

# Information in practice

## Presentation on websites of possible benefits and harms from screening for breast cancer: cross sectional study

Karsten Juhl Jørgensen, Peter C Gøtzsche

### Abstract

**Objective** To investigate whether information on mammographic screening presented on websites by interest groups is balanced, is independent of source of funding, and reflects recent findings.

**Design** Cross sectional study using a checklist with 17 information items.

**Setting** 27 websites in Scandinavian and English speaking countries.

**Results** The 13 sites from advocacy groups and the 11 from governmental institutions all recommended mammographic screening, whereas the three from consumer organisations questioned screening ( $P=0.0007$ ). All the advocacy groups accepted industry funding, apparently without restrictions. In contrast the three consumer organisations acknowledged the risk of bias related to industry funding, and two of them did not accept such funding at all. Advocacy groups and governmental organisations favoured information items that shed positive light on screening. The major harms of screening, overdiagnosis and overtreatment, were mentioned by only four of these groups, but by all three sites from consumer organisations ( $P=0.02$ ). In addition, the chosen information was often misleading or erroneous. The selection of information items for websites did not reflect recent findings, apart from the consumer sites, which were much more balanced and comprehensive than other sites (median of 9 information items *v* 3 items,  $P=0.03$ ).

**Conclusions** The information material provided by professional advocacy groups and governmental organisations is information poor and severely biased in favour of screening. Few websites live up to accepted standards for informed consent such as those stated in the General Medical Council's guidelines.

### Introduction

Women can get information about the possible benefits and harms of mammographic screening from governmental institutions and professional advocacy groups. This information could be biased, however, since the success of a screening programme depends on the participation rate. Another potential conflict of interest is industry funding of advocacy groups.

A review of 58 Australian pamphlets in 1998 showed that the information presented to women invited for breast cancer screening was biased and insufficient and did not allow fully informed consent.<sup>1</sup> Another Australian study, of 54 publications used to inform about screening mammography in New South Wales, showed that only 18% of the publications gave any infor-

mation on false positive and false negative results, and only 48% gave any information on adverse effects.<sup>2</sup>

In the European Union an average of 23% of the population use the internet to find information about health issues; Denmark has the highest rate, at 47%.<sup>3</sup> If the information about screening on the internet is biased, women's status as autonomous individuals could be violated.<sup>4</sup> The importance of balanced information is underlined by a study which found that 61% of women decided for themselves whether to have a screening mammogram, and a further 26% made the decision together with their doctor.<sup>5</sup>


In 2001 the quality of the randomised trials of mammographic screening was criticised in a comprehensive Cochrane review that questioned the benefit of screening.<sup>6</sup> In addition, important harms related to overdiagnosis and overtreatment were demonstrated.<sup>7,8</sup> We therefore decided to study whether the current information on the internet was balanced and reflected the recent findings.

### Materials and methods

We studied whether the information presented on the internet by major interest groups gave a balanced account of the possible benefits and harms of mammographic screening; whether funding of interest groups was related to type of information; and whether the information was different from what was previously provided in pamphlets.<sup>1</sup>

We located websites produced by professional advocacy groups (such as cancer charities), governmental institutions, and consumer organisations from Australia, Canada, Denmark, New Zealand, Norway, Sweden, the United Kingdom, and the United States. All of these countries have screening programmes, although so far only regionally in Denmark and Norway. We searched for "breast cancer" and "mammography" and "screening" and one of the included countries, primarily with the search engines Google and Yahoo (see appendix on [bmj.com](http://www.bmj.com) for details). By using these major search engines, we hoped to find the same websites that women would on the internet. The most popular sites with the best match to the search terms top the lists. We located the major organisations in each country with these search engines, and we identified extra websites by links and personal contacts.

One of the authors (KJJ) searched the sites systematically and printed all relevant information. When sites had their own search machine or site map, these were used to locate relevant pages. The printout of each website was evaluated independently

 Details of the search engines used and the websites reviewed in this study appear on [bmj.com](http://www.bmj.com)

## Information in practice

by each author, and any disagreements were settled by discussion. We used a data sheet that contained the same 10 information items as in the review of pamphlets<sup>1</sup> and seven additional relevant items recommended by the Ethical Council in Denmark.<sup>9</sup> When a site had separate information for professional healthcare workers and the general public, we evaluated the information for the public. Scientific articles linked to a site were not evaluated. When information on funding was unclear, we contacted the organisations. We accessed all the sites during September and October 2002.

We divided the websites into three groups, primarily based on the information provided in the "About us" section, according to whether they were from governmental institutions, professional advocacy groups, or consumer organisations. We defined advocacy groups as those whose general purpose is to promote the interests of patients and their relatives and consumer organisations as those whose general aim is to assess the quality of the healthcare services that are offered to patients and citizens.

We hypothesised that the information provided by consumer organisations would be more comprehensive and would more often give information on possible harms than the two other types of organisations. We compared the number of information items provided with a Mann-Whitney test, and individual items with Fisher's exact test.

## Results

### Recommendations on websites

We located 27 websites, 13 from professional advocacy groups, 11 from governmental institutions, and three from consumer organisations (see appendix on [bmj.com](http://bmj.com)). The governmental and advocacy sites all recommended mammography screening, at least implicitly, whereas the consumer sites questioned the value of screening ( $P=0.0007$ ).

### Funding

All 13 advocacy groups accepted sponsorship from industry, apparently without restrictions. The Canadian Cancer Society noted that "Partnership with the Canadian Cancer Society can assist your company in reaching your commercial objectives." In contrast, the three consumer organisations explicitly acknowledged the risk of bias related to industry funding: two (Breast Cancer Action and Center for Medical Consumers) said that they did not accept grants from industry, while the third (National Breast Cancer Coalition) noted that only 15% of its budget can come from corporations, only 5% from any single source, and that this funding is restricted to general operating support.

### Information items

The sites had a median of three information items out of the 17 possible; the highest number was 13 (Center for Medical Consumers). Five sites had none, and these sites mainly addressed practical issues related to the examination. The median number of items was nine for the three consumer sites, which were sceptical about screening, and three for the other sites ( $P=0.03$ ). Our two independent assessments of the sites identified a total of 98 and 99 information items; after discussion, we agreed on 118 items. The discrepancies were mainly caused by oversight. The significant difference between the consumer sites and the other sites persisted for the individual assessments ( $P=0.03$ ).

The four most common information items were the same as in the 1998 study of pamphlets (table 1), but more websites described the relative and absolute risk reduction of death from breast cancer ( $P=0.006$  and  $P=0.005$ , respectively), the proportion of women recalled ( $P=0.006$ ), and the predictive value of a positive mammogram ( $P=0.02$ ). The relative risk reduction was usually given as 30%, but estimates varied from none to 50% reduction. Three times as many sites provided the

**Table 1** Presence of information items about screening for breast cancer on 27 websites (from professional advocacy groups, governmental institutions, and consumer organisations) and in a 1998 survey of 58 pamphlets<sup>1</sup>

Information items	No of sites mentioning information item				Occurrence (%)	
	Advocacy sites (n=13)	Governmental sites (n=11)	Consumer sites (n=3)	Total (n=27)	On websites	In 58 pamphlets <sup>1</sup>
<b>Included in 1998 review of 58 pamphlets<sup>1</sup></b>						
Lifetime risk of developing breast cancer	5	6	1	12	44	60
Lifetime risk of dying from breast cancer	1	2	1	4	15	2
Survival from breast cancer	1	1	1	3	11	5
Relative risk reduction of death from breast cancer	5	7	3	15	56	22
Absolute risk reduction of death from breast cancer	1	2	2	5	19	0
Number needed to screen to avoid one death from breast cancer	0	0	2	2	7	0
Proportion of screened women who would be recalled	6	4	2	12	44	14
Proportion of breast cancers detected by mammography (sensitivity)	2	3	2	7	26	26
Proportion of women without breast cancer who would have a negative mammogram (specificity)	0	0	0	0	0	0
Proportion of women with a positive mammogram who would have breast cancer (positive predictive value)	2	1	1	4	15	0
<b>Added in this study</b>						
Relative risk reduction of total mortality	0	1	1	2	7	
Carcinoma in situ	4	3	3	10	37	
Overdiagnosis and overtreatment	2	2	3	7	26	
Effect of screening on number of mastectomies or lumpectomies	1	4	2	7	26	
Risks related to radiotherapy	1	2	1	4	15	
Psychological distress related to false positive results	4	3	3	10	37	
Pain at mammography	8	5	1	14	52	

relative risk reduction as provided the absolute risk reduction (table 1).

