators after receiving a letter. Letters were sent to these 93 women after Navigators were unable to make contact via phone after three attempts.

Pending (Unable to Contact)

202 women are still pending. All the women in this category were sent a letter and this was because either there was a problem with their phone number or Navigators were

unable to contact them by phone after several attempts. The status of these 202 women can be further broken down as follows:

- Unable to contact after several attempts, letter sent: 113 women
- Disconnected phone numbers, letter sent: 46 women
- Wrong number, letter sent: 28 women
- No phone number provided, letter sent: 14 women
- Fax number, letter sent: 1 woman

Already Screened

57 women had already been screened between the time of their initial missed appointment and the Navigator making contact or they had already made an appointment to be screened and were awaiting their appointment date. Of these 57 women, 2 said they had been screened at work, 1 stated that she is screened routinely every year, 1 was screened in France and the remaining 53 were screened through the normal channels via the South East London Breast Screening Programme.

Travelling

A significant number of women (39 women), as of writing this report, were abroad on an extended trip; many were expected to be out of the country for several months.

Declined

37 women declined the offer by Navigators for a breast screening appointment to be made for them. Two of these women declined because they found their last breast screen too painful and didn't want to subject themselves to the experience again, one lady was over the age of 70 and didn't feel it was necessary, 1 lady preferred to be screened elsewhere, 1 lady was very busy and the remaining 32 women were simply not interested in being screened.

Moved/Wrong address

It was confirmed that 30 women had moved from their GP registered address. Confirmation was received either through returned letters or speaking to the new resident. In addition, there appeared to be an error with the address of one of the women. The new contact details for these women were not known and hence they could not be followed up.

Other

The remaining women in the SE15 area either now live abroad (13 women), are unable to attend for screening because they have a medical condition that prevents them from doing so (3 women) or are deceased (3 women). One woman would like to discuss breast screening with her GP and the final lady's date of birth was incorrect, her actual data of birth makes her too young for screening.

Reasons for Not Attending Initial Breast Screening Appointments

104 women from the SE15 area provided reasons for not attending their initial mammography appointment and this is summarised in figure 1. The most common reason given was not receiving the invitation letter (30% of women) followed by being busy on the date the appointment was scheduled for (18% of women) and the third most common reason stated for not attending was travelling at the time of the appointment (16% of women).

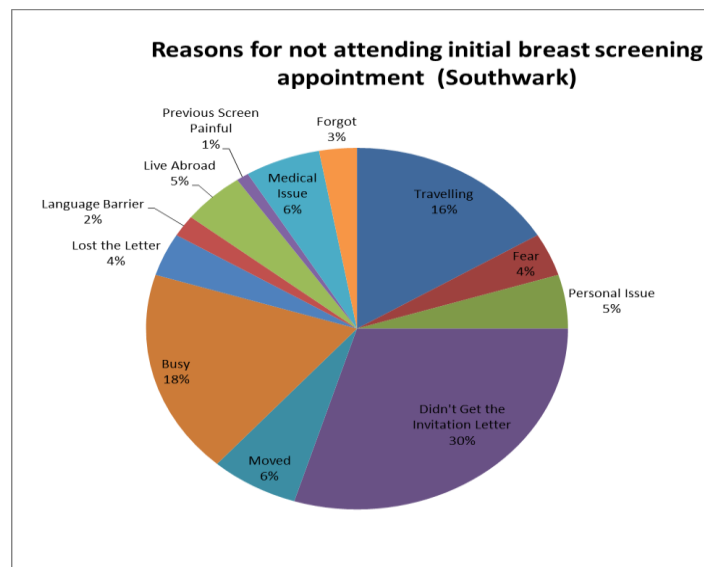


Figure 1: *Reasons why women (n=104) in Southwark did not attend their initial screening appointment*

Screening Uptake: Southwark, Non-SE15

25 women residing in Southwark outside of the SE15 area were referred to Patient Navigators. These women had not attended their breast screening appointment between the time period of January to September 2010. Navigators attempted to contact women in order to identify and address any barriers to attending breast screening appointments and to make new appointments for these women. Table 2 summarises the status of the 25 women.

Appointments

Of the 25 women referred to Patient Navigators appointments were made for 8 women.

