

Invitations for mammography screening: Basis for informed consent?

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Background

- Participation should be based on informed consent (GMC and European Guidelines)
- Balanced presentation of benefits and harms is necessary
- Letters of invitation play a central role due to general distribution and official origin, although other sources of information contribute
- Known misperceptions among invited women and flawed information in pamphlets and on web-sites

Methods

- We collected:
 - Letters of invitation (incl. Pamphlets)
 - Letters to non-responders
- Included countries had publicly funded screening programs and invitations in English or a Scandinavian language
- Evaluation using previously published data-sheet with benefits and harms

Material obtained

- Samples were obtained from Australia, Canada, Denmark, New Zealand, Norway, Sweden and the UK
- 31 of 51 contacted entities provided samples (61%)
- 21 included a pamphlet (68%)

Information included

- Major benefit: Reduced breast cancer mortality was mentioned in 30 invitations (97%) but estimated size provided in only 7. Size invariably mentioned as RRR, never ARR or NNS
- Major harm: Overdiagnosis/overtreatment not mentioned in any invitation

Information included

- 10/31 (32%) mentioned the lifetime risk of breast cancer
- 3/31 (10%) mentioned the chance of surviving breast cancer
- 6/31 (19%) mentioned the risk of being recalled for further investigations at each round

Information included

- 15/31 (48%) mentioned that the procedure can be painful, but 8/15 downplayed the effect
- 6/31 (19%) mentioned the psychological distress related to a false positive diagnosis
- 6/31 (19%) mentioned that screening leads to less mastectomies/simpler treatment
- Carcinoma in situ not mentioned

Other results

- 21/31 invitations stated a date of appointment (68%)
- Direct appeals for participation appeared in 18/31 invitations
- 19/20 pamphlets had persuasive headlines
- The wording of some letters to non-responders were rather harsh

“We strongly recommend that
you use this free service”

From letter of invitation

NT, Australia

“Have a screening mammogram,
it may save your life”

Headline in pamphlet, Western Australia

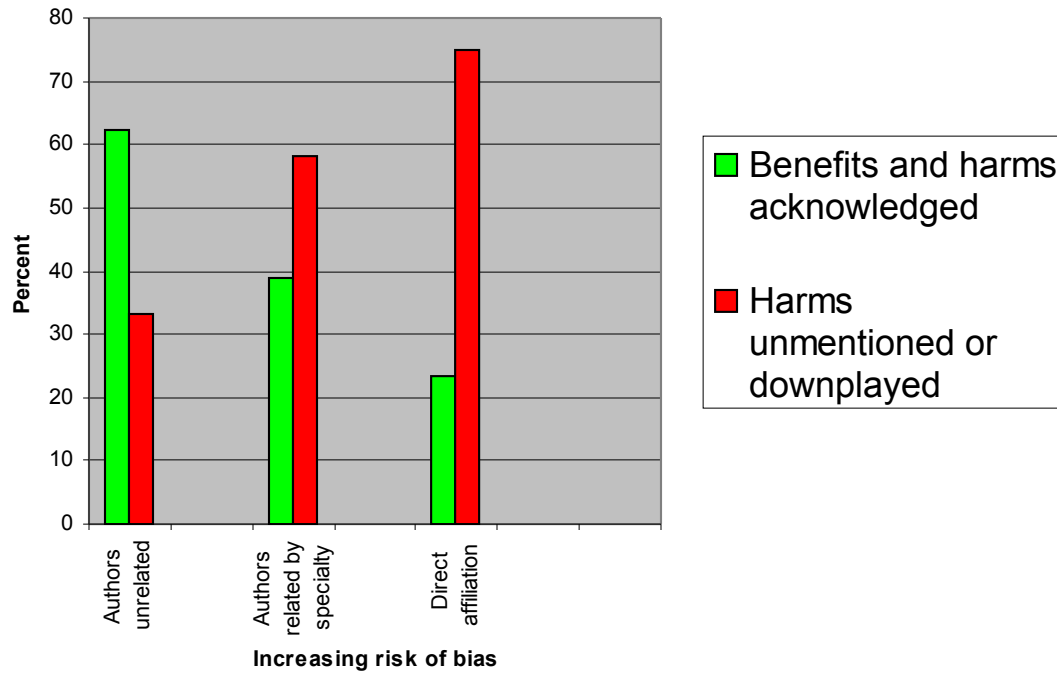
“As Medical Coordinator of the breast cancer screening service I am **concerned** that you have been sent **a number of invitations** to the screening service and have not yet responded. (...) I would like to give you some facts which may help. Breast cancer is very common. It affects up to 1 in 11 women in Australia.”

Re-invitation, BreastScreen NSW

Conclusions

- Invitations to mammography screening are biased in favour of participation, emphasize benefits by positive framing and omits the most important harm of screening
- Invitations do not provide a basis for informed consent, available to everyone invited
- Ensuring high uptake is valued over providing balanced information on benefits and harms

Bias in scientific articles



Implications

Invitations and information material on mammography screening should be prepared by independent institutions with consumer participation to ensure unbiased presentation of benefits as well as harms and avoid conflicting interests, such as high uptake rates