For the seven new items we added to those used in the survey of pamphlets, information was rarely provided on relative risk reduction of total mortality (only two sites did so) and risks related to radiotherapy (four sites). Information on the other items was provided by a quarter to half of the websites (table 1). The three consumer sites mentioned overdiagnosis and overtreatment, but only four of the other 24 sites did so ( $P=0.02$ ).

### Bias in selection and presentation of information

The essence of the messages varied widely (see box). Most websites omitted information on important harms (table 1) and emphasised possible benefits in a way that would be expected to increase uptake of screening. For example, 12 sites mentioned lifetime risk of developing breast cancer, usually followed by the annual number of diagnoses. In contrast, only three sites mentioned the relatively reassuring message that women have a more than 50% chance of surviving breast cancer once it is diagnosed, and only four stated that the lifetime risk of dying from breast cancer is about 3-4% (depending on country). Twelve sites stated the number of women recalled and presented this as about 5% at each screening round.

Issues related to carcinoma in situ, overdiagnosis and overtreatment, and number and type of operations were mentioned by a quarter to a third of the sites (table 1), but often in a misleading or erroneous fashion (see box). Four governmental websites and one advocacy site indicated that screening leads to fewer mastectomies. One governmental and three advocacy sites noted that it is beneficial to detect and remove carcinoma in situ since it would then not recur. Only two such sites mentioned that screening can detect cancers that may never progress, compared with all three consumer sites ( $P=0.007$ ). Only four sites noted that there could be risks associated with radiotherapy, but the risks were downgraded on three of the sites (see box).

The three consumer sites described psychological distress related to false positive findings, compared with seven of the governmental or advocacy sites ( $P=0.08$ ); seven sites described it vaguely as "anxiety," and no sites gave an estimate of the incidence. The potential pain inflicted by the mammographic procedure was mentioned by 14 sites, three of which claimed that the procedure shouldn't be painful.

## Discussion

The material about screening for breast cancer that was provided by professional advocacy groups and governmental organisations was information poor and severely biased in favour of screening. The material provided by the consumer organisations was much more comprehensive and balanced. It is worrying that so few websites live up to accepted standards for informed consent<sup>12</sup> since it is possible to persuade people to accept or decline cancer screening by withholding or including particular information items.<sup>13 14</sup>

The way data are presented can also substantially affect views on therapeutic effectiveness.<sup>15</sup> To mention that screening reduces the risk of dying from breast cancer by 30%<sup>16</sup> (relative risk reduction) is much more impressive than the equivalent finding—reported in the same overview—that the absolute risk of dying from breast cancer is reduced by 0.1% after 10 years.<sup>16</sup> On the Danish Cancer Society site, this estimate was increased by a factor of 10 to 1%. The inflated estimate also appears in a Danish governmental report that recommended screening be intro-

duced, and in which the results from the screening trials had been extrapolated far beyond the actual data until the women became 80 years of age, assuming they did not die from other causes and disregarding the fact that only women aged 50-69 are invited to screening.<sup>17</sup>

Breast cancer mortality is a biased outcome that favours mammographic screening,<sup>6-8 18</sup> and screening increases cardiovascular mortality because of the increased use of radiotherapy.<sup>8 11</sup> Total mortality is therefore relevant, but only the National Breast Cancer Coalition noted that an effect on total mortality has not been demonstrated.<sup>6-8 19 20</sup> Since misclassification of cause of death often occurs with deaths from other cancers,<sup>6-8</sup> it is also relevant that the screening trials failed to find an effect on death from any cancer (including breast cancer), contrary to what is expected from the claimed 30% reduction in breast cancer mortality.<sup>21</sup> This was not mentioned by any site.

### Overdiagnosis and overtreatment

The most important harms of screening—overdiagnosis and overtreatment—seem to be the best kept secret about screening. The level of overdiagnosis can be studied reliably in those two screening trials that were not flawed and were not contaminated by early, systematic screening of the control group.<sup>22 23</sup> It was 30% (table 2), which corresponds to the 31% overtreatment previously reported.<sup>7 8</sup> The overdiagnosis was 33% for the Swedish trials that screened the whole control group when only cancers before this screen were included.<sup>24</sup>

