Word of Mouth Mammography e-Network (WOMMeN): a feasibility study

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Background:

Problem: First time attenders to mammography feel unprepared1.
Enablers: i) Women share information about mammography using word-of-mouth communication (talking to each other)2.
   ii) NHS strategy advocates the use of digital media and patient-generated data for improving service-user experiences3.
   iii) The most frequent users of on-line social media are women aged 30 – 494.
Solution: Provide women with an on-line space to share and access information about breast screening and breast health; the WOMMeN: Word of Mouth Mammography e-Network
Aim: Explore the feasibility of WOMMeN.

Method:

Mixed: survey and focus group interview
Sample: Convenience sampling. Questionnaire was posted on intranets of 1 university and 2 NHS Trusts targeting females 45 -55 years. The focus group was constructed from respondents volunteering for follow-up.
Exploratory survey: Eight item questionnaire exploring 3 concepts:
   i) preferred format for socialising/sharing on-line
   ii) preferred format for static information
   iii) importance of expert presence
Participants were also asked to comment on the potential usefulness of WOMMeN
Focus group interview: 1 group of 5 participants all of whom had completed the questionnaire. Results of survey were reflected back to participants for comment to help understand responses.

Results: survey (n=92)
• 79% of respondents use social media.
• Only 8.5% of women use social media for sharing/accessing information regarding health.
• Women want to view uploaded videos but not to upload their own.
• Written text and images are the preferred method for factual information.
• Access to experts on-line is important.
• WOMMeN is viewed as potentially useful by 45% but 32% are unsure.

Results: focus group themes
Intimate conversations (general)
“I wouldn’t come into work and say to my colleagues, ‘well you know, I’ve got this problem’, just wouldn’t do it”
Intimate conversations (on-line)
“my first experience of a site like that would not be for something as personal as mammography”
Age/generational differences
“as generations move forward, we are going to use these an awful lot more, you know, this way of communicating”
Social media negative opinions
“I don’t believe in Facebook and I don’t use it… I think they can be quite dangerous sites”
Fear of negative stories
“people don’t share their experiences as much as if it’s negative, so I think you have to be very careful”

Conclusion and recommendations:
1) Results contradicted the literature: women in our study were not likely to network with other women about health problems; either face-to-face or on-line. There may be a number of reasons:
   • Cultural: sharing stories about intimate health may not be embedded in the UK culture.
   • Methodological: the focus group women were a convenience sample and may not be representative.
   • Sample bias: the questionnaire was completed by health professionals who may ‘fear’ engaging with service users on-line.
2) The term ‘social network’ is negatively associated with Facebook. On-line networking was positively viewed when couched in terms such as ‘chat room’ and ‘forum’ related to a private site which assures anonymity.
3) There is a need for more patient information: text and images are preferred but access to an on-line expert is very important. Preferred media is likely to change with the next generation, who may be more receptive to WOMMeN.

References
4. DGH (2002) Quality and excellence: liberating the NHS. TS5