

Preparing women for breast screening mammography: a feasibility study to determine the potential value of an on-line social network and information hub

Abstract

This feasibility study explored the attitudes of women towards social media for support about breast screening mammography. It sought their ideas about what a dedicated breast screening hub or Digital Support Network (DSN) might comprise; how they would network with other women on the DSN; what format information might take; and whether a health professional should be available on the DSN. Data comprised 94 survey questionnaires and two focus groups; one comprised women in the breast screening population age group, the other was a younger group. A socio-ecological framework was used to identify key influencers and potential barriers for the implementation of a mammography DSN. The study identified issues related to three intersecting concepts which influenced women's behaviour: on-line conversations about health in general; on-line conversations about breast screening mammography and the culture of privacy which makes conversing about intimate health (either face to face or on-line) difficult. Also, the transient nature of the mammography episode (three yearly), could mean an on-line breast screening digital network is challenging to sustain. super-users' may be needed to continue on-line conversations. The health professional was also seen as essential for moderating potential misinformation shared by women although the participants were also insistent that 'truth' be shared.

Keywords

Mammogram, Qualitative, Socio-ecological, Social Media, Digital Support Network,

Introduction

As part of the UK NHS Breast Screening Programme (NHS BSP) women over the age of 50 are invited for screening every three years. Mammography, an x-ray examination of the breast, comprises four images during which the breast is compressed between two paddles. This examination is associated with high patient anxiety related to fear or expectations of pain, the possibility that a cancer could be discovered, false positive findings and the use of ionising radiation¹. Good quality patient information and preparation can address some of these fears, leading to a more positive experience and ensuring that non-attendance is as a result of considered decision-making rather than fear of the unknown².

However, Robinson et al¹ found that women attending for breast screening said they were “*not well informed*”. Although women in Robinson’s study received NHS BSP patient leaflets (available at <http://www.cancerscreening.nhs.uk/breastscreen/publications/ia-02.html>) they said these were not memorable and preferred listening to the experiences of their friends and relatives in order to understand what breast screening entails. Others have found a similar preference for women to engage in family discussions about mammography³⁻⁵.

The advent of internet functionality which enables users to generate and co-create content and therefore be involved in an active rather than passive manner might be a way of supporting this preference for word-of-mouth information. Women who want to talk about breast screening have an alternative space in which to network with others; furthermore, on-line communication can provide anonymity and 24-hour access. This study therefore explored the feasibility of creating an on-line social space to provide information and also to enable women to share their lived experiences of breast-screening mammography with the purpose of informing and alleviating the potential anxieties of first time users.

Background Literature

Patient-generated DSNs are prolific. Fox⁶ reported that 23% of people with a chronic disease in the USA who have access to the internet turn to on-line communities for support, access patient generated information and each other. On-line approaches are felt to be particularly relevant because they provide a non-judgemental, anonymous and safe environment for the discussion of sensitive health conditions and benefits include 24 hour availability and asynchronous communication which means patients can react or respond to others if and when they chose⁷.

However, some studies have found people may be reluctant to share information using DSNs. Cutrona⁸ looked at adults’ behaviours with regard to promoting health screening using electronic means of communication. Whilst 14.6% of (438) women had used email to share information about breast screening only 3.9% had used other forms of electronic communication such as DSNs. However, it is important to state that this study concerned screening examinations. Because of the different fiscal health model in the USA where

screening must be paid for by the individual (or their insurer), motivation to attend for screening may vary compared to say the UK where health screening is free at the point of delivery. This could influence how individuals rate screening as a topic for discussion on-line.

Nevertheless, DSNs focussed towards the *symptomatic* population do exist in abundance. In a content analysis of Facebook groups, Bender et al⁹ found 620 sites related to breast cancer with more than 1 million members between them. Yet, their study, which aimed to characterize the purpose, use, and originators of breast cancer-related Facebook groups found that these were created mainly for fundraising (44.7%). Only 7% were created for patient or care giver support. Interestingly, though, the support groups were associated with the greatest number of user-generated posts. In contrast to Cutrona's⁸ study, this may suggest people who need support for symptomatic disease are more likely to create a sharing on-line network than people who just want information.

The difference between Cutrona's⁸ and Bender et al's⁹ studies may suggest that behaviour is dependent on the different motivations and needs which drive someone to visit or join on-line groups. Bender et al⁹ were concerned with breast cancer groups (i.e. symptomatic patients and their families/carers) whereas Cutrona⁸ was concerned with the asymptomatic screening population. Thus the motivation to sustain long term support networks for an asymptomatic population may be limited.

Despite the proliferation of on-line support networks identified by Bender et al⁹, there are few which focus specifically on breast screening. Yet, the authors suggest, the breast screening context is particularly suited to support through social media because the Office of National Statistics (ONS)¹⁰ report that 68% of women in the UK, aged 35-44 and 54% aged 45-54 have a profile on sites such as Facebook or Twitter. This trend reflects the up-coming population of first-time attenders for mammography breast screening.

To address the assumptions posed by Cutrona's⁸ and van Bender et al⁹ as to whether a screening social network is sustainable and useful for sharing information and having conversations about health a feasibility study was designed. The overarching question was:

Would women users of the UK NHS BSP find a dedicated DSN useful in preparing for their mammography screening?

The specific areas explored with participants in order to address this question were:

- i) Were women already using social media to discuss health or breast screening?
- ii) Would the use of a DSN for gaining information and support about breast screening be a good idea?
- iii) In what format should *information* about breast screening be presented on the DSN?
- iv) What method would they prefer for *networking* with other women about breast screening on the DSN?

- v) Would the presence of a health practitioner on the DSN be important?

Methodology

A two stage, iterative approach was employed to both collect and analyse data¹¹ where information gained by surveying a large group of women was then used to explore attitudes and behaviours in more depth with an initial focus group and then, as a result of analysis, a purposively sampled second group.

Sample

1) Survey:

This comprised a convenience sample of women working at three large institutions (2 x National Health Service (NHS) Hospital Trusts and 1 x Higher Education Institution (HEI)) which employ women of the screening population age. All women aged 45-55 working in these institutions were invited to take part (the total number of this population is not known). The survey instrument comprised 14 questions structured around the key study questions detailed above (fig 1). The survey was piloted with a group of 10 female employees for comprehensibility.

Fig 1 here

2) Focus groups:

Two focus group interviews were held (identified as FG1 and FG2 respectively).

- i) FG1: 5 women who had agreed to be followed up after the survey and therefore fell within the breast screening population demographic. These were not selected, they were the only 5 women who agreed to follow up. Nevertheless, this smaller size of focus group is recommended for the discussion of sensitive issues¹². Three were administrators and two were non-radiography lecturers (Occupational Therapy and Social Policy). Data collected at the focus group were iterative in that women were shown and asked to interpret the survey results.
- ii) FG2: a 'younger' sample of 5 women (18-45 years). The decision to interview a younger group of women emerged from FG1, where age was suggested as a potential influencer of health behaviours and the use of social media. These younger women comprised 3 university students, 1 recent graduate and 1 college leaver about to start university.

Ethics statement

Ethical approval was obtained from the University of Salford Research, Innovation and Academic Engagement Ethical Approval Panel (ref HSCR13/15). All participants provided written consent and were assured that anonymity would be preserved. Permission was also

granted by the Research and Development Committees at the two Trusts where the survey was conducted.

Analysis

1) Survey:

The survey data were analysed using standard descriptive functions on Microsoft Excel and then presented graphically to the project team (the authors) for discussion. Items for further exploration by the focus groups were identified. For instance, the survey showed that respondents appeared to prefer written text to video information. The project team highlighted this as an area for further clarification by the focus groups.

2) Focus Groups:

The transcripts of the focus group data were analysed by three researchers individually who then came together to agree on the common themes within the data. These were considered using the socioecological model of public health intervention to determine where the barriers and enablers for an on-line DSN for breast screening might exist, and therefore where the intervention needs to be focused.

Analytical Framework

In 1988, McLeroy et al¹³ proposed the socio-ecological model of health promotion which outlines how an individual's health behaviour is affected by multiple levels of influence. This acknowledges that individuals rarely make choices about health and well-being in isolation but that their decisions are influenced by: (i) intrapersonal factors - their own skills/knowledge/self-efficacy; (ii) interpersonal factors - relationships with others; (iii) organisational factors - the environments and organisations in which they carry out their occupations; (iv) community factors - the communities and cultures in which they live; and (v) public policy - which governs how resources related to health are made available or promoted (see Fig. 2). McLeroy et al's model emphasises how public health interventions must be designed to consider multiple levels of influence if they are to ultimately impact on the health and well-being of an individual. This model has been adopted widely in the field of Public Health, (cited 1209 times in ISI Web of Science (26/10.14)) and was therefore selected as a useful model for understanding the results in this study. This model is re-visited in the summary of the results and discussion.

