Using Knowledge Management Tools and Techniques to Increase the Rate of Attendance at Breast Screening

Rajeev K. Bali[1], Jacqueline Binnersley[1], Vikraman Baskaran[2] and M. Chris Gibbons[3]

[1]*BIOCORE Applied Research Group, Coventry University, Puma Way, Coventry, U.K.*
[2]*College of Continuing and Professional Studies, Mercer University, Atlanta, U.S.A.*
[3]*Johns Hopkins Urban Health Institute, John Hopkins University, Baltimore, U.S.A.*

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Abstract: Breast screening is an important method of detecting cancer early, with around a third of breast cancers now diagnosed through screening. Previous research has demonstrated that there are many contributors to health inequalities, with poor access to good health services chief among them: there are significant disparities in the use of health services linked to income, ethnicity and education. Empirical data was analysed from a breast screening service (n=159,405) using advanced data mining techniques, as well as being collected from service users by way of two focus groups conducted before and after the use of a detailed questionnaire (n=102). The results were used to make recommendations of interventions to reduce the rate of non-attendance.

1 INTRODUCTION

Breast cancer is the most common cancer in women, with over 40,000 being diagnosed each year in the UK (Cancer Research UK, 2005). Screening is an effective way to detect cancer early, with around a third of breast cancers being diagnosed in this way. There is currently a screening program catering to almost two million women in the UK (Cancer Research UK, 2005), which screens all eligible women every three years. The information published by the UK Government Statistical Service has shown that for the ten years since 1995, the uptake has remained constant at around 75%.

Previous research has shown that non-attendance is associated with having to travel long distances to a screening centre (Baskaran, 2008), with a woman's economic background and a lack of family support (Katz et al., 2000). According to Bekker et al. (1999), non-attendance can be attributed to disinterest, negative attitudes, beliefs, medical problems and fear of X-rays. These factors could be addressed by educating people about the importance of screening and tackling some of the socio-cultural and personal barriers to attendance (Cassandra, 2006). Baskaran (2008) was able to predict breast screening attendance using factors such as age,

previous attendance, postal area, past cancer history, history of a false positive result and a representation of socio-economic status called the Townsend score (Townsend et al., 1988).

Semi-permanent factors such as ethnicity, age, marital status, income, education and long term conditions may affect whether women attend screening (Katz et al., 2000). These may be more difficult to address than temporary factors such as employment, personal apprehensions, beliefs, knowledge and access to screening facilities (Sin and Leger 1999, Bekker et al., 1999). It has been found that using mobile screening units rather than expecting women to travel long distances can improve attendance rates (Day et al., 1989). Interventions with educational materials have limited effectiveness but when used in conjunction with primary care initiatives they can help women to make informed decisions about screening (Jepson et al., 2000). Primary care can address some of the temporary factors, such as personal apprehensions, beliefs and knowledge (Fox et al., 1991; Bekker et al., 1999). Bankhead et al. (2001) found letter based interventions by primary care to be effective and Atri et al. (1997) found a telephone intervention to be effective.

Baskaran (2008) used the techniques and tools of knowledge management to identify women with

characteristics associated with non-attendance at breast screening. Knowledge management is an approach that is concerned with the creation and sharing of knowledge, with the aim of improving the efficiency and effectiveness of organisations (Bali et al., 2009). Early detection has a huge impact on reducing cancer related deaths (Baskaran, 2008) and therefore, the primary concern is to reduce non-attendance (Bankhead et al., 2001).

2 AIMS AND OBJECTIVES

The current project aimed to use the tools and techniques of knowledge management to identify women who face barriers to breast screening attendance and to suggest effective ways of overcoming these. The objectives were to:

- Show that screening non-attendance can be attributed to demographic factors and screening history
- Understand the reasons why some women fail to participate in the program
- Examine inequalities and disparities in relation to accessing screening
- Recommend interventions to reduce the impact of the barriers and increase the rate of attendance at breast screening

3 METHODS

Stage One: (Quantitative) Analysis of Screening Records

The Warwickshire, Solihull and Coventry Breast Screening Service is part of the National Breast Screening Program and invites around 55,000 women to participate each year. Data mining techniques were used to analyse a large number of the records of service users.

Stage one of the current study used two distinct approaches. The first approach focused on predicting non-attendees and the second approach used results generated at the end of the screening episodes to identify those women who had failed to attend.

The first approach used an artificial intelligence algorithm (which embedded knowledge management activity) to predict non-attendance. It employed Neural Network algorithms and included a Service Orientated Architecture to deliver the knowledge. This work combined the existing

National Breast Screening Computer System software into a single platform and created a prototype software component based on Open Source technologies. The prototype software was automated to produce the pre-processed data and eventually normalise the data for artificial intelligence (neural network) assimilation. These activities were performed sequentially.

The Java Based Attendance prediction by Artificial Intelligence for Breast Screening model was simulated on the Open Source technology platform. It used historical screening data and demographic information from the National Breast Screening database as predicting factors. This was converted to a flat file and formed the dataset that was presented to the input neurons. The output neuron remained at 'zero' when a woman was predicted to attend screening and showed 'one' for a non-attendee (see Figure one). Earlier research had confirmed that one hidden layer would suffice to map any multivariate type of input domain to the output domain. During the training stage, the error function was fed back through the network from the output neuron. The knowledge capture was implemented using the architecture shown in figure one.

The user (via the GUI interface) pointed the neural networks to the location of the historical data (in the flat file) to train the network. Once the training was completed, the net was pointed to the normalised data so that prediction could be initiated. Any errors during the pre-processing, training and the actual prediction activities were stored in individual log files which could be viewed at a later point in time.
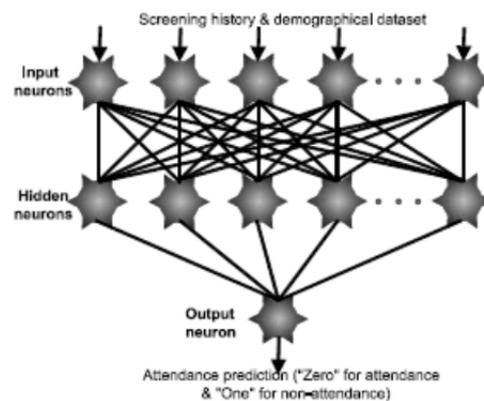

Figure 1: Knowledge creation captured within artificial intelligence neural networks.

The GUI gave the option to the user to initiate the Simple Object Access Protocol (SOAP) message. The message body was instantiated with

reference to an eXtensible Markup Language (XML) schema definition designed on the Health Level 7 version 3 standards. The message was called upon by the software to generate the SOAP envelope and attached the XML message to the SOAP body with a digital signature (for security). The Java-based web services technology provided encryption to make the message completely secure. The message was transmitted via web services to the general practitioner's mailbox server.

Once the doctor's server connected with the mailbox it downloaded the messages and automatically updated the womens' records with the likelihood of non-attendance. Meanwhile the breast screening service continued its routine process of inviting women by dispatching an appointed letter (with details of the screening date and time). General practitioners were now aware of those women who are likely to miss breast screening appointments. If those women visit the doctor for other services the doctor can initiate an opportunistic intervention, thereby increasing the likeliness of improving screening uptake.

The second approach relied on knowledge generated through a bespoke software program written to capture non-attendees from results generated by the National Breast Screening Software. The prototype

framework incorporated the artificial intelligence model for creating a list of predicted non-attending women. The screening service produced the results of the screening activity and used a report template to export the batch list. The user (via GUI) pointed to the location of the flat file to segregate the non-attendees. Once segregation was complete, a new message was generated using the same procedure as before and it was sent to the respective general practitioners. This updated the women's medical records with their non-attendance. The prototype combined the demographic data pertaining to the non-attending women and sent this information to the General Practitioner as a messaging package.

The package triggered the generation of an electronic message based on the Health Level 7 version 3 standards and utilised Service Orientated Architecture as the message delivering technology. The system has been designed in a way that will enable it to be integrated into the UK health system. Both approaches relied on the ability of the general practitioner to intervene once women had been identified as having characteristics that had been shown to be associated with non-attendance.

Stage one of the project used quantitative techniques to establish that non-attendance can be predicted. The results can be shared with healthcare providers in order to target interventions at women who have characteristics associated with non-attendance and overcome some of the barriers that they face.

As the data collected in stage one was impersonal (in addition to being anonymised), personalised (human) components such as personal apprehension, ethnicity-based influences, age-based factors, personal economic circumstances and socio-cultural factors also needed to be considered. To address these "softer" issues and in order to triangulate the results (from a qualitative perspective), the use of focus groups was a natural evolution of this study. In order to explore these aspects further, two focus groups were carried out (which straddled a detailed questionnaire).

Stage Two: (Qualitative) First Focus Group

The information from the analysis of the records was used to form a list of topics for discussion in the first focus group, the aim of which was to identify barriers to breast screening attendance. Participants for the focus groups and questionnaire were clients of Age UK, an organisation that aims to improve the lives of older people (Age UK, 2013). Data from the focus groups was analysed using thematic analysis as described by Aronson (1994).

Stage Three: (Quantitative) Questionnaire

The results of the initial focus group were compared to the literature review and used to form a questionnaire, using a technique described by Hoppe et al. (1995) and Lankshear (1993). The aim of the survey was to find out whether the views expressed by the small number of people in the focus group were shared by a larger and more representative sample.

Stage Four: (Qualitative) Final Focus Group

A second focus group discussed ways of tackling the barriers to screening that had been identified.

4 RESULTS

Stage One: Analysis of Screening Records

Data mining techniques were used to analyse records from the local breast screening service. The valid records constituted 86% (n=159,405) of the extracted dataset. From 2002, women in the age range 65-70 had an uptake of 70%. The efficiency of the program can be mapped to attendance and the number of non-attendees has been increasing so that it has now reached half a million. Simple projection of this data suggests that nearly 4,000 cancer incidences would have been missed due to non-attendance. A literature review identified factors that have been shown to be associated with non-attendance and for this reason analysis of the records focused on key fields like Townsend Deprivation Score, postcode and distance that women travelled to a screening appointment.

Stage one of the current study produced bespoke software developed within an open source environment that was able to use demographic data to identify individuals who were likely to face barriers to attendance. Sharing this knowledge with primary care enabled health professionals to deliver interventions that helped the women make informed decisions about whether to attend screening.

Stage Two: First Focus Group

Six participants took part in the first focus group. They were five women and one man, with ages ranging from 45-87 years. They all stated that their ethnicity was English or British and they were either retired or a housewife. Participants were asked why they thought some women did not attend breast screening and a variety of possible reasons were discussed. Three main themes were identified and the results will be presented under headings related to these.

Communication Problems

The theme of communication problems incorporated sub-themes of people not understanding English, people being hard of hearing and people not understanding medical terms.

The group thought interpreters and/ or representatives from the patient's community should be available to support people who do not understand English. It was also suggested that in order to tackle all the forms of communication

problems, health professionals should avoid using jargon and check that they have been understood.

Transport Problems

Public transport was thought to be unreliable, journeys often took a long time and participants were reluctant to ask other people for lifts. One participant had used hospital transport and thought it would be helpful to raise awareness of this service.

Reasons Associated with Beliefs and Attitudes

Three sub-themes were identified: embarrassment, anxiety and not realising the importance of screening. The group thought that older people were more likely to be embarrassed about having to undress for examinations than younger people and people with a cultural background that emphasised female modesty might find screening examinations particularly difficult.