Epidemiological data show similar levels of overdiagnosis. When screening was introduced in the United States, the incidence of invasive breast cancer increased by 26% in only seven years and has remained elevated ever since over a span of 20 years.<sup>24 25</sup> If carcinoma in situ cases are added, the overdiagnosis increases to about 35%.<sup>24 25</sup> In the United Kingdom the incidence of invasive cancer increased by 37% and cases of carcinoma in situ increased by 373% from 1990 to 2001, when screening was introduced.<sup>26</sup>

These results indicate that the five websites that noted that screening leads to fewer mastectomies are seriously misleading. The opposite seems to occur. In the screening trials 20% more mastectomies were performed in the screened groups than in the control groups,<sup>7 8</sup> and in the United Kingdom mastectomies increased by 36% for invasive cancer and by 422% for carcinoma in situ when screening was introduced.<sup>25</sup> Because of overdiagnosis, screening also increases the use of radiotherapy,<sup>8</sup> but only four sites gave the important information that radiotherapy was associated with risks,<sup>11</sup> and three of the four sites downgraded this information (see box).

### Downgrading of other harms

The websites' statements that about 5% of screened women would be recalled at each screening round is far less disturbing than the information that the cumulated risk is 49% after 10 mammograms.<sup>10</sup> The information that false positive findings can sometimes create "anxiety" is also much more soothing than the information that more than 10% of women screened will at some point experience important psychological distress for many months.<sup>6 8</sup>

The websites generally downgraded the potential pain inflicted by the mammographic procedure, and the claim by three websites that "the procedure shouldn't be painful" is highly misleading. A survey of five studies found that 31% of women felt pain during their first mammogram and that a further 23% felt it was very uncomfortable.<sup>27</sup> Furthermore, half of 81 women who declined an invitation to the second round of

## Comments on possible harms from breast cancer screening by websites

### Carcinoma in situ

"There is no advantage to early detection of [carcinoma in situ]; in fact, there is a huge disadvantage of unnecessary treatment"—Breast Cancer Action

"Women in this situation sometimes have more extensive surgery than women with invasive cancer"—BreastScreen Aotearoa

"There is virtually no risk of the cancer coming back once it has been removed"—Cancer Research UK

"These early tumors cannot harm patients if they are removed at this stage and mammography is the only proven method to reliably detect these tumors"—RadiologyInfo

### Overdiagnosis and overtreatment

"Regular mammography screening may actually increase a woman's chances of losing a breast... Mammograms find some early cancers that might never have been diagnosed and some of these early cancers are treated by mastectomy"—Center for Medical Consumers

"We cannot determine at the time of diagnosis the type of tumor a woman has. The result is that we mistreat or over-treat many women diagnosed with breast cancer in our effort to help the others"—Breast Cancer Action

"There are some types of early breast cancers that will never spread to other parts of the body, and mammograms probably find many of these breast cancers... The result is that many women get treated for breast cancer when they may not need to be treated at all... This is called 'overtreatment'. Overtreatment can be harmful to women"—National Breast Cancer Coalition

"Over-diagnosis and over-treatment are estimated to account for between 0-10% of cancers detected by breast screening"—BreastScreen Aotearoa (Our comment: it amounts to 30% (see table 2 and text))

"Screening detects primarily those early changes which will later develop into cancer [our translation]"—Kræftens Bekæmpelse (Our comment: this is not true for carcinoma in situ)

"Only in 11% of false positive cases was it necessary to remove the lump in order to exclude the suspicion of cancer [our translation]"—Kræftens Bekæmpelse (Our comment: since the proportion false positives is about 5% at each screen, the quote gives the impression that only 0.5% of screened women get an unnecessary biopsy. However, over 10 mammograms, the cumulated biopsy risk for those screened was estimated to be 19%,<sup>10</sup> or 40 times higher)

### Numbers of mastectomies and lumpectomies

"Mammography screening leads to more false-positives, more unnecessary surgeries, and more use of aggressive breast cancer treatments... Mammography screening also increased the number of mastectomies by 20% and the number of mastectomies and lumpectomies combined by 30%"—National Breast Cancer Coalition

"Treating breast cancer when it is small... increases the likelihood that she can be offered surgical options which conserve the breast"—BreastScreen Aotearoa

"With early detection the need for radical surgery or radiation therapy, with their adverse side effects, can be minimized"—Health Canada-Womens Health Bureau

### Risks related to radiotherapy

"Women may undergo unnecessary and/or inappropriate treatments... chemotherapy and radiotherapy are toxic and should not be given to women who do not need them"—National Breast Cancer Coalition