Fig. 2 here

Results

Ninety two questionnaires were returned. Because the survey results informed the questions for the subsequent focus groups, and for reasons of brevity, only the focus

group data is reported here. However, comments are made where there was a contradiction with the survey data.

Findings are reported aligned to the research questions.

i) Were women already using digital social media to discuss health or breast screening?

Only 1 of the women in FG1 used social media for social interaction. Another used it for professional purposes. None of the others in FG1 used social media at all. All the women in FG2 had social media profiles using platforms which included Facebook, Twitter, Whatsapp, Pinterest and Snapchat.

None of the women in FG1 used digital social media to access information or support about matters related to health. Conversely all women in FG2 used SM for access to health information;

“I would probably go to a website more than I would go to friends” (FG2).

Two of the women in group 2 were involved in managing and contributing to a health-related social networking site;

“We go on chat rooms don’t we?”

“Yes, they are about midwifery topics and that’s the chat and they are fantastic, aren’t they?” (FG2),

but on the whole women tended to read others’ experiences rather than share their own. One woman suggested why,

“it is not that they don’t want to... they might think that people just wouldn’t be interested”(FG2).

This reluctance to share own experiences was also reflected in the survey results.

However, it also emerged that some women were reluctant to talk to other women at all (face-to-face or on-line) about their mammogram or other intimate health issues.

“I didn’t share it with my children and my friends, you know it’s different, we talk about kids” (FG1).

One woman suggested this was dependent on their access to female relatives and groups,

“My family’s all men, apart from my two daughters, I’ve no sisters, I’ve got brothers, my mother passed away an awful long time ago, and it was just my dad, so it was kind...all this I’ve had to learn for myself” (FG1).

Another respondent identified that sharing experiences on-line provides anonymity which is not found face-to-face,

“Sometimes that anonymity is nice as well, a space to chat where it is not people who you actually know and you can talk more openly about intimate personal things, especially if you are quite a private person” (FG2).

Women in both groups said they would not use Facebook for socialising with other women about health-related matters;

“it wouldn’t be my first port of call to think, oh I’m going for a mammogram, I’ll join Facebook and see what other people think” (FG1),

“I would never look for medical advice or help via Facebook. I would more than likely use websites” (FG2).

ii) Would the use of a DSN for gaining information and support about breast screening be a good idea?

Overall there was a positive response to the idea of a DSN for breast screening. The women expressed a need for more information than what was currently available;

“my first mammography is due in two years and I know I will just get a letter through the post won’t I? Is that enough really, is that enough?” (FG2).

Women in the second group tended to be more positive than women in the first group, possibly because they were already users of social media for health; indeed the reason some women in the first group gave for not using a DSN for mammography was that they were not users of social media anyway;

“I don’t use those sites for anything else, so my first experience of a site like that would not be for something as personal as mammography” (FG1).

One woman in the first group suggested the term ‘Social’ (as in DSN) also has negative connotations;

“I think that you’ve got to get away from the ‘social’... the thing that threw me with that is this social networking, because what came across to me as Facebook and me getting me bosom out and it wasn’t going anywhere ‘social’ my bosom (FG1).

Another concern raised was the sustainability of a DSN for a transient community such as the breast screening population. Whilst this population is large, each woman would only require

information and support every three years which reduces her motivated to go on-line to share her experiences;

“But then you go away, you drive off and you go and do your shopping and move on” (FG1).

iii) In what format should “information” about breast screening be presented on the DSN?

Women in both groups said they agreed with the survey results that textual information supported by images was preferable to video and audio. The reasons given related to ease of use;

“you can go back to certain paragraphs quite quickly, whereas with videos, I wouldn't re-wind it” (FG1).

There was also a belief that written text was somehow more trustworthy;

“I read the book and I think it's just our generation really, it's like solid, dependable and you can believe it” (FG1)

“I think you tend to trust written text, it's seen as more factual, more I don't know, academic in a way, whereas video is more, anyone can pop up and do it” (FG2).

iv) What method would they prefer for “networking” with other women about breast screening on the DSN?

Participants in both groups expressed a desire for the social function to be embedded within a web page as an optional link, rather than for it to be the main concept of the page;

“a website all about mammography breast screening and actually one of the functions we've got, if you click here, if you want to talk to other women...yes, that would be far better” (FG1).

