The case against

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On the day that the Forrest report was published Norman Fowler announced that the government was going to implement its recommendations. Those who were invited to give evidence to the working party were bound to secrecy about the matters discussed, and as a result dissent was, at least in the short term, effectively silenced.

The Forrest report is a consensus document that does not mention the arguments of the dissenting minority. Its recommendations are based on selective evidence, which ignores data that might undermine its unrealistic estimates. Published evidence is distorted. Ethical issues are avoided.

The other side of the story

The Swedish trial that served as the centrepiece of evidence in favour of population screening is incompletely documented. Only by accident did I discover the data on overall mortality—in the correspondence columns of the Swedish medical journal *Läkartidningen*.[1] The Forrest report makes no mention of the fact that in the Swedish trial the overall mortality in the screened group was slightly higher than in the control group. In other words, not a single life was "saved" in a trial that included over 130 000 women. The Forrest report quotes misleadingly a "30% reduction" in deaths from breast cancer in screened women. As only 34% of the deaths from breast cancer were determined at necropsy in the screened group[1] and as the cause of death was not ascertained by an independent panel the possibility of bias from misdiagnosis, which could reduce or annul the observed reduction in deaths from breast cancer, cannot be excluded. The paper in the *Lancet* used by the Forrest group gave no data on overall mortality, on interval cancers (cancers that appear between screenings), on the number of women with breast cancer excluded before randomisation (about two thirds of the deaths from breast cancer that would be expected to occur in the sample are unaccounted for), or on the case fatality of breast cancer (as opposed to mortality from breast cancer).[2] Another disturbing feature was the constant shifting of the age limits in the Swedish trial. I have recorded the following age ranges in various publications between 1981 and 1986: 40-⩾75, 40-46; >40; 40-69, 40-74, 40-69, and 40-74.

No amount of squirming on the statistical hook will change the fact that there was no net benefit for the women offered screening. The quoted 30% reduction is a relative percentage obfuscating the fact that the yearly benefit was one death fewer in each 15 000 women screened, provided that deaths from breast cancer were correctly ascertained. This "gain" was, however, more than offset by deaths from other cancers and other causes. Somebody should explain to women that this is what the 30% reduction means in absolute terms—not that one woman in three will not die.

The Forrest report distorts the evidence on interval cancers by claiming that no more than 5-10% of interval cancers would be expected if its recommendations were implemented. In large trials such as the Health Insurance Plan trial[3] and the Nijmegen case-control study[4] between one third and one half of all detected cancers were interval cancers.

No mention is made in the report of the positive predictive value of mammography, the single most important piece of information for any screening test. In the Canadian national breast screening study (still in progress) the positive predictive value was 5-10%.[5] This means that out of 100 mammograms showing positive results, 90-95 are false positives. The implementation of the Forrest report, with an estimated positive predictive value of 5% would result in 65 000 mammograms a year showing false positive results.

Disadvantages of screening

The report claims, contrary to existing evidence, that population screening is unlikely to produce a significant overdiagnosis. Yet the authors of the Swedish study reported 30-40% overdiagnosis in the screened group, which persisted for the duration of the trial.[2] In another paper by the same group the screening programme increased the rate of breast operations twofold.[6] One of the coauthors of the Swedish study expressed concern about "a very serious situation" of "unacceptable divergence of opinion" among the pathologists who interpreted the breast biopsy specimens and about the "overall muddling of statistics which invalidates any serious attempts to analyse the screening programme in its entirety."[7]

The harm of screening is not confined to overdiagnosis. Overdiagnosis implies overtreatment, unnecessary biopsies, unnecessary mastectomies, and widespread anxiety and fear. The advocates of screening should assess the harm by stating how many mammograms need to be taken and biopsies performed for one life saved. Wright calculated that if a woman subjected to operation for benign disease is considered to be harmed by screening the ratio of harm to benefit is 62 to 1.[8] I have argued elsewhere that screening healthy people without informing them about the magnitude of inherent risks of screening is ethically unjustifiable.[9]

Widely different estimates on the cost-benefit of mammography have been published. If, as I believe is the case, they are based on false premises they are meaningless. How do you calculate the cost of the benefit when there is no benefit?

Towards effective screening

The wisdom of population screening needs reappraisal. Firstly, it must be established that screening does alter the natural course of breast cancer in an appreciable proportion of screened women. Thirteen out of 14 long term follow up studies of patients with breast cancer failed to show evidence of cure, regardless of the stage at diagnosis. Secondly, if evidence shows that screening prolongs life the next question is whether the best achievable results from university centres translate into the real world of routine screening centres and private clinics. Judging from the ineffectiveness of the British cervical screening programme, there are no grounds for optimism. The horror of the private clinics has already been exposed.[10] Finally, only when these two hurdles have been cleared does the time come to discuss cost. What would be the cost of a permanent national programme? And, more importantly, in terms of opportunity cost is it worth while?

Who will be blamed, and who will assume responsibility for screening in Britain, if, say, in 10 years time mortality from breast cancer shows no improvement? As Richard Feynman, the Nobel laureate, observed after pinpointing the cause of the *Challenger* shuttle

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disaster: "Reality must take precedence over public relations, for nature cannot be fooled."