Status	No. of Clients	Percentage of Clients
Already Screened	4	16%
Appointments Made	8	32%
Declined	1	4%
Pending (Unable to contact)	9	36%
Travelling	4	4%
Moved	1	4%
Temporarily relocated to Manchester	1	4%
Total	25	100%

Table 2: Current Status of African Caribbean Women Residing in non-SE15 Postcodes that were referred to Patient Navigators

Pending (Unable to Contact)

9 women are still pending. All the women in this category were sent a letter and this was because either there was a problem with their phone number or Navigators were unable to contact them by phone after several attempts. The status of these 9 women can be further broken down as follows:

- Unable to contact after several attempts, letter sent: 3 women
- Disconnected Phone Numbers, letter sent: 4 women
- Wrong Number, letter sent: 1 woman
- No Phone Number Provided, letter sent: 1 woman

Already Screened

4 women had already been screened between the time of their initial missed appointment and the Navigator making contact or they had already made an appointment to be screened and were awaiting their appointment date.

Other

2 women had travelled; one of these women had temporarily relocated to assist her daughter with child care. One woman had moved and one woman declined the offer for an appointment to be made for her to be screened.

Screening Uptake: Lewisham

336 African Caribbean women residing in Lewisham were referred to Patient Navigators. These women had not attended their breast screening appointment between the time period July and September 2010. Navigators attempted to contact women in order to identify and address any barriers to attending breast screening appointments and to make new appointments for these women. Table 3 summarises the status of the 336 women.

Appointments

Patient Navigators were able to make appointments for 121 women. Of these 121, 39 appointments were made as a result of women contacting Navigators after receiving a letter. Letters were sent to these 39 women by Navigators after Navigators were unable to make contact via phone after three attempts.

Status	No. of Clients	Percentage
Appointments Made	121	36%
Already Screened/Had already made an appointment	60	17.9%
Declined	19	5.6%
Live Abroad	2	0.60%
Moved (new details not available)	3	0.89%
Travelling	16	4.8%
On-going medical issues	4	1.2%
Pending (Unable to contact)	111	33.0%
Total Clients	336	100%

Table 3: Current Status of African Caribbean Women Residing in Lewisham who were Referred to Patient Navigators

Pending (Unable to Contact)

111 women are still pending. All the women in this category were sent a letter and this was because either there was a problem with their phone number or Navigators were unable to contact them by phone after several attempts. The status of these 111 women can be further broken down as follows:

- Unable to contact after several attempts, letter sent: 35 women
- Disconnected Phone Number, letter sent: 40 women
- Wrong Number, letter sent: 26 women
- No Phone Number Provided, letter sent: 8 women
- Fax Number, letter sent: 2 women

Already Screened

60 women had already been screened between the time of their initial missed appointment and the Navigator making contact or they had already made an appointment to be screened and were awaiting their appointment date. Of these 60 women, 2 were screened privately, 1 said she had been screened at work and 1 was screened in Zimbabwe. The remaining 56 were screened through the normal channels via the South East London Breast Screening Programme.

Travelling

16 women, as of writing this report, were abroad on an extended trip; many were expected to be out of the country for several months.

Declined

19 women declined the offer by Navigators for a breast screening appointment to be made on their behalf. One of these women declined because she found her last breast screen too painful and didn't want to subject herself to the experience again, one woman didn't feel it was necessary, three women stated that they were currently very busy and unable to attend, three women had some concern or fear about the procedure, one woman had recently been discharged from hospital and wanted a break from the high volume of tests she has undertaken over the past year and one woman was currently experiencing some family issues making it hard for her to attend. The remaining nine women were simply not interested in being screened.

Other

In addition to the above, 2 women no longer live in the UK, 4 women are unable to attend screening because they have a medical condition and 3 women have moved from their GP registered address and their new contact details were not provided therefore these three women could not be followed up.

Reasons for Not Attending Initial Breast Screening Appointments

52 women residing in Lewisham have now provided a reason for not attending their initial mammography appointment and this is summarised in figure 2. The most common reason given was not receiving the invitation letter (33% of women) followed by being busy on the date the appointment was scheduled for (21% of women) and the third most common reason for not attending was travelling at the time of the appointment (15% of women).

