

ORIGINAL ARTICLE

Communicating the balance sheet in breast cancer screening

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(members listed at the end of the paper)

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Objective Despite the difficulties, there is a moral responsibility to provide the public with the best estimates of benefits and harms of breast cancer screening.

Methods In this paper we review the issues in communication of benefits and harms of medical interventions and discuss these in terms of the principles of the balance sheet proposed in this supplement.

Results The balance sheet can be seen as a tool to convey estimates based on the best available evidence and addressed to a readership wider than just potential screening participants. It reflects a re-assessment of screening efficacy, showing again that screening is effective and brings more benefits than harms. It can be viewed as an opportunity to re-affirm some basic principles of good evidence-based communication. Further research is needed to improve communication strategy, to assess the impact of this communication on women's awareness and to evaluate its utility in the informed decision-making process.

Conclusion The balance sheet could be a starting point for a broader vision of informed decision-making in screening, which should also recognize the role played by 'non-numerical' factors on women's choice of participating in breast cancer screening.

THE BALANCE SHEET: A TOOL FOR MORE TRANSPARENT INFORMATION

In the past, public information about cancer screening has been accused sometimes of overemphasizing the benefits, underestimating harms and understating scientific controversies, though there has been a public health objective to achieve high attendance rates.^{1–3} In recent years, there has been debate about the issues and potential conflicts associated with providing information on mammographic screening. Information must reflect the fact that screening would not be offered if it were not considered sufficiently beneficial. However, there is a need to enable those invited to screening to make an informed choice. Health professionals have started to reflect on what 'good quality information' means in practical terms and invited women have taken a more active role in their decisions about screening.^{3–5} Such changes have been consistent with other processes since the late 1980s: the abandonment of the paternalistic model of medical information, and citizens' demand for greater involvement in health, environmental and civil rights issues.^{6,7}

Transparency about benefits and harms is a key principle for producing good quality information – a maxim that should hold true for any kind of information, in all activities of human interaction. Most European screening

programmes are moving in this direction, making efforts to improve the way they communicate with the public. European guidelines for quality assurance in breast, cervical and colorectal cancer screening contain specific recommendations that aim to help professionals to understand the complexities of screening communications and to develop more effective information strategies^{8–10}, and in recent times, information materials have been revised and updated.¹¹

In cancer screening, the communication of quantitative information for, *inter alia*, individual risk, mortality and survival data and overdiagnosis is particularly complex, and to this end the screening balance sheet, as a tool that conveys simple estimates based on the best available evidence, is key both for women who must make decisions about screening and for professionals who must communicate screening strategy.¹²

THE BALANCE SHEET BACKGROUND

In this supplement, evidence from European service screening programmes is collated on the effect of mammographic screening on breast cancer mortality, overdiagnosis and false-positive results, and synthesized into a balance sheet.¹³ This should help screening professionals to deliver

more complete and transparent information, and when it is considered that most European programmes are population-based (people are invited to screening by letter), the balance sheet, with adequate adjustments, can be a very useful resource in developing information materials. Moreover, it is important that screