Quality in Primary Care 2013;21:39–42

Patient perspective

Breast cancer screening: an ethical dilemma, or an opportunity for openness?

Mitzi Blennerhassett BA RSA Cert (Counselling Skills)
Patient Advocate, Medical Writer and Artist, York, UK

ABSTRACT

The NHS Breast Screening Programme was hailed as a life-saver when it was set up, but research has raised concerns about efficacy and levels of harm. The honesty and adequacy of screening information was challenged: proof of the '1400 lives a year saved' claim was not offered and some serious harms were not mentioned. The report of the independent review of breast screening exposed grave concerns, but brought more controversy. Doctors, patients and the doctor/patient relationship may be adversely affected.

Keywords: all-cause-mortality, breast, diagnosis, efficacy, patient information, payments, screening

How does this fit in with quality in primary care?

What do we know?

Breast screening causes major harms and little, if any, benefit. Recent research has shown improved survival rates are due to better treatments.

What does this paper add?

Although counterintuitive, recent research continues to show breast screening mammography has either limited effect on breast cancer mortality or none at all. Eminent doctors, researchers, epidemiologists and others have joined with patients and patient advocates to speak out and call for change. Professor Sir Mike Richards, the Cancer Czar, says consent to breast screening should be a woman's choice, but at the same time advises that women should continue to attend for screening. Advice seems to conflict and ethical questions need answers. General practitioners are signposted as a point of information for patients invited to breast screening, yet may be paid to encourage them to accept the screening invitation: they seem caught in the middle.

My experience of user involvement, working alongside health professionals to improve health services has included membership of the Royal College of General Practitioners' Patient Partnership Group and spans 20 years. As a former breast cancer patient turned patient advocate/activist, I have a particular interest in breast screening issues.

When the NHS Breast Screening Programme (NHS BSP) was set up in 1988 it was hailed as life-saving as well as breast preserving by doctors and patients, but it has become clear that regular screening with mammography (as opposed to diagnostic mammography) causes unacceptable levels of harm, not just from false negatives, false positives and radiation-induced cancers, but from over-diagnosis: over-detection of cancer 'look-alikes' ('pseudo cancers') that, if left undetected, might never threaten a person's life.

And not only over-diagnosis of ductal carcinoma in situ (DCIS): there is now clear evidence that between 10 and 50% of invasive cancers detected and treated radically as a result of screening would never threaten life.[1,2] Research findings published in leading peer-reviewed journals have shown that the benefit of screening healthy populations by mammography was questionable and had little, if any, effect on mortality.[2] But these concerns have not been shared with women invited to participate in screening.

In a letter to *The Times* (19 February 2009)[3] Professor Michael Baum and 22 international signatories, including public health specialists, epidemiologists, oncologists, general practitioners (GPs) and patient representatives, said of the NHS BSP, 'none of the leaflets it offers came close to telling the truth about what screening can and cannot do'. The next day, Professor Mike Richards, the National Cancer Director, announced that the leaflet 'Breast Screening the Facts', 2002, would be scrapped and a new one written by the autumn of that year. But, as previously, it would be written by those who ran the service. According to Chris Smith,[4] in *The Times*, Professor Julietta Patnick, Director of the Breast Screening Programme, said 'women didn't want too thick a leaflet' and 'putting too much numerical information meant women just put the leaflet down'. This defence did not inspire hope in those of us calling for honesty and change. Fortunately, a new evidence-based leaflet posted on the Nordic Cochrane Centre website excited much interest and has now been translated into many different languages.[5]

On 22 October 2010, I was one of a group of signatories to another letter in *The Times* which raised questions of ethics and informed consent.[6] I wondered if those involved in breast screening and treatments were aware of these concerns and if so, how this knowledge affected them. They had not sought a career that caused harm. And what were women being told if they asked a GP's advice?

A revised NHS breast screening leaflet was published in 2010, but still was not wholly honest about the benefits and harms, while pretty pink flowers on its cover page drew contempt from patient advocates and health professionals alike. It continued to claim '1400 lives saved a year', though now with questioned evidence, but did not mention major harms. Unlike men diagnosed with prostate cancer, women were not given the choice of 'treatment or watchful waiting'.[7]

Breast screening had become a hot topic, invading medical journals, the media and social networking sites.[8] I contributed to several websites and wrote my own blog[9] but the general public and patients did not understand about biases of screening that give a false impression of benefit (lead-time bias, length bias and self-selection bias) or the need to consider all-cause mortality, not case survival.

Eminent people wrote books explaining screening issues.[10–12] but cancer charities seemed unable to accept the evidence and echoed the NHS BSP 'mantra' about numbers of lives saved, while at least one charity successfully lobbied parliament for extensions to the screening age at both ends, 47–49 and 71–73. On 28 July 2011, the *British Medical Journal* (*BMJ*) published a paper based on the WHO database which demonstrated that the much-welcomed fall in breast cancer mortality over the past 20 years was the result of better treatment and nothing to do with screening programmes.[13] It seemed acceptance of a screening invitation had become a breast cancer lifestyle risk.

In the summer of 2011, aged 73, I was invited to screening as part of the extended programme, but declined. However, it seemed my decision to opt-out of any future screening would not be respected unless I completed and returned a form. Yet I had never opted-in to screening!

When, months later, I read Professor Mike Richards' announcement of the long awaited Independent Review[14] I was shocked to discover that the age extension screening invitation I had received had been part of a randomised controlled trial (RCT).[15] The information which accompanied the letter had not explicitly stated 'you are being invited to participate in a randomised controlled trial', as is usual in RCTs. The signpost to further information about the trial was simply a web link which brought up the NHS Breast Screening Programme website home page.[16] It was difficult to access further information. The trial continued despite the independent review; had such a trial proposal come before me when I sat on a local research ethics committee, I felt sure it would have been refused approval. Questions about the trial dating from November 2011 to relevant ethics committees, the NHS BSP and parliament have so far proved fruitless, but the *BMJ* posted my online rapid response.[17]

Once the independent review had reported, it was planned to rewrite all screening programme public information. Along with breast cancer experts and others who had been calling for change, I was invited to sit on a King's Health Partners screening information panel, chaired by Professor Amanda Ramirez, which met in London on 29 March 2012 to consider 'A new approach to developing information about NHS Cancer Screening Programmes'. I commented that the drafted first page of the breast screening leaflet mentioned benefits, but not harms and was told 'not everything can go on the first page'. I agreed to comment on the forthcoming information as it was drafted, but this has not happened and the panel has not met again, but received the final draft leaflet for comment in early February 2013.

The Marmot Report found that women invited to mammographic screening were three times as likely to be 'over-diagnosed' as they were to have their lives saved.[18] So why will women continue to receive an unsolicited appointment which seems to endorse screening as a beneficial procedure? And will the new leaflet explain how serious the problems are? Following the Marmot Report, Professor Sir Mike Richards said the decision to be screened should be a woman's choice – but he also said screening was still recommended. The Nordic Cochrane Centre published a review of the Marmot Review on its website.[19] A citizens' jury[20] was convened to consider ways of presenting to eligible women, data on benefits and harms of breast screening arising from the findings. Nigel Hawkes' comments in the *BMJ* on the jury's deliberations drew several noteworthy, if critical, responses.[21]

Despite a significant body of research highlighting lack of effectiveness and major harms, and before the independent review had reported, the director of NHS screening programmes urged GPs to persuade their patients to attend for breast screening.[22] But how would doctors feel if they complied and then learned that the Marmot Report had concluded that 4000 women a year in the UK were harmed by attending breast screening and being 'over-diagnosed' (possibly an underestimate) though screening mammography had been shown to have a limited impact on breast cancer mortality, if any?

Writing in the *New York Times*, H Gilbert Welch in discussing recent research[23] said,

> screening proponents have encouraged the public to believe two things that are patently untrue: First, that every woman who has a cancer diagnosed by mammography has had her life saved. Second, that a woman who died from breast cancer 'could have been saved', had her cancer been detected early. The truth is, a few breast cancers are destined to kill no matter what we do.

He suggests

> using screening mammography as a measure of how well our health care system is performing is beginning to look like a cruel joke: cruel because it may lead doctors to harass women into compliance; a joke because we can no longer argue this is either a public health imperative or a valid measure of the quality of care.[24]

GPs are signposted in screening information as 'advisers' to help women decide whether or not acceptance of screening is the right decision for them. Do they have time to access the necessary research and websites?[25] Have they been trained in critical analysis? Are they content to be placed in a position which undermines trust and could break the doctor/patient relationship? And how would women feel if screening invitations were to state: talk to your GP if you have concerns about screening, but be advised that if a health authority deems recruitment to screening is getting too low, it may pay GPs to encourage women to participate in breast screening (as well as other interventions) as part of 'local enhanced services payments'.[26]

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26 Confirmed by the Department of Health in a telephone conversation 26 November 2012.

PEER REVIEW

Commissioned; not externally peer reviewed.

CONFLICTS OF INTEREST

None. Mitzi Blennerhassett is a former breast cancer patient turned patient advocate/activist with experience spanning 20 years. She has a particular interest in breast screening issues.

ADDRESS FOR CORRESPONDENCE

Mitzi Blennerhassett, Wyville Lodge, Slingsby, York YO62 4AQ, UK. Email: b_mitzi@yahoo.co.uk

Received 4 December 2012
Accepted 11 December 2012