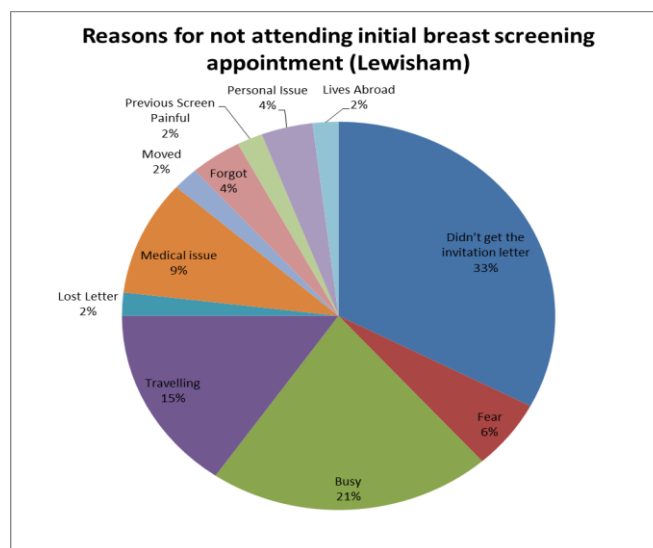


Figure 2: *Reasons why women (n=52) in Lewisham did not attend their initial screening appointment*

3.2 Community Outreach

In addition to the work of engaging with women who had not attended their routine mammography appointments the Patient Navigation pilot project involved community outreach to raise awareness in the African Caribbean community of breast cancer and the importance of screening. Table 4 summarises the awareness raising activity of the project thus far. There is still the potential for more activity as a number of community groups are yet to confirm with Navigators their interest in organising a breast health awareness session for their organisation.

Date	Event	Type of Community Group/Event	No. of Attendees
2 nd Oct 2010	Presentation and Q&A	Holy Redeemer Church, Lambeth	10
9 th Oct 2010	Presentation	State of Black Britain, Elephant and Castle	50
10 th Oct 2010	Radio Interview	Galaxy Radio	>500 listeners
12 th Oct 2010	Talk	Black Elderly Group of Southwark	15
16 th Oct 2010	Stall	Peckham Health Information Day	30
26 th Oct 2010	Radio Interview	Ban2 Radio	>500 listeners
30 th Oct 2010	Radio Interview	ZimOnline Radio	>500 listeners
13 th Nov 2010	Presentation and Q&A	New Testament Assembly, Deptford	26
20 th Nov 2010	Radio Interview	Voice of Africa Radio	>500 listeners
21 st Nov 2010	Radio Interview	BBC 94.9	>500 listeners
Nov 2010	Article	Keep The Faith Magazine	National distribution
Nov 2010	Article	BBC Scrubbing Up	National distribution
7 th Dec 2010	Presentation	NHS Southwark Peckham Health Event	40
9 th Dec 2010	Round table discussion	Black Elderly Group of Southwark: Somali Women's Group	15
8 th March 2011	Patient Navigation Launch	House of Parliament	50
21 st March 2011	Presentation and Q&A	Emmanuel Pentecostal Church, Lewisham	24
22 nd March 2011	Stand	King's College Hospital, Southwark	>200 people
28 th March 2011	Presentation and Q&A	The New Testament Church of God, Lee, Lewisham	40
21 st April 2011	Presentation and Q&A	Guernsey Grove Community Association, Lambeth	10
28 th April 2011	Presentation and Q&A	Somali Women's Group, Southwark	12
30 th April 2011	Presentation and Q&A	Word of Life Ministries, Lewisham	5
8 th May 2011	Presentation and Q&A	Micah Ministries	31
30 th May 2011	Short Presentation	Word of Life Ministries, Breakfast Meeting, Lewisham	30
26 th June 2011	Presentation and Q&A	Seven Day Adventist, Health Screening Day	25
16 th July 2011	Short Presentation	WOW Ministries, Breakfast Meeting, Lewisham	23

Table 4: A Summary of the Outreach Activity of the Patient Navigation Pilot Project

For events where the sole focus was on breast cancer awareness and the sessions were led by Betterdays Cancer Care and Cancer Black Care feedback forms were distributed to attendees. In addition for events in Lewisham an Evidence Report Form was completed by the Patient Navigator and submitted to NHS Lewisham. The information received from the feedback forms are summarised in the following section.

