

# Are we educating women to be afraid?

UK health reporter questions the value of simplistic screening messages

Breast screening programmes won't work if women don't attend. But can this justify campaigns that exaggerate both the risk of getting breast cancer and the benefits of screening? **Margaret McCartney** believes not. She won a Best Cancer Reporter Award for her article, *Reality Check*, which was first published in the *Financial Times* weekend supplement, and is reprinted below.

**O**ne morning in 1991, Hazel Thornton found a letter on her doormat inviting her to attend an NHS breast cancer screening. Thornton, a self-employed businesswoman, then aged 57, decided she'd go. This was what responsible people did, after all, and she was nothing if not responsible: aware of her body, interested in keeping healthy, and happy to comply with guidelines on medical check-ups.

The screening revealed a 'ductal carcinoma in situ', or DCIS, which meant that the cells lining Thornton's milk ducts were cancerous. However, those cells had remained in the ducts: they hadn't grown through to surrounding tissue. DCIS is an uncertain condition. It is sometimes considered pre-cancerous or non-invasive but it may, over time, develop into invasive breast cancer, spreading into other tissue.

Immediately after confirmation of the diagnosis – reached by surgical excision of the affected area of tissue – Thornton was offered a place in a UK DCIS trial. This

was the moment her easy compliance ended: all of this seemed too sudden. The study she'd been invited to join would start her on one of several treatments: radiotherapy, the drug tamoxifen, radiotherapy plus tamoxifen or no treatment at all. Thornton was struck by the magnitude of difference in the options. Her own research, meanwhile, had suggested that DCIS patients might do just as well

untreated. And if she were to enter the trial, she realised, two of the trial options involved radiotherapy, which she knew she wanted to avoid.

Thornton was astounded by how poor the information given to her was, by the uncertainty about her diagnosis – and by the speed with which she was expected to make decisions after being diagnosed with, well, "cancer". She wrote to the organisers of the study as well as her surgeon, and then, realising this was an issue which must also affect others, she wrote to the medical press outlining her concerns. That piece, published in the *Lancet*, turned out to be the beginning of a second career in advocacy.

In 1995, Thornton co-founded, with Michael Baum, professor emeritus of surgery at University College London, the Consumers' Advisory Group for Clinical Trials, a joint lay and professional group. She also began to publish papers in academic journals (she is now a contributing



Margaret McCartney

editor at the *International Journal of Surgery*), and in 2002 she was awarded an honorary doctorate of science from the University of Leicester.

That year, too, she began a book project with two others, Imogen Evans, a medical doctor and journalist, and Sir Iain Chalmers, a health services researcher. Published in 2006, *Testing Treatments: Better Research for Better Healthcare* was hailed for its critical appraisal of how uncertainties in healthcare should be assessed and how treatments should be evaluated fairly.

Thornton's 17-year odyssey in the world of breast cancer has, then, had far-reaching and positive outcomes. Unfortunately, that has not been the experience for everyone in Britain with the disease.

It's almost October, which is Breast Cancer Awareness month in the UK. For 31 days we will be invited to buy watches, bags, T-shirts, training shoes, brooches, body washes and more, all in a certain shade of pink, to aid research and breast cancer 'awareness'. There will be fun runs, cake stalls, bingo evenings. It's a phenomenon that started in 1993, two years after Thornton's diagnosis, when Evelyn Lauder, a philanthropist in search of a cause (she had married into the Lauder beauty empire), founded the Breast Cancer Research Foundation. The group funds breast cancer research around the world, as well as programmes aimed at "increasing public awareness about good

breast health". As Lauder explained to the *Independent* newspaper five years ago, "the older generation just doesn't discuss [cancer]... in my view, the more you speak about something, the more knowledge you have. And the more knowledge you have, the less fear you have."

Fair enough. Yet recent studies suggest that Lauder's formula – that awareness campaigns increase knowledge and decrease fear – does not bear scrutiny. A study by University of Michigan Health System researchers in 2005 found that women tended to overestimate their risk of getting breast cancer by about three times. The same year, the *European Journal of Cancer* published a study from Ireland which found that 66% of women overestimated their risk of developing breast cancer and 88% underestimated the age at which it was most likely to develop. Fifty-six per cent of these women also underestimated the five-year survival rate after a diagnosis of breast cancer. In other words, young women think that they are more likely to get breast cancer than they are; older women do not realise that their increased age places them at higher risk; and all underestimate how likely they are to survive.

The fact is that the incidence of breast cancer has been increasing in the UK in recent decades. In 1975, the rate of diagnosis was 74 per 100,000 women. In 2005, that rate had increased to 123. Concurrently, survival rates from breast cancer have increased. The five-year survival rate for women diagnosed in the UK between 1971 and 1975 was 52% per cent. For women diagnosed between 2001 and 2003, it was 80%. Some of this is down to better, innovative treatments for breast cancer. However, some of the apparent improvements are, at least in part, artificial. DCIS is a diagnosis produced by breast cancer screening, but the condition is



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# The review concluded: 'Women invited to screening should be fully informed of both benefits and harms'

seldom fatal. Thus it appears that more women are surviving breast cancer for longer. But these are not the cancers that pose the greatest threat to life.