It was clear that there was no single reason for the anxiety that many women experience in relation to screening. Two participants who had not yet been invited to attend screening were anxious because other people had told them that the procedure was painful. Other group members had first-hand experience of painful breast examinations and this made them reluctant to return. One woman had extensive scarring on her chest that made screening unbearable. It was suggested that professionals should acknowledge that the procedure could be uncomfortable and offer ultrasound scans where appropriate. The anxiety about receiving a positive result was also discussed and it was also suggested that some people might be unaware of the value of screening.

Stage Three: Questionnaire

147 questionnaires were given out and 102 were completed, giving a response rate of 69%. 93 women and 9 men completed the questionnaire and their average age was 65. Although the majority (69) stated their ethnicity to be White British, 16% were from an Asian Background and 12% were from a Black background. People from an Asian background make up 12% of Coventry's population and people from a Black background make up 3% (Coventry Link, 2012). These are the largest minority groups in Coventry and were well represented in the survey. The pie chart (see figure two) shows the ethnic origins of the survey participants. Four Irish people took part in the
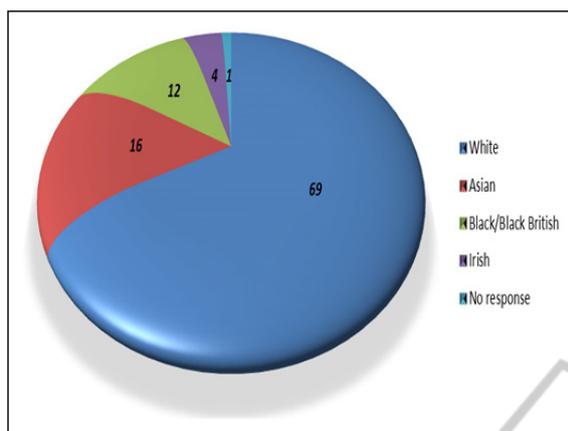
Figure 2: Pie chart comparing the ethnic origins of the participants in the questionnaire survey.

survey and one participant did not answer the question about ethnic origin.

75% of the participants had been invited to attend screening and only four had not done so. Their reasons for non-attendance were: the appointment being at an inconvenient time, being afraid of X-rays, not wanting to get a cancer diagnosis and being put off by adverse publicity about over-diagnosis.

78% of the participants thought problems with communication might be a reason for non-attendance. They suggested having more interpreters, providing the information in different languages, strengthening links with local communities and improving the communication skills of professionals.

56% of the participants thought that difficulties getting transport would affect attendance. Solutions included having more mobile units and holding screening at locations convenient for users of public transport.

11% of the participants thought that embarrassment might put women off attending screening. They thought creating links with local communities and reassuring women that screening is carried out by female professionals would help.

Anxiety about the procedure or the possibility of receiving bad news was the most common reason that participants gave for non-attendance, with exactly 50% of the participants mentioning anxiety. Eleven of the participants said that having more information about the procedure would be useful. The use of television to educate people about what happens and providing a helpline where women can ask for more information were suggested. Two participants thought the recent bad publicity about over-diagnosis might make some women reluctant to

attend and three participants thought that some women might not appreciate the importance of screening.

It was clear from both the focus group and questionnaire results that anxiety was not a single factor but included concerns about the procedure (including ignorance about what was involved and concerns that the procedure would be painful) and anxiety about receiving a cancer diagnosis. Educating people about the procedure was suggested as a way to reduce anxiety. It was also suggested that the service should balance recent negative publicity about over-diagnosis with positive stories of how early diagnosis and treatment can enable cancer to be treated while it is still at an early stage.

The results from the questionnaire and the focus group informed the discussion that took place in the final focus group, the purpose of which was to suggest ways in which the barriers to screening could be overcome.

Stage Four: Final Focus Group

Five participants took part in the group. They were all women and their ages ranged from 54-77.