Summary of the feedback received about the outreach sessions

Feedback forms were distributed at each event that was led by Betterdays Cancer Care and Cancer Black Care. In total 83 forms were completed and returned. The feedback form aimed to be as concise as possible to encourage attendees to complete them. The form included eight questions, three multiple choice and five opened ended questions.

Multiple Choice Questions Summary

- When asked if attendees found the presentation useful all 83 respondents said yes.
- When asked to rate the speakers, 76 respondents (91.6%) rated the speakers as excellent, 4 (4.8%) rated the speakers as good and 3 (3.6%) left this question blank.
- When asked to rate the content of the presentation, 78 respondents (94%) rated the content of the presentation as excellent, 4 (4.8%) rated the content as good and 1 (1.2%) left this question blank.

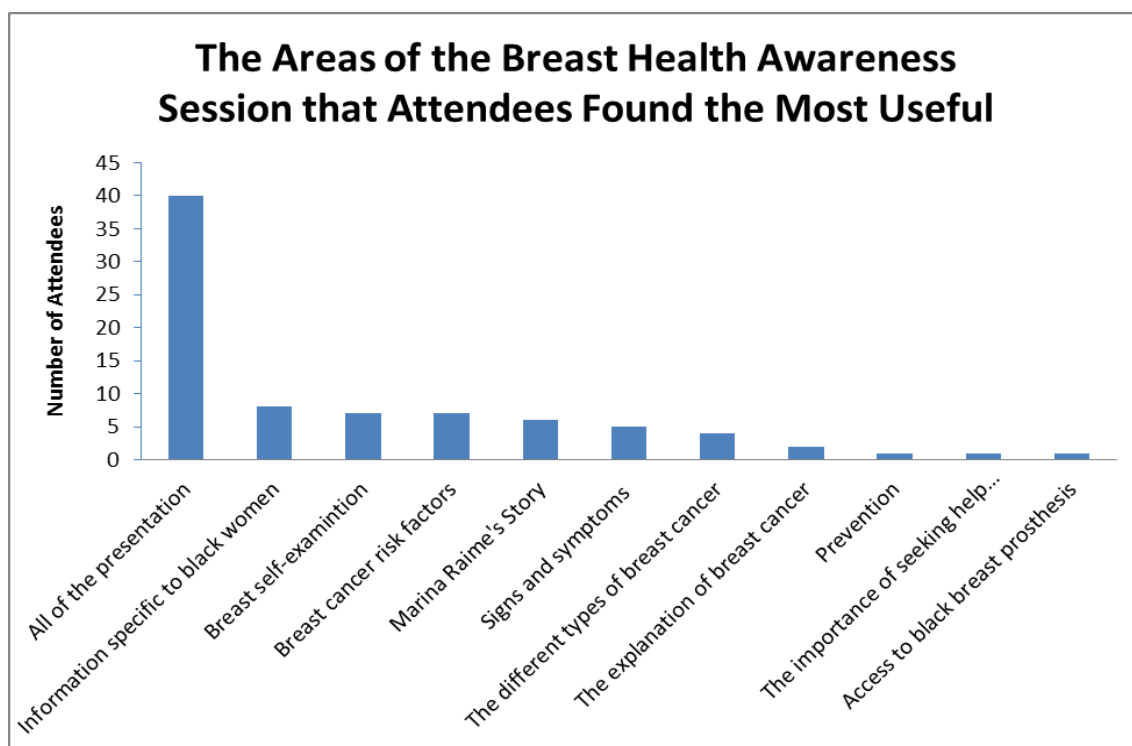
Opened-Ended Questions Summary

1. Attendees were asked what part of the presentation they found to be the most useful. 72 attendees completed this question and their responses are summarised in graph 1.

40 respondents (56%) stated that the whole presentation was useful. 8 (11%) noted that the information specific to black women was the most useful part of the presentation whilst 7 respondents (10%) indicated that the explanation on how to conduct a breast self-examination was the most useful. In addition, another 7 respondents (10%) identified that the information about risk factors as the most useful and 6 attendees (8%) found Marina Raime's story to be the most useful. Furthermore, 4 attendees (6%) selected the description of the signs and symptoms of breast cancer to

be the most useful aspect of the presentation. Other responses given for this question were as follows :

- The explanation of breast cancer
- Breast cancer statistics
- Prevention
- The importance of seeking help promptly
- Access to black breast prosthesis

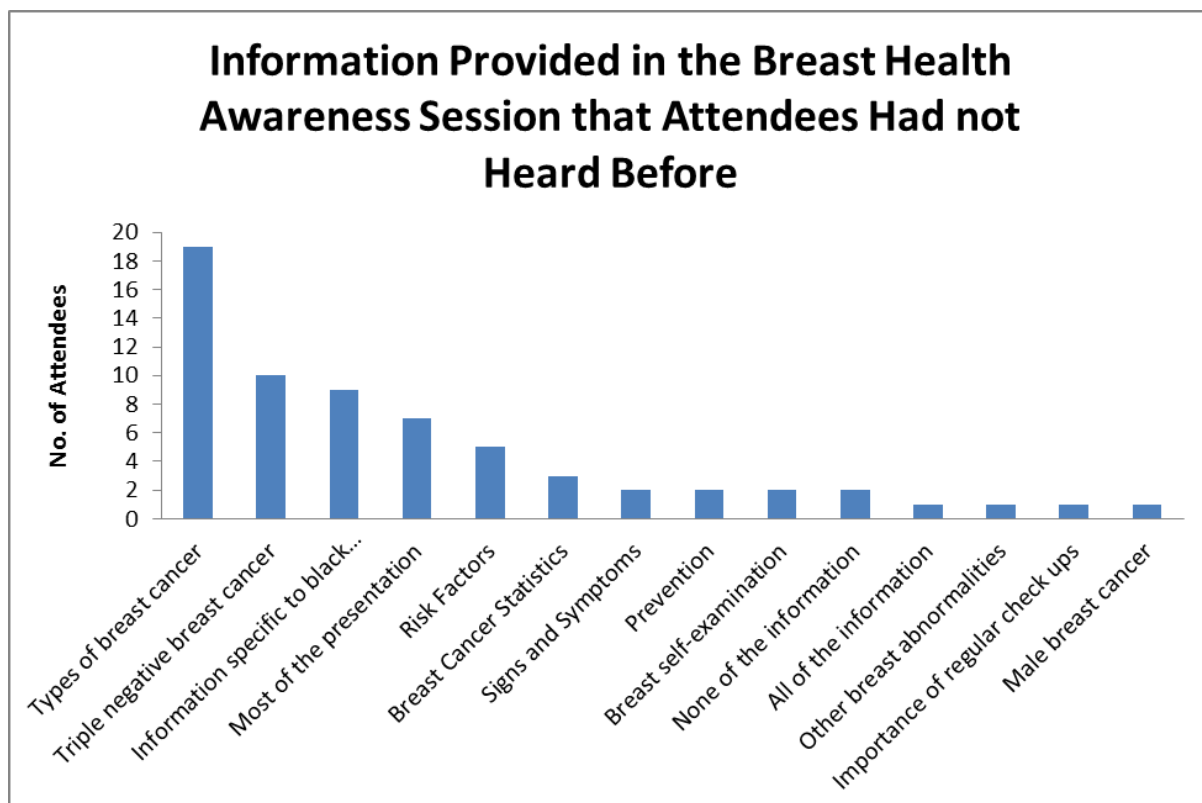


Graph 1: A summary of the responses received by attendees when asked what aspect of the breast health awareness session they found to be the most useful

2. Attendees were asked whether there was anything in the presentation that they had never heard before. 63 attendees completed this question and the responses received are summarised in graph 2.