"Because the current technique of radiotherapy defines both doses and target volume precisely, the doses to healthy near-by tissues are minimal. A Danish study with 12 years of follow-up did not find an increase in heart disease after radiotherapy (Højris et al, *Lancet* 1999). The claims that current radiotherapy of breast-cancer patients causes heart disease are therefore not correct [our translation]"—Krefregistret (Our comment: this study had too little power and too short a follow up to exclude this possibility (11 v 11 vascular deaths), and a systematic review of radiotherapy indicated that in low risk women, such as those with cancers found by screening, it would be expected to increase mortality from all causes<sup>11</sup>)

"There are other more severe, but much rarer long-term side effects. Many of these don't happen now. This is because the treatment planning is much more exact"—Cancer Research UK (Our comment: there was no indication that the subject discussed was radiotherapy and no mention of the finding that radiotherapy can cause fatal cardiovascular disease)

### Pain at mammography

"Most women find this uncomfortable and some find it painful"—BreastScreen Aotearoa

"May cause some temporary pain, but it is usually not severe"—Health Canada-Womens Health Bureau

"They are so satisfied that they recommend fellow sisters to get x-rayed in this way. They do this although two out of three experience the examination as slightly uncomfortable (52.3%), hurting (11.4%) or painful (2.5%) [our translation]"—Den Norske Kreftforening

"You should not feel pain"—American Cancer Society

"Fast and almost painless examination [our translation]"—Cancerfonden

"Shouldn't be painful"—Cancer Research UK

### Other citations

"Show up when invited for population based control (screening) [our translation]"—Den Norske Kreftforening

"The leaflet includes an explanation about false positive and false negative results"—NHS Cancer Screening Programmes (Our comment: there is no such explanation in the leaflet)

"If the programme is to be successful for women it is very important that you return for screening every two years"—BreastScreen Aotearoa (Our comment: the focus is on the programme, not on the women)

"Women in the 50-69 target group who have regular two-yearly mammograms can reduce their risk of dying from breast cancer by up to 50%"—BreastScreen Australia (Our comment: this percentage is seriously misleading<sup>6-8</sup>)

"Early detection of breast cancer saves lives. Therefore, there is no need to re-evaluate the value of general mammography screening [our translation]"—Cancerfonden



**Table 2** Numbers of cancers detected, and lumpectomies and mastectomies in the trials of breast cancer screening from Canada (after 7 years)<sup>22</sup> and Malmö, Sweden (after 8.8 years)<sup>23</sup>

Trial	No of women		No of cancers detected		Relative risk (95% CI)	No of lumpectomies and mastectomies		Relative risk (95% CI)
	Screened group	Control group	Screened group	Control group		Screened group	Control group	
Canada <sup>22</sup> :								
Women aged 40-49	25 214	25 216	426	327	1.30 (1.13 to 1.50)	415	313	1.33 (1.15 to 1.53)
Women aged 50-59	19 711	19 694	460	365	1.26 (1.10 to 1.44)	448	351	1.28 (1.11 to 1.46)
Malmö <sup>23</sup>	21 088	21 195	588	447	1.32 (1.17 to 1.49)	561	419	1.34 (1.18 to 1.52)
Overall					1.30 (1.20 to 1.40)			1.31 (1.22 to 1.42)

CI=confidence interval.

screening said that their major reason for doing so was because their first mammogram was painful.<sup>28</sup>

### Potential conflicts of interest

The three consumer organisations, which all questioned the value of screening, did not have an apparent conflict of interest. In contrast, all advocacy groups accepted financial support from industry, apparently without restrictions. Receiving financial support from companies with an economic interest in screening programmes, or the treatments associated with them, potentially undermines the objectivity of the organisation, with a mutually beneficial relationship as a possible outcome.<sup>29 30</sup>

Governmental organisations that offer screening are also potentially biased. They have made a decision and must defend this position.<sup>4</sup> Furthermore, the success of screening depends on a high participation rate to make the programmes fit the preceding cost-benefit analyses. This bias can result in complete misrepresentation of unwelcome research results.<sup>31</sup>

### Had the websites selected the most important information items?

Six of the seven information items we added to the previous survey of pamphlets addressed possible harms of screening (table 1), although some of them were sometimes described as benefits. Sites with a positive presentation of screening could therefore seem relatively more information poor. However, this cannot explain why most sites downgraded the harms that they did mention and omitted information that is vital to make an informed decision.<sup>32</sup> Our study shows that it is not the relative importance of the information items that determines whether they are mentioned. The risk of becoming a cancer patient unnecessarily and the increased risk of losing a breast<sup>8 26</sup> are obviously important for informed decision making but were rarely mentioned.