While the most recent research into breast cancer screening points to it being effective in reducing death from breast cancer, the margins are slender and do not take into account the possibility of over-diagnosis: counting women as cured when they never had a life-threatening cancer in the first place. The last systematic review of breast cancer screening studies, published in the Cochrane Library, was updated in 2006. It found that screening does, in fact, lead to over-diagnosis and overtreatment. "For every 2,000 women invited for screening throughout 10 years, one will have her life

prolonged," the authors said. "In addition, 10 healthy women, who would not have been diagnosed if there had not been screening, will be diagnosed as breast cancer patients and will be treated unnecessarily."

The review concluded: "It is thus not clear whether screening does more good than harm. Women invited to screening should be fully informed of both benefits and harms."

## EXAGGERATED AND OVERSTATED

Cornelia Baines was deputy director of the Canadian National Breast Screening Study when she was diagnosed with the cancer in 2004. She might have been expected to use the experience to fuel a

campaign to increase 'awareness'. But Baines, an emeritus professor in the department of public health sciences at the University of Toronto, says instead that the experience made her realise the extent to which risks of getting breast cancer have been exaggerated, and the effectiveness of screening overstated.

"In North America," she says, "there is virtually an epidemic of lobular cancer in situ." This is where the cells in the lobes of a woman's breasts have undergone changes. And while it may increase a woman's chances of a cancer diagnosis in the future, many screening experts would counter that such women do not have breast cancer but have simply been over-diagnosed. And yet, says Baines, "women with this diagnosis [who then undergo treatment of one sort or another] believe they have been cured of cancer".

As it is, Baines says, "the attitude I frequently encounter is that of a state of almost terror about breast cancer – even before the diagnosis is encountered." Women, she says, have been educated to be afraid and to believe in mammography as their salvation. Baines met one woman in her twenties who was so afraid of a breast cancer diagnosis that she said she wished she could have a mammogram daily.

Some women will always be this anxious, even without the awareness campaigns: the grandmother of the woman referred to by Baines had had breast cancer, after all. But it's also clear how the



# FINANCIAL TIMES

**Reality check**  
 Women in Britain face a one-in-nine chance of getting breast cancer. Except they don't. So why is this figure still being used in awareness campaigns? And is his type of cancer overdiagnosing leading to pointless screening and unnecessary courses treatment?  
 by Roger McCartney  
 @rjmccartney

**Thermostat**  
 by the uncertainty about how long it will last. The thermostat is a device that maintains a constant temperature. In the case of the thermostat, the device is the thermostat itself. The thermostat is a device that maintains a constant temperature. In the case of the thermostat, the device is the thermostat itself. The thermostat is a device that maintains a constant temperature. In the case of the thermostat, the device is the thermostat itself.

**GM**  
 GM announces rebirth with vow to start listening to its customers

**THE SALE**  
 I RESPONSE SUIT £500

**REVENUE**  
 27

Award winning writing. This feature in the FT Weekend gave readers the balanced and accurate information they need to make informed decisions about whether to attend screening and how to respond to the results

media influences women's fears. When Kylie Minogue announced she had breast cancer in May 2005, some hospitals reported a surge in young women turning up at breast clinics asking to be screened. A report in *The Lancet* in 2006 showed that one clinic had received a huge surge in referrals for younger women but, despite this, no more breast cancers were found compared with the absolute numbers that would have been expected anyway. This meant that more women were exposed to X-rays. And concerns were expressed elsewhere that older women with worrying breast symptoms had been pushed down the queue.

Meanwhile, critics of breast cancer screening face an uphill battle. Baines says: "In the past I was on the advisory committee of a very large cancer voluntary organisation. We were discussing scientific issues about breast cancer screening. We were told at the end of the day that 'we can't accept the committee's recommendations because they are counter to the beliefs of the fundraising volunteers and their support is essential'."

Donald Berry agrees with Baines' view. A statistician and professor of cancer research at the University of Texas, he has spent much of his career involved in the design and execution of breast cancer trials. Most significantly, he served on a National Institutes of Health "consensus development" panel in 1997, which drew up US guidelines for screening women in their forties for breast cancer. The group recommended that women be given information about "positives and negatives" associated with screening, and be allowed to make their own decisions about whether to be screened – in consultation with their doctors. "This hit the

press all over the world," recalls Berry. "[We were] widely criticised. We had all kinds of charges against us, suggesting that we hated women, even though over half the panel were women."

"If you find breast cancer at a very early stage," adds Berry, "you don't know what you've got. You don't know if that cancer is never going to harm anyone – it might even be disposed of by the body. What would this kind of test lead to: double mastectomy in most of the population?"

"In this country," he says, referring to the US, "we have many researchers looking for earlier and earlier means of detecting breast cancer. And it scares the bejesus out of me."