19 respondents (30%) stated that they had never heard of the different types of breast cancer and 10 attendees (16%) indicated that they had never heard of triple negative breast cancer. 9 women (14%) explained that they had never heard the information specific to black women before and 7 (11%) stated that they had never heard most of the content of the presentation before. In addition, 4 attendees (6%) stated that they had never heard of the risk factors for breast cancer and finally other answers given to this question were:

- The breast cancer statistics
- The signs and symptoms
- Prevention
- Breast self-examination
- All the information
- None of the information
- The description of breast cancer
- Male breast cancer
- The importance of regular check ups
- Other breast abnormalities besides breast cancer



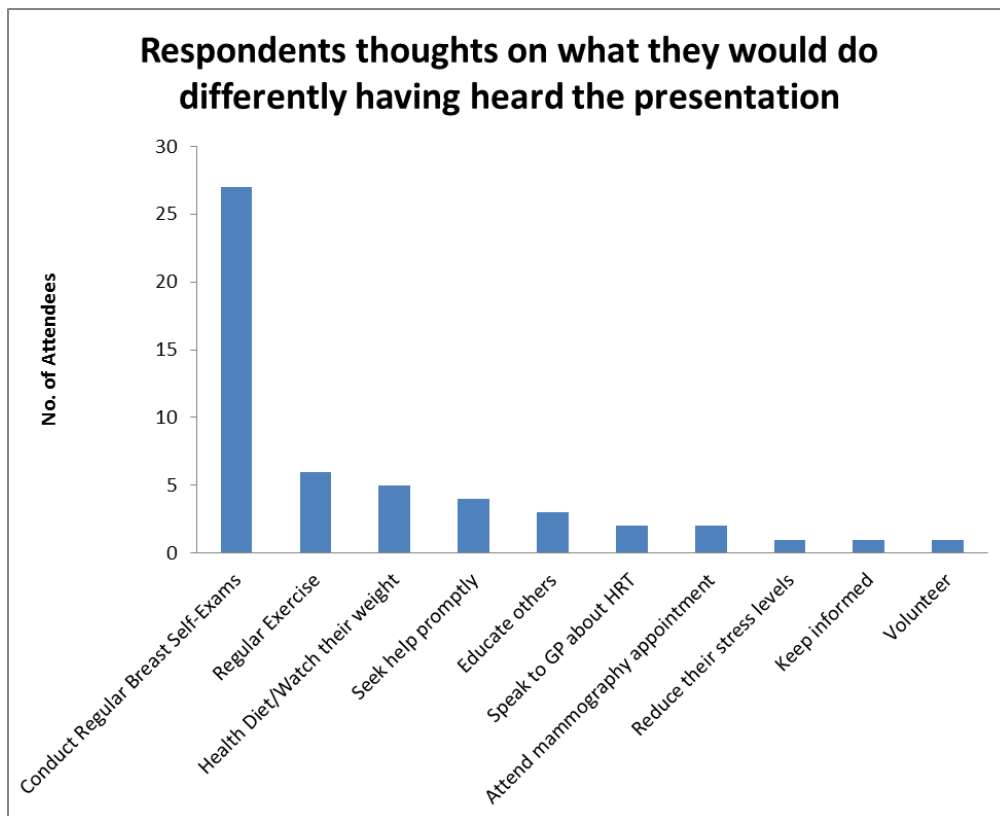
Graph 2: A summary of the responses received by attendees when asked what part of the presentation they had never heard before

3. The third open-ended question that attendees were asked was what they would do differently having heard the presentation. 41 attendees completed this question and their responses are summarised in graph 3.

27 respondents (66%) said that they would endeavour to conduct a regular breast self-examination; 6 (15%) stated that they would attempt to do more regular exercise, 5 respondents (12%) indicated that they would change to a more healthy diet and try and watch their weight; and 4 stated that they would be pro-active and visit their GP promptly if they ever noticed any of the signs of breast cancer. Other answers given were:

- Attend regular mammography appointments

- Reduce stress levels
- Keep informed
- Volunteer
- Tell others about the information presented at the event
- Speak to their GP about HRT



Graph 3: A summary of what attendees would do differently after hearing the breast health awareness presentation

- Attendees were given the opportunity to comment on how the breast health awareness session could be improved. The majority of people who responded to this question, 40% of respondents, stated that there was a need for more such events so that the information is made available to more of the black community. 27% of respondents to this question did not provide a suggestion for improvement but commented that the

session was well delivered and that the speakers did a good job. 2 respondents felt that more publicity was needed for the event another 2 respondents gave general feedback on the topic stating that they felt that breast screening should be conducted more frequently than every three years. Other suggestions for improving the session included the following:

- Session should be delivered at secondary schools to ensure early breast cancer awareness
 - Events should be held on the weekend to ensure that more women can attend
 - The leaflets and information should be made available at GP surgeries and chemists
 - More information on how to do a breast self-examination should be made available to the community
 - It was suggested that less medical terms be used in the presentation.
5. Finally, respondents were asked if they would like to make any further comments about the session or the topic of breast cancer.