It could be argued that some women would have trouble understanding the meaning of an absolute risk reduction. But it is not more difficult to understand than a relative risk reduction, and it is more important for informed decision making,<sup>15</sup> in particular when the event rate is low, as it is for breast cancer mortality. Nor is it difficult to understand that screening can detect harmless tumours.

### Tension between informed consent and high uptake

In accordance with policies of national screening programmes,<sup>33</sup> most sites stated that women's decision whether to participate should be based on informed consent. Requirements for informed consent should be stricter when the healthy population is approached than when a sick patient consults a doctor, since healthy people have not asked for help and are considering participation in tests on a different basis. For breast screening, however, our healthcare systems have done the opposite and have sacrificed the obligation of a fully informed consent

for a paternalistic role, as shown in the NHS leaflet that asks "Why do I need breast screening?" rather than "Do I need breast screening?"<sup>34</sup> If the concern is, as screening advocates have suggested, that too few women would participate if they were presented with the relevant issues,<sup>4 35</sup> screening may be too controversial to be justifiable.

### The bottom line of mammography screening

The effect of screening is uncertain since most trials are of poor quality.<sup>6-8</sup> The most optimistic and most quoted result is a 30% reduction in breast cancer mortality.<sup>16</sup> If it were true, it would mean that one woman would be saved from dying from breast cancer for every 1000 women invited to screening for 10 years.<sup>16</sup> After 10 years of screening, 90.3% of the women would be alive, whereas if they were not screened 90.2% would be alive.<sup>16 36</sup> However, it is also possible that no one will be saved, since the women may die from something else, such as from complications from the breast cancer treatment,<sup>8 11</sup> and since an effect of screening on mortality from all causes has not been demonstrated.<sup>6-8 19 20</sup>

The overdiagnosis means that for every 1000 women invited to screening for 10 years, five additional women will be diagnosed with cancer; two additional women will have a breast removed and three will have a lump removed.<sup>8</sup>

Thus, most optimistically, for every woman who has her life prolonged, five healthy women, who would not have received a breast cancer diagnosis if there had not been screening, will be converted into cancer patients. Whether this is a too high price to pay is open to debate, but if women and policy makers are not informed of this balance between major benefits and major harms—which they have not been so far—then there cannot be any discussion or rational decision making. The present situation is that a woman customer who visits a "screening shop" doesn't know what she is buying into, and most often the shopkeeper either doesn't know or doesn't tell. This is untenable.

### Suggested improvements in the information women are offered

It is inappropriate to continue to use information about screening purely for encouraging high uptake.<sup>4</sup> Whatever is presented should be balanced and should reflect fairly the level of scientific uncertainty, allowing women to reach a decision by themselves. Furthermore, there should be links to more detailed information for those who need it.

Possible benefits and harms should get similar attention and should be presented in a similar fashion. If, for example, the benefit is presented as a 30% reduction in breast cancer mortality, then the overdiagnosis and overtreatment should be given as a 30% increase. However, it would be preferable to use absolute risk reductions and numbers<sup>15</sup>—for example, most optimistically, one woman has her life prolonged for every five women who get an unnecessary cancer diagnosis and treatment. The fact that

## What is already known on this topic

A 1998 survey showed that the information material in pamphlets presented to Australian women invited for breast cancer screening was biased and insufficient, and did not allow fully informed consent

## What this study adds

In 2001 the quality of the randomised trials of mammographic screening was criticised in a comprehensive systematic review, which questioned the benefit of screening and documented important harms

Despite these findings, the information presented to women on websites by professional advocacy groups and governmental organisations was selective and biased and failed to mention major harms

Websites from consumer groups were more balanced and comprehensive than sites by professional advocacy groups and governmental organisations

screening can detect cancers that may never progress is little known to women and should be emphasised in information material.<sup>32</sup> It also seems relevant to note that the detection of carcinoma in situ can cause problems for women applying for medical or life insurance, even for their daughters.<sup>37</sup>

The symmetry of information should also be respected for cumulated risks. If the lifetime risk of getting breast cancer is noted, then the lifetime risk of getting a false positive diagnosis should also be noted rather than the risk at each screening round.