Communication Problems

One of the group suggested having more interpreters available and another pointed out that people often have cultural barriers to overcome in addition to language barriers. Suggestions of how these could be tackled included promoting screening at women's groups and encouraging community elders to support the program.

It was noted that it is not always obvious if people have difficulty hearing. Health professionals should be aware that this might be the case and check that they have been understood. Several group members had experienced being unable to understand the terms used by professionals and thought it would help if familiar language was used.

Transport Problems

Although providing transport was suggested, this was thought to be expensive and ensuring that screening is carried out in locations convenient for public transport was suggested as a more realistic solution. It was also thought to be important to offer appointments at a range of times, including evenings, to make these convenient for the service users.

Beliefs and Attitudes

Participants thought that creating links with communities would help women to feel comfortable about attending screening. Two participants thought it was important for screening to be carried out by female professionals and for potential clients to be made aware of this. It was suggested that women should be encouraged to ask professionals about screening so they get accurate information and reassurance. One participant who had been successfully treated for breast cancer as a result of this being picked up at screening thought women who had similar experiences would be good at persuading others of the importance of screening.

5 LIMITATIONS

A local sample of participants was used in the study and it is not clear how far the results can be generalised to other areas of the country. Although care was taken to ensure that the participants were representative of the local population of older adults, there are ways in which people who attend Age UK meetings may differ from those who fail to attend breast screening. Those who attend the meetings are able to arrange transport to do so and it can be assumed that they will also be able to arrange transport to attend screening. People attending activities organised by Age UK are also interested in their health and in socialising. These characteristics may not be shared by people who fail to attend screening. It is clear that ethnicity and family support are factors affecting attendance. Women who do not speak English, rarely socialise outside their community and have family responsibilities that make it difficult for them to attend appointments may also be unlikely to be involved with the type of activities offered by Age UK.

6 RECOMMENDATIONS FOR PRACTICE

It is clear from the results that the barriers to breast screening attendance are varied and include social influences like family support and psychological factors such as anxiety. It is likely that women who do not attend screening face a combination of barriers. Contemporary approaches like knowledge management offer a means by which intelligence about individuals can be shared between primary care and the breast screening service, in order to identify women who may face barriers to attendance. Targeted interventions, such as providing information in their own language can then be deployed.

The main barriers to breast screening attendance that were identified during the study included those associated with communication. Problems getting transport to appointments was also a barrier but the most common reason for non-attendance was thought to be anxiety. This ranged from concern that the procedure would be painful to being afraid of receiving bad news. In common with a recent local study (Coventry Link, 2012), many participants thought that there was a lack of knowledge about screening and that educating people about its importance and what is involved would increase attendance rates. The results of the current study suggest that attendance could be improved by:

- Providing invitations and information about screening in simple language and in different languages where appropriate
- Having interpreters and community representatives available to support women at appointments
- Ensuring screening is carried out at locations that are easy for women to get to by public transport
- Creating links with local communities, educating people about screening and encouraging them to talk to professionals about their concerns
- Publicising stories of women who have been successfully treated for breast cancer as a result of being diagnosed early

It will be important to evaluate the effect of these initiatives on attendance rates.

7 CONCLUSIONS

Baskaran (2008) identified individual characteristics, such as age, ethnicity and socio-economic status that were associated with breast screening non-attendance. This study demonstrated that such characteristics could be used to predict non-attendance and provide health professionals with the opportunity to carry out interventions, such as ensuring information is provided in a language that will be understood by potential participants.

The current study identified additional barriers to attendance that were concerned with

communication, transport, beliefs and attitudes. The results were similar to another local study (Coventry Link 2012) which considered barriers faced by people from ethnic minority backgrounds when trying to access screening services. Both studies identified communication problems, transport problems and attitudes as barriers to attendance. The recommendations that were formed from the results of the current study provide suggestions of interventions that would be expected to increase screening attendance rates.

Future work should include evaluating the effect of the suggested interventions on the attendance rate. Research should also be carried out in other areas of the country to see how far the results can be generalised.

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