They felt this made the chat more private. Furthermore, they wanted the option of remaining anonymous and for the page to be closed;

“I preferred private, I wouldn't like the idea of going onto one of these...where lots of people are logged in” (FG1),

“sometimes you might go ‘yes that's an interesting person’ and that might help me personally so try and get them to have a private conversation if I wanted some more personal information to go offline” (FG2).

This finding contradicts the survey data where respondents expressed a preference for open post forums. This may be because survey respondents envisaged themselves as using the site to receive rather than contribute information, in common with 90% of all internet users according to van Mierlo¹⁴ and this would be easier if the forum was ‘open’ rather than closed.

v) Would the presence of a health practitioner on the DSN be important?

Both groups agreed with the survey data that the presence of a health care professional would be important. This was related to moderating “incorrect” information, thus ensuring a balanced view;

“I think it is very important, yes, to have a balanced view, there are too many scaremongers out there” (FG2),

and adding veracity to the site information;

“if there was something factually inaccurate that they could say ‘actually when we perform mammograms, we don’t do that’”(FG2),

although it was also felt important that both positive and negative stories were allowed to be told;

“I think people should be free to express how they found the experience” (FG2),

In summary, a number of important issues relating to the study’s key themes of social networking, health information and the role of the health practitioner have been uncovered which need to be taken into account when considering the development of a digital resource to support women attending for breast screening.

Discussion

It is important to acknowledge that this was a feasibility study which explored the potential for a breast screening DSN. There was no intention to generalise the findings or to claim a causal link related to the discriminating feature of age, explored further in the study. Nevertheless, by triangulating the findings which emerged from the two groups it was possible to identify a number of important themes which were then explored using the socio-ecological model to suggest whether attitudes and behaviours may be influenced by factors at the intrapersonal, interpersonal, organisation, community or policy levels.

Socio-ecological levels of influence

Community level

The study uncovered the importance of privacy when chatting about intimate health on-line and this was also reflected in a reluctance to share or ‘upload’ experiences.

Ledbetter¹⁵ identifies self disclosure and social connection as fundamental motivations that foster online interpersonal communication. However, it appears topics related to health are not easily disclosed. Jin¹⁶ examined different layers of personal disclosure on Twitter by American undergraduates. Although personal information relating to daily life activities and entertainment interests were disclosed easily participants were most reluctant to discuss health related issues in a public online space. This suggests the social function of a breast screening DSN may be difficult to develop and sustain.

Furthermore, the women in our study expressed a preference for reading about other people's experience rather than up-loading their own. Similarly, Ofcom's Media Use and Attitudes Report¹⁷ shows that user generated content (ugc) on the internet acts as an information source in the UK for 98% of internet users yet the percentage of individuals posting content is low. In a 2013 study of moderated digital health social networks (DHSNs), van Mierlo¹⁴ identified that the 90-9-1 principle used in direct marketing was also evident here. Ninety per cent of DHSN users reviewed content posted but did not contribute posts; 9% occasionally contributed and 1% of DHSN users created the vast majority of content.

Because these appear to be universal behaviours, the socioecological model suggests they may be as a result of community held beliefs. The model therefore dictates that remedial interventions also need to impact on the wider culture of the community which may not be a realistic aim in the short term. Instead web-designers should be respectful of a woman's need for privacy by providing an option for private discussion online. Nevertheless it is also important to seek out and encourage those 1% of women 'super-users' who according to van Mierlo¹⁴ are the generators of content, to drive the DSN if it is to provide an authentic and rich source of experiential information which is to be sustained in the longer term.

Organisational Level

Women in our study stressed the importance of factual information which must be reliable, suggesting a culturally-embedded, positivist understanding of medical knowledge as being singular and objective. The participants also expect a health professional to possess this accurate, factual knowledge. Research into breast cancer and the value of screening is contentious¹⁸ and continually changing, making it impossible for the health practitioner to provide definitive answers. Conversely, our participants identified that a more relative form of truth, that is, user generated experiences was equally important. Unlike factual knowledge, because experiences are relative, being real to the person experiencing them, they can not by definition be contradicted. Yet, participants saw a role for the practitioner in moderating 'incorrect' accounts, again placing a burden of unrealistic responsibility and expectation on the health professional.

