

**Leslie Robinson**

**CoRIPS Research Grant 117**

**£9,984 awarded**

**Title: Mammographers' on-line communication with service-users:  
changing attitudes, developing capability and improving practice**

### **Principle Aim**

To enable mammography practitioners to communicate on-line with clients in order to offer them support and promote breast screening.

### **Primary research question**

What actions are required to enable mammography practitioners to communicate on-line with clients?

### **Secondary research questions**

To explore the potential barriers to, and enablers for, radiographers to use on-line approaches to engage with the public.

### **Outcomes**

Short term: recommendations for practitioner engagement on-line. Long term: To have one champion at each breast screening unit whose role it is to respond to clients' queries on-line.

### **Review of literature and identification of current gap in knowledge**

This is the practitioner arm of a project which aims to create and critically evaluate a breast screening hub for women to share positive stories of mammography.

As part of the UK NHS BSP women are invited for breast screening mammography every three years. Mammography, whilst crucial for improving health outcomes, is associated with high patient anxiety related to expectations of pain, positive diagnoses and the use of ionizing radiation. Anxiety related to such fears can result in non-attendance. Furthermore, patients who do attend can experience more discomfort if they are in heightened states of anxiety (Robinson et al 2013) which may lead to non-attendance at subsequent screening invites.

However, Robinson et al (2013) found that women attending for breast screening for the first time said they were “not well informed”. Although women in Robinson’s study received NHS BSP patient leaflets 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. Maclean et al (1984) and Bilodeau and Degner (1996) found a similar preference for women to engage in family discussions about mammography and Poulos and Llewellyn (2005) showed that ‘women-talk’ about mammography was sustained and elaborated through social networks.

The advent of web 2.0 technology which enables users to generate and co-create content and therefore be involved in an active rather than passive manner, has enabled the proliferation of on-line Digital Support Networks (DSNs). Consequently, women who want to talk about breast screening have an alternative space in which to network with others; Brenner (2014) suggests 82% of women between 30 and 49 years of age use on-line social networking sites reflecting the up-coming population of first-time attenders for breast screening. Furthermore, this is an on-line space that provides anonymity and 24-hour access. Our plan to develop a breast screening hub therefore responds to women’s preferences both for word-of-mouth approaches to gathering information about mammography and for on-line socialisation. Our proposal also reflects NHS policy to improve patient access to on-line user-generated information, articulated in the government’s 2010 NHS White Paper (DOH 2010).

Patient/user specific social networking is not a new phenomenon (Moorhead et al 2013). For example; Medhelp, PatientsLikeMe and FacetoFace Health all provide on-line opportunities for patients to share experiences. Fox (2011) reports that 23% of people in the USA who have access to the Internet and have a chronic disease turn to on-line communities for support and guidance. However, whilst there are a number of on-line networks for women having been diagnosed with breast cancer, there is no forum for asymptomatic women invited for screening mammography to share information.

The project team submitting this bid have already undertaken a pilot study to determine what women would want in a breast screening hub (Robinson, Hill et al 2014). The findings from this study showed eighty seven per cent of women (n=94) thought that the presence of a health professional on-line should be an

essential element of the hub, with 27 of the 94 respondents stating this was very important. Focus group participants explained

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

and health practitioners were seen as being able to add veracity to information;

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

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”

However, concern was expressed by clients that being available on the site would make unacceptable demands on health care professional distracting them from their clinical roles;

“you’re taking time away from the duties that they should be doing, you’re putting more bureaucracy in and I don’t think you should do that”

This data shows that whilst a practitioner would be an essential feature of an on-line hub, they will need support in fulfilling this role because of conflicting communicational demands. In the first instance, the participants expect a health professional to possess accurate, factual knowledge. However, research into breast cancer and the value of screening is contentious (Marmot et al 2013) and continually changing, making it impossible for the health practitioner to provide definitive answers. Conversely, participants also identified that facts of a relative nature, i.e. user generated experiences, were equally vital. 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. This role will therefore require training and development for health professionals. Furthermore, employers will need to consider more imaginative ways of redeploying staff to engage with women accessing the DSN. There are currently no professional guidelines which support radiographers in this dilemma.

This project will therefore explore the complex interactional demands on practitioners supporting clients on-line. However, the project will take an action research approach in order to identify solutions to these problems.

## **Methodology**

A qualitative research approach is appropriate because the work is explorative in nature; little is known about the perceptions and attitudes of mammographers in terms of engaging with clients in an on-line space. An Action Research (AR) methodology will be used because as well exploring perceptions and attitudes, solutions will be generated by the participants. AR seeks to bring about change by engaging those involved in a particular community of practice to explore their practices. Then through this collective understanding the participants are in a position to transform the situation. Bradbury and Reason (2003) suggest the underlying principles of action research as: (1) grounded in lived experience, (2) developed in partnership, (3) addressing significant problems, (4) working with, rather than studying, people, (5) developing new ways of seeing the world, and (6) leaving infrastructure in its wake. The research is therefore carried out 'with' the practitioners and not 'on' or 'for' them. In this way those who will be engaging in, or resourcing, on-line communication will have a deeper understanding of what is involved and have pre-empted potential problems and solutions specific to their own contexts.