The comments provided about the session were very positive with respondents stating it was a very good, informative session, examples of the comments provided include:

“An excellent presentation with real testimonies delivered in an open and honest way – should be taken to schools/colleges as well as PCTs”

“The information was well presented, relevant and well-paced”

“The presentation was excellent. The presenter was extremely good and positive considering that cancer is not an easy topic to talk about.”

Additionally, a number of respondents felt that that session should be repeated to ensure that more women were able to access the information. Another comment was directed at the NHS stating that they should consider lowering the age of screening for black women.

4. Discussion

Screening Uptake

In general the final outcomes of the women residing in the SE15 area and those residing in Lewisham were very similar.

- i. Patient Navigators were able to make mammography appointments for 39% of the SE15 women (250 women) and 36% of the Lewisham women (121 women). Of the women that appointments were made for 66% of SE15 women and 63% of Lewisham women attended their appointments.

7 out of the 250 women from SE15 were called back for further assessment and 2 out of the 121 from Lewisham were called back for further assessment. Thus in total 9 women required further investigations. Seven of these nine women had a clinical procedure following which their status was listed as "Routine Re-call After Further Assessment". One of the nine women was lost to follow-up and the final lady was referred to a surgeon.

- ii. There were a significant number of women that Patient Navigators were unable to contact even after extensive follow up where possible.

In the SE15 area and in Lewisham, Navigators were unable to contact 32% (202 women) and 33% (111 women) of women respectively. The data summarised in the results section indicates that a number of these women have probably moved from their GP registered address. This conclusion is made based on the fact that 23% of the 202 women in SE15 that Navigators were unable to contact had phone numbers that were disconnected the same was true for 36% of the 111 women in Lewisham that Navigators were unable to contact. In addition to this 14% of the 202 women in SE15 and 23% of the 111 women in Lewisham that Navigators were unable to contact had wrong numbers listed for them.

Finally, Navigators were unable to contact 56% of the 202 women in SE15 and 32% of the 111 women in Lewisham after several attempts through phone calls and sending a letter. No conclusions could be made as to why these women were unreachable; it could be that they were busy, have moved or are travelling.

- iii. A number of women had made an appointment to be screened since DNA'ing so that when Navigators made contact 8.9% (57 women) of the SE15 women stated that they had already been screened or were awaiting their appointment date and 18% (60 women) of the Lewisham women stated the same.

- iv. 6% (39 women) of the SE15 women and 4.8% (16 women) of the Lewisham women were out of the country when the Navigators attempted to contact them. Many of these women were expected to be out of the country for a significant period of time in some cases up to six months.
- v. 5.8% of the SE15 women (37 women) and 5.6% (19 women) of the Lewisham women declined the offer for a mammography appointment to be made for them. The majority of women who declined 86% of the 37 women from SE15 and 47% of the 19 women from Lewisham were simply not interested. Others declined for very specific reasons such as a bad past experience with screening, being busy, fear, concern over the procedure or family issues.
- vi. The remaining women in Lewisham or SE15 had either moved, died, live abroad or had a medical condition.

Looking at the outcomes of the women in Lewisham and SE15 there appears to be three issues:

1. Lack of correct or up-to-date information on GP lists.

Looking at the SE15 women 22% of women fit into this category and in Lewisham 24% of women fit into this category. Follow up by Navigators helped to identify the whereabouts of some of the women. For instance some women now live abroad or have died. The remaining women either have moved and their new contact details were unable to be determined by Navigators; their phone numbers were disconnected or wrong; or no phone number was provided for them. None of these women responded to the letters that were sent to them by Navigators.

2. The need for follow up of women

A number of women who DNA'd were quite willing to attend screening but either the date provided for them was not convenient, they didn't receive their invitation letter, they had travelled, or they needed a bit of reassuring. These women just required some follow up to ensure that they were able to access the mammography service at a time that was convenient for them or needed a bit of encouragement to attend. By following up with these women 250 women from the SE15 area and 121 women from Lewisham, a total of 370 women, who would have been lost to the system were successfully engaged by Navigators and appointments made for them.