1 Projektgruppen för WE-studien. Replik om mammografi. *Läkartidningen* 1985;**82**:2674.
2 Tabár L, Fagerberg CJG, Gad A, *et al.* Reduction in mortality from breast cancer after mass screening with mammography. Randomised trial from the Breast Cancer Working Group of the Swedish National Board of Health and Welfare. *Lancet* 1985;i:829-32.
3 Shapiro S, Venet P, Strax P, Roeser R. Ten to fourteen year effect of breast cancer screening on mortality. *JNCI* 1982;**69**:349-55.
4 Verbeck ALM, Hendricks JHCL, Holland R, Mravunac M, Sturmans F, Day NE. Reduction of breast cancer mortality through mass screening with modern mammography. First results of the Nijmegan Project, 1975-1981. *Lancet* 1984;i:1222-4.
5 Baines CJ, Miller AB, Wall C, *et al.* Sensitivity and specificity of first screen mammography in the Canadian National Breast Screening Study: a preliminary report from five centres. *Radiology* 1986;**160**:295-8.
6 Holmberg L, Adami L-O, Presson I, Lundström T, Tabar L. Demands on surgical inpatient services after mass mammographic screening. *Br Med J* 1986;**293**:779-82.
7 Gad A. Ten years' experience from a randomised controlled breast cancer screening programme. II. Diagnostic aspects. In: *Proceedings of a conference on cancer screening.* Florence: Centro Per lo Studio e la Prevenzione Oncologica, 1987:37-8.
8 Wright CJ. Breast cancer screening: a different look at the evidence. *Surgery* 1986;**100**:594-8.
9 Skrabanek P. The physician's responsibility to the patient. *Lancet* 1988;i:1155-7.
10 Fentiman IS. Pensive women, painful vigils: consequences of delay in assessment of mammographic abnormalities. *Lancet* 1988;i:1041-2.

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How To Do It

Communicate with cancer patients: 2 Handling uncertainty, collusion, and denial

Peter Maguire, Ann Faulkner

Breaking bad news often prompts patients to ask questions about their future like: How long have I got? You then have to help them cope with uncertainty without them becoming demoralised.

Handling uncertainty

When asked: How long have I got? it is tempting to give a finite (Oh, three months) or range (Anything from a month to six months) of time. But such predictions are usually inaccurate, tend to err on the optimistic side, and cause problems for patients and their families. Patients then pace themselves according to the time they believe is left. If they deteriorate earlier than expected and are prevented from achieving planned goals they will feel cheated and bitter. Relatives can find an unexpectedly prolonged survival ("borrowed time") hard to cope with because they have used up their physical and emotional resources. So it is better to acknowledge your uncertainty and the difficulties that this will cause.

Doctor: You asked me how long he has. The trouble is, I don't know. I realise this uncertainty must be difficult for you.
Mrs W: It is. It is terrible knowing that he is going to die but not knowing when. I mean it could be in one month's time or next Christmas.
Doctor: That's the trouble, I just don't know how long it will be.

You should next check if she would like to know the signs and symptoms that would herald further deterioration.
Doctor: What I can do, but only if you would like me to, is tell you what changes would suggest he is beginning to deteriorate further.
Mrs W: Yes, I think that would help me.
Doctor: He will probably complain of feeling breathless, weak, and start going off his food.

You can then encourage her to try to use the intervening time.

Doctor: But as long as there are no signs like that I think you can take it that he is relatively OK. So, you should try to make the most of this time if you can. Is there anything you would particularly like to do?

Later, add that you are prepared to check him regularly, and show a willingness to negotiate the frequency of such check ups.

Doctor: I think it would help if I saw him from time to time to monitor how he is doing. How often would you like me to do that?
Mrs W: Would every month be OK?
Doctor: Yes, fine.

You should explain that if anything unforeseen occurs between these assessments you should be contacted immediately. This gives patients and relatives confidence that they have a "life line."

Doctor: If you are worried at any stage between his appointments you must get in touch with me. I can then assess him and decide what needs to be done.

Few patients or relatives abuse this offer.
When some patients or relatives face uncertainty they show that they do not want any markers.

Doctor: Would you like me to tell you how you might recognise if Peter's health is deteriorating?
Mrs B: No, I'll leave it to you. You're the expert.

Sometimes the uncertainty concerns issues other than "how long." Again you should acknowledge the uncertainty and establish any resulting worries.

Doctor: I sense that this uncertainty is a major problem for you.
Mr J: It is. I feel helpless not knowing what's going to happen or how it's going to happen.
Doctor: What are you worried about in particular?
Mr J: I'm worried about how I'm going to die. I don't want to be a burden on my family, and I'm not sure what to expect after death.
Doctor: Any other concerns?
Mr J: Isn't that enough?
Doctor: Yes, it is, but I just want to make sure I establish all your concerns before we discuss them in detail.

By separating out and exploring each concern the patient begins to see that there is some prospect that they can be tackled.

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