Since people should be informed about the uncertainties of screening,<sup>12</sup> they need to know that the effect of screening is uncertain. A recent review by the US Preventive Services Task Force gave mammography screening a grade B recommendation, which means: "Evidence is sufficient to determine effects on health outcomes, but the strength of the evidence is limited by the number, quality, or consistency of the individual studies; generalizability to routine practice; or indirect nature of the evidence on health outcomes."<sup>38</sup>

We will send a copy of this article to the organisations whose websites we surveyed.

We thank Lacie Koppelman (science analyst, National Breast Cancer Coalition), Mary Ann Napoli (director, Center for Medical Consumers), and Marjukka Mäkelä (director, Finnish branch of the Nordic Cochrane Centre, and director, Finnish Office for Health Care Technology Assessment) for helpful advice and encouragement. The views expressed in this article represent those of the authors and are not necessarily the views or the official policy of the Cochrane Collaboration.

Contributors: PCG conceived the project, KJJ wrote the draft protocol, did the searches, and wrote the first manuscript. Both authors extracted data and contributed to the protocol and the manuscript. Both are guarantors.

Funding: None.

Competing interests: One of the authors was involved in the systematic review of breast screening trials that questioned the value of screening.

- 1 Slaytor EK, Ward JE. How risks of breast cancer and the benefits of screening are communicated to women: analysis of 58 pamphlets. *BMJ* 1998;317:263-4.
- 2 Croft E, Barratt A, Butow P. Information about tests for breast cancer: what are we telling people? *J Fam Pract* 2002;51:858-60.
- 3 European Opinion Research Group. European Union citizens and sources of information about health. 2003. [http://europa.eu.int/comm/health/ph\\_information/documents/eb\\_58\\_en.pdf](http://europa.eu.int/comm/health/ph_information/documents/eb_58_en.pdf) (accessed 3 Oct 2003).