3. A mobile population

The data shows that African Caribbean women over the age of 50 residing in Lewisham and SE15 form a group that is very mobile. Navigators were unable to contact a number of women after several attempts via phone and after sending letters. 113 women from the SE15 area and 35 women from Lewisham, a total of 148 women, fell into this category. Also Navigators confirmed that a number of women have now moved from their GP registered address but were unable to determine their new addresses.

In addition, with women coming towards the end of their working life or having already retired and still having close links to Africa and the Caribbean a number of women were travelling and expected to be out of the country for a significant period of time. 39 women from SE15 and 19 women from Lewisham, a total of 58 women, as of writing this report had travelled.

Community Outreach

In addition to engaging directly with women who had DNA'd their mammography appointments a programme of breast health awareness was implemented within the African Caribbean community in Southwark, Lambeth and Lewisham. These sessions aimed to raise awareness of breast cancer, the signs and symptoms and the importance of breast screening within the African Caribbean community. Through the sessions we were able to identify a number of areas that the community lacked awareness of. These included the types of breast cancer, risk factors, the signs and symptoms, breast self-examination and information related to how breast cancer affects black women specifically. It demonstrated that messages about breast cancer have not been reaching the African Caribbean community especially the key messages that are important to black women, such as the younger age of onset and the increased risk of developing more aggressive forms of the disease.

In addition, the feedback from sessions highlighted the interest and need for such events with all attendees giving the workshops positive feedback, with many requesting the event be repeated and stating it was useful and informative. The parts of the workshop that attendees found to be the most useful were all of it, the information describing how breast cancer affects black women, breast self-examination, the risk factors, the signs and symptoms and Marina Raime's story. This identified that an approach that provides the key breast cancer information that is specifically relevant to black women in addition to sharing the personal experience of a black breast cancer patient is an effective approach at raising

awareness in the community. This approach is more effective than a generic breast health awareness presentation that is aimed at the general population.

Another success of these sessions were the life style changes that attendees were prepared to make to reduce their risk of developing breast cancer or ensure early detection. These included the majority of women stating that they would now perform monthly breast self-examinations and other women stating that they would exercise regularly, improve their diet or watch their weight.

5. Conclusions

Through Patient Navigation women who would otherwise have been lost to follow-up were identified and subsequently attended screening as a result of Navigators making appointments on their behalf. This has increased the uptake of screening within the African Caribbean population in Southwark and Lewisham and hence demonstrates the effectiveness of Patient Navigation.

The data suggests that the major contributing factor to the low uptake of screening is that this population is very mobile with many women being unreachable, on an extended trip abroad; have moved from their GP registered address or now live abroad. Therefore an effective strategy for follow-up of screening invitation letters is of utmost importance for this population; this can be addressed through Patient Navigation.

The community outreach aspect of the pilot was successful in raising awareness about breast cancer in the African Caribbean community in Lewisham, Lambeth and Southwark. Feedback from the breast health awareness sessions highlighted the need and high interest of the outreach work as well as the effectiveness of the format used in getting the key messages across to this community.

6. Further Work

Having demonstrated the effectiveness of Patient Navigation in engaging with women who have DNA'd their mammography appointment further work can be conducted in other boroughs of London where breast screening uptake is low. In addition, the content of the Patient Navigation project can be extended to include diagnostic and treatment Navigation where Navigators guide patients through the further assessment and treatment process to ensure that patients have all the support, resources and information that they need.

Finally, other cancer areas can benefit from Patient Navigation such as bowel and cervical cancer. Talks are already underway with Bowel Cancer UK and Jo's Cervical Cancer Trust to determine how Patient Navigation can be utilised in these areas to increase screening uptake, provide support to patients and understand some of the barriers to accessing services.

7. Recommendations

Based on the Patient Navigation Pilot project the following are recommended:

- I. Update GP lists to ensure the details of women are correct.
- II. Better follow up of women who have DNA'd to introduce a more personalised approach to the screening process. This can be achieved through a Patient Navigation approach.
- III. Introduce more flexibility in the appointment system such as evening or weekend appointments.
- IV. More community outreach work targeting the African Caribbean community

8. References

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