It is clear that women want access to a practitioner on-line but in designing a DSN it is necessary to be mindful of these competing demands. It will be important to ensure that health professionals who engage in the DSN in a facilitative capacity must be up to date in terms of factual knowledge and current research whilst also engaging in such a way as to allow subjective perspectives to be aired. This will require training and development for health professionals, and employers will need to consider more imaginative ways of redeploying staff to engage with women accessing the DSN. The intervention for these changes therefore needs to target organisational level influencers to ensure resources are available.

Intra-personal, inter-personal level

All members of the younger group and only one member of the older group used social media. Although the numbers in our focus groups were small, this reflects UK national figures produced by Ofcom¹⁷. Whilst 66% of UK adult internet users have been shown to have a social networking profile, use is greatest in those under the age of 45. This generational difference may be related to greater exposure to digital environments for learning, i.e. in schools and the consequent development of on-line social networks with peers.

The use of social media is therefore influenced by interpersonal level factors; expressed in the ways women prefer to communicate with their friends, family and peers. These findings suggest that whilst some older women may need support in the development of skills (the intrapersonal level) interventions might also include encouraging younger family members to introduce the DSN to their older female relatives. However, this may also be a short term problem because as the younger generation moves into the breast screening population age group there may be more acceptance of social media for such purposes.

There was a range of preferences about how women want information to be presented: written, images, audio or video. This may be influenced by intra-personal factors such as individual cognitive and learning styles¹⁹, but may also relate to how technology is changing consumption habits and particular individuals' self-efficacy in relation to internet and mobile technologies. For instance, Ofcom¹⁷ report that between 2012 and 2013, the percentage of mobile users sending personal video content to others via their phones increased from 41% to 48% suggesting increasing familiarity in using mobile technologies to post 'live' content.

"It's about capturing a whole range of options and choices, women's choices, women's conversations"

The choices a woman makes about disclosing personal and intimate health details to others may be related to her own self-efficacy but also the inter-personal relationships to which she has access which might promote or inhibit such discussions. Certainly in

our study women reported being more or less enabled to discuss such things based on whether they were generally surrounded by female or male family members. There is little research to suggest that family gender mix influences disclosure about intimate health although McAllister et al²⁰ looking at the male perspective found that men were often excluded from family conversations about breast cancer in families with a genetic disposition for the disease. Others have also reported that understanding social networks and their influence on intra-personal health behaviours is a complex concept which needs further exploration^{21, 22}. Nevertheless, regardless of the underpinning research related to the development and role of interpersonal networks, the socio-ecological model acknowledges the importance of these relationships on behaviour. Whilst a breast screening DSN can not change a woman's inter-personal context, it can provide a female oriented place of support to those women who are otherwise surrounded by a male dominated, and/or otherwise unsupportive, environment.

Cultural differences may also account for the variances reported here and explain the lack of consensus in the literature^{6, 8, 9, 23} with regard to the use of DSNs for health-related issues. Unlike age, other social categories such as religion and ethnicity which might influence such things were not collected. This is therefore an area which needs further research; exploring why some women are more willing than others to talk about intimate health issues and how this is influenced by culture.

Key learning points for the development of a breast screening support hub

- Take an inclusive approach by involving a diverse range of users and mammographers in the design
- Ensure factual information is provided that is in textual format with images and video
- Link with national information based on current research (NHS BSP)
- Provide option to network in private
- Develop health practitioners who can provide a balanced perspective in facilitating the sharing of true experiences
- Work with employers to implement organisational changes
- Target implementation with certain groups in more direct ways (i.e. those with lower self-efficacy in terms of on-line skills)

Conclusion

This feasibility study aimed to determine whether women users of the NHS BSP would find an on-line breast screening DSN useful in preparing for their mammogram and has shown that, with certain caveats, they would. Where women were hesitant it was for (i) practical reasons, they could not imagine going on-line at some time after their examination; (ii) reasons of self-efficacy related to social media skills; or (iii) because they were anxious about privacy or disclosing information about their intimate health. The socio-ecological model has helped us to identify where to target activity to resolve the majority of these issues. For point (iii), further research is recommended to help understand why women are hesitant to talk about and seek support for their intimate health issues. Understanding this will not only support the development of the DSN, but further our understanding of the choices women make more generally about breast screening.

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Legends

Fig 1. Survey questionnaire

Fig 2. The socio-ecological model of health promotion. Adapted from McLeroy et al¹³ and Winch²⁴.