## **Method**

Sampling will be purposive which is appropriate for qualitative research (Silverman 2004). This allows the researcher to ensure that key informants are targeted. As this is AR it will be important to make sure the participants are those who can effect change.

Key informants for this research will therefore be:

- Breast screening service managers in (because they are responsible for allocating resource and thus providing time for mammographers to engage in on-line communication with clients)
- Educational leads from the 5 national training sites for mammography (because they can drive the principles and practice of in-line communication into the curriculum)
- Mammographers: one champion to be identified from each site (because these will be the practitioners eventually piloting the recommendations emerging from the research)

- Key individuals from a number of CCGs with responsibility for or influence over policy decisions will also be invited – specific people will be determined nearer the event depending on post holders at that time.
- For financial reasons, this work will be confined to the English NHS Breast Screening Service. There is the potential to role this out to Wales, Scotland and Northern Ireland in the future however.

### *Recruitment process*

All key informants will be contacted with information about the project and be invited to attend one of the 4 exploratory workshop events (see below). Contacts will be made through the national breast screening group's mailing list. Managers will be asked to identify one champion from their unit to attend. Educational leads will be contacted through the list on the NHS BSP website

### *Sampling size*

Issues of sample size are not relevant for qualitative research however for AR, applicability is. This is because it will be important to ensure actions which are derived by the participants are applicable to local practices. With the devolvement of the National Screening Programmes to CCGs, there will be different approaches to, for instance, disseminating information about the breast screening hub to clients depending on local screening awareness and invitation systems. For this reason we hope to attract attendance from at least one person from each breast screening centre across England,

### *Data collection method*

Participants will elect to attend one of four one-day exploratory workshops conducted at each of the NHS BSP Training Centres in England (Jarvis National Breast Screening Training Centre; Nottingham International Breast Education Centre; Manchester Breast Screening Training Unit; South East London National Breast Screening Training Centre; St George's Hospital NHSBSP National Training Centre (one event in London for financial reasons)). Each exploratory workshop will be divided into four sections which will include group discussions summed up in a plenary session. Data will be collected during the plenary sessions which summarise the discussions. The plenary sessions will also be video recorded to ensure key verbal information is also captured. Whilst audio is less intrusive, this medium can struggle to capture information clearly in large groups.

The four sections will cover:

- Exploring and identifying the potential of communicating with clients on-line in with the breast screening population, drawing on examples from other healthcare contexts.
- Exploring the barriers and solutions to introducing an on-line breast screening champion at each of the breast screening sites.
- Exploring the approaches to real-life patient stories and questions encountered on-line
- Creation of ideas, solutions and a good practice guide for on-line engagement with clients

### *Data analysis*

Data will be analysed by three university researchers independently and then in consultation, using a socio-ecological framework for understanding complex public health interventions (McLeroy et al 1988) which 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

### *Credibility/ trustworthiness of data*

Credibility will be ensured through an inclusive approach to recruitment; ensuring a wide range of opinions have been represented from staff at key decision-making levels but also those involved in implementing the intervention at 'ground level'. Patients and mammographers will also be involved in producing the workshop materials and in delivering the workshop, satisfying the requirements for user involvement. Trustworthiness will be assured through multiple data capture (written and video) and a consensus analytical approach involving more than one researcher. The analytical model grounds the data in an established theoretical framework. The analysts all hold doctoral level qualifications. The final report will be disseminated to the participants for comment before wider circulation.

### *Ethical implications of the study*

Ethical approval will be sought from the University of Salford Research, Innovation and Academic Engagement Ethical Approval Panel. All participants will be asked to complete an informed consent sheet which will include agreeing to be video-taped and ensuring anonymity and due consideration of the opinions of other participants. Data will be kept in a secure and password protected place and will be destroyed after the outcomes of the study have been met.

### **Potential impact**

Outputs will include recommendations and guidelines for enabling radiographers to engage with patient and clients on-line. This will inform SCoR member guidelines on use of Social Media (as a member of the SCoR Radiographic Informatics Group the PI has been tasked with drafting these guidelines), as well as mammography and radiography curricula.

Longer term, this would support the development of radiographer role extension into public health and the health promotion arena, raising public awareness of the radiography profession.

Implementation of the recommendations coming from this CoRIPS study will also ultimately impact on clients of the NHS BSP through improved information enabling them to make choices about screening which will enhance their experience.

Further funding will be sought to evaluate these impact predictions for the WOMMeN hub using a mixed methods approach as recommended by the Medical Research Council for evaluating complex interventions (2006). We are also in the process of recruiting a PhD student to determine the value of WOMMeN which will also include evaluation of this practitioner intervention arm.

### **Dissemination Strategy**

- Report to the SCoR as per requirements of the CoRIPS funding scheme
- Article in peer-reviewed journal Radiography
- Presentation at Symposium Mammographicum July 2016
- Social Media: A blog will be posted and tweeted on Twitter and the WOMMeN open and closed Face book (for service-users to access)

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*Websites*

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