- 4 Raffle AE. Information about screening—is it to achieve high uptake or to ensure informed choice? *Health Expect* 2001;4:92-6.
- 5 Davey HM, Barratt AL, Davey E, Butow PN, Redman S, Houssami N, et al. Medical tests: women's reported and preferred decision-making roles and preferences for information on benefits, side-effects and false results. *Health Expect* 2002;5:330-40.
- 6 Olsen O, Gøtzsche PC. Screening for breast cancer with mammography. *Cochrane Database Syst Rev* 2001;(4):CD001877.
- 7 Olsen O, Gøtzsche PC. Cochrane review on screening for breast cancer with mammography. *Lancet* 2001;358:1340-2.
- 8 Olsen O, Gøtzsche PC. Systematic review of screening for breast cancer with mammography. 2001. <http://image.thelancet.com/lancet/extra/fullreport.pdf> (accessed 8 Jan 2004).
- 9 *Screening—en redegørelse*. København: Det Etske Råd; 1999.
- 10 Elmore JG, Barton MB, Moceri VM, Polk S, Arena PJ, Fletcher SW. Ten-year risk of false positive screening mammograms and clinical breast examinations. *N Engl J Med* 1998;338:1089-96.
- 11 Early Breast Cancer Trialists' Collaborative Group. Favourable and unfavourable effects on long-term survival of radiotherapy for early breast cancer: an overview of the randomised trials. *Lancet* 2000;355:1757-70.
- 12 General Medical Council. *Seeking patients' consent: the ethical considerations*. London: General Medical Council, 1998. [www.gmc-uk.org/standards/consent.htm](http://www.gmc-uk.org/standards/consent.htm) (accessed 8 Jan 2004).
- 13 Wolf AM, Nasser JF, Wolf AM, Schorling JB. The impact of informed consent on patient interest in prostate-specific antigen screening. *Arch Intern Med* 1996;156:1333-6.
- 14 Ransohoff DF, Harris R. Lessons from the mammography screening controversy: can we improve the debate? *Ann Intern Med* 1997;127:1029-34.
- 15 Naylor D. Measured enthusiasm: does the method of reporting trial results alter perceptions of therapeutic effectiveness. *Ann Intern Med* 1992;117:916-21.
- 16 Nyström L, Rutqvist LE, Wall S, Lindgren A, Lindqvist M, Ryden S, et al. Breast cancer screening with mammography: overview of Swedish randomised trials. *Lancet* 1993;341:973-8.
- 17 *Tidlig opsporing og behandling af brystkræft: statusrapport*. København: Sundhedsstyrelsen, 1997.
- 18 Early Breast Cancer Trialists' Collaborative Group. Effects of radiotherapy and surgery in early breast cancer: an overview of the randomized trials. *N Engl J Med* 1995;333:1444-55.
- 19 Gøtzsche PC. Update on effects of screening mammography. *Lancet* 2002;360:338.
- 20 Nyström L, Andersson I, Bjurström N, Frisell J, Rutqvist LE. Update on effects of screening mammography: authors' reply [correction appears in *Lancet* 2002;360:1178]. *Lancet* 2002;360:339-40.
- 21 Gøtzsche PC. Screening for breast cancer with mammography: author's reply. *Lancet* 2001;358:2167-8.
- 22 Miller AB. The costs and benefits of breast cancer screening. *Am J Prev Med* 1993;9:175-80.
- 23 Andersson I, Aspegren K, Janzon L, Landberg T, Lindholm K, Linell F, et al. Mammographic screening and mortality from breast cancer: the Malmö mammographic screening trial. *BMJ* 1988;297:943-8.
- 24 Gøtzsche PC. On the benefits and harms of screening for breast cancer. *Int J Epidemiol* (in press).
- 25 Ries LAG, Eisner MP, Kosary CL, Hankey BF, Miller BA, Clegg L, et al. eds. *SEER cancer statistics review, 1973-1999*. Bethesda, MD: National Cancer Institute, 2002. ([http://seer.cancer.gov/csr/1973\\_1999/](http://seer.cancer.gov/csr/1973_1999/)).
- 26 Douek M, Baum M. Mass breast screening: is there a hidden cost? *Br J Surg* 2003;90(suppl 1):June (Abstract Breast 14).
- 27 McNoe B, Miller D, Elwood M. *Women's experience of the Otago-Southland breast screening programme—a compilation of five studies*. Dunedin: Hugh Adam Cancer Epidemiology Unit, 1996.
- 28 Elwood M, McNoe B, Smith T, Bandaranayake M, Doyle TC. Once is enough—why some women do not continue to participate in a breast cancer screening programme. *N Z Med J* 1998;111:180-3.
- 29 Bekelman JE, Li Y, Gross CP. Scope and impact of financial conflicts of interest in biomedical research: a systematic review. *JAMA* 2003;289:454-65.
- 30 Lexchin J, Bero LA, Djulbegovic B, Clark O. Pharmaceutical industry sponsorship and research outcome and quality: systematic review. *BMJ* 2003;326:1167-70.
- 31 Gøtzsche PC. Office of NHS cancer screening programme misrepresents Nordic work in breast screening row. *BMJ* 2001;323:1131.
- 32 Schwartz LM, Woloshin S, Sox HC, Fischhoff B, Welch HG. US women's attitudes to false positive mammography results and detection of ductal carcinoma in situ: cross sectional survey. *BMJ* 2000;320:1635-40.
- 33 Mateau TM. A measure of informed choice. *Health Expect* 2001;4:99-108.
- 34 NHS. *Breast screening, the facts*. London: Health Promotion England, 2001. [www.cancerscreening.nhs.uk/breastscreen/publications/ia-02.html](http://www.cancerscreening.nhs.uk/breastscreen/publications/ia-02.html) (accessed 8 Jan 2004).
- 35 Horton R. Screening mammography: setting the record straight. *Lancet* 2002;359:441-2.
- 36 Nyström L, Larsson LG, Wall S, Rutqvist LE, Andersson I, Bjurström N, et al. An overview of the Swedish randomised mammography trials: total mortality pattern and the representativity of the study cohorts. *J Med Screen* 1996;3:85-7.
- 37 Thornton H. Consequences of breast screening. *Lancet* 2000;356:1033.
- 38 US Preventive Services Task Force. Screening for breast cancer: recommendations and rationale. *Ann Intern Med* 2002;137:344-6.

(Accepted 9 November 2003)

bmj.com 2004;328:148

Nordic Cochrane Centre, H:S Rigshospitalet, DK-2100 København Ø, Denmark  
Karsten Juhl Jørgensen physician  
Peter C Gøtzsche director

Correspondence to: Peter C Gøtzsche [pcg@cochrane.dk](mailto:pcg@cochrane.dk)