Berry wants the same thing Lauder wants: a knowledgeable population. "I don't like ignorance," he says. But he sees the enthusiasm for screening without consideration of its limitations as inimical to the spread of knowledge. "I don't like it when some people's opinions are foisted on others... I've never understood what possibly could be so wrong about spelling out [the pros and cons of screening]. 'These are the benefits as we know them – they are uncertain. These are the risks as we know them – and these are more certain.' What could be a rational argument against letting women know what we know?"

#### WEIGHING RISKS AND BENEFITS

Supporters of breast cancer screening say that it is a proven saver of lives. Certainly, systematic reviews examining the quality evidence on the subject suggest that is true. But this decrease in mortality comes at the price of many other women being diagnosed and treated for a cancer that was never going to shorten life. Some

women may be happy with this uncertainty; others may wish to make different decisions. Apart from overtreatment – radiotherapy and operations for cancers that were never going to impact on mortality – the other harms include those of radiation to the breast, and the anxiety and damage connected with the diagnosis and all of these tests.

The two women in the best position to relay this information to the British public are Jane Hatfield, director of policy and campaigns at Breast Cancer Care, a UK-based breast cancer charity, and Professor Julietta Patnick, director of the NHS Cancer Screening Programmes.

Type "breast cancer" into a UK web browser, and Breast Cancer Care's site is the first link to appear. The group is "the UK's leading provider of information, practical assistance and emotional support for anyone affected by breast cancer". As for the content of that information, Hatfield says, "we [awareness advocates] don't always get it right". She is responding to my question about a woman's chances of getting breast cancer. The number often quoted in this country is one in nine but in fact for a woman aged up to 85 the risk is one in 10. For a woman aged 50 or younger, her estimated risk of being diagnosed with breast cancer is one in 50. Women under the age of 30 are looking at odds of one in 1,900.

I can't help but feel that "one in nine" – which has featured in high-street advertising campaigns and is quoted by many breast cancer charities – must contribute to the fear Baines and other doctors describe seeing in patients.

"People obviously ask what the incidence of breast cancer is, and yes, we have used this statistic," says Hatfield. "But we

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**Distorted image.** This poster gives the risk of breast cancer as one in eight, almost 250 times greater than the true risk for women of this age

also look to stress the link between age and risk. We would always promote breast awareness among any age group of women so women get used to knowing what is normal for them and noticing any changes.”

Last year, a study appeared in the *British Journal of General Practice* showing that less than 1% of women surveyed knew that the risk for breast cancer was highest in the oldest age groups. It concluded that there was “a serious lack of knowledge” about the subject. Despite the fact that Patnick was one of the study’s two authors, the standard leaflets provided by her NHS programme say merely that “one in nine women will develop breast cancer at some time in their life. Breast screening is more common in women over 50.”

When I confront Patnick about the simplistic use of this statistic, and the

failure to point out that the risk of cancer increases with age, she says: “Well, that is the popular figure, so to give a different figure was going to cause confusion.

“I’ll tell you what happened,” she adds. “We were debating what to put on the leaflet and I was going to work, following a bus. And there it was, ‘one in nine’, on an advert on the bus. I realised that if we [didn’t] put that on, we were going to confuse like mad.”

I press her: should consistency trump accuracy? “We do advertise our website in our leaflet. [There] women can get more information.”

### NO BLACK AND WHITE OPTIONS

Jane Keidan is no stranger to serious illness. A practising haematologist, she deals with patients who have serious blood and lymphatic disease. But, she says, “in my line of work, the options for people are more clearly black and white, and I can therefore advise a patient on the best course of action.” When she was diagnosed with breast cancer, however, there were huge decisions to make, and even with a medical background, she found it very difficult to understand all the information and make informed, dispassionate choices.

Just after her diagnosis, Keidan read about the drug Herceptin, which was being praised as an ‘instant cure-all’ in the popular press. The release of the drug’s trial data at an oncology conference prompted a standing ovation. And yet the National Institute for Health and Clinical Excellence (NICE) needed to rule on its cost-effectiveness before it could be made available in Britain, and Keidan needed to decide whether she could wait.

“At the time, from what I could read

on the Breast Cancer Care website and in the media in general, it didn’t seem logical to deny women the drug... I wrote to the Primary Care Trust, my MP, the prime minister – everyone I could think of, really. The *Sun* newspaper contacted me. The idea was that they would somehow ‘shame’ people into getting us this drug. It felt very nice. Someone was offering to help.”

At that stage, she was relying on the popular reporting of Herceptin; when she took advantage of her role as a doctor to learn more, from professionals, she decided not to take the drug: “I was fortunate because I also started to discuss it with medical colleagues – other oncologists – an immense privilege.” But the feeling that the offer of help from the *Sun* prompted in Keidan is telling. If breast cancer charities have succeeded, it is in making people with the disease feel cared for and empowered. If they have failed, it is in doing so at the expense of a well-informed population, that is instead unnecessarily fearful and misunderstands the real chances of getting breast cancer.

But at least this shows us what the critics of the current system need to do in order to change it: if doctors and researchers want patients to trust them, they need to talk to those patients – all of them, not just the haematologists among them – as people needing both information and empathy. Pushing women towards breast cancer screening and every intervention available for the disease is, in the end, not always the same thing as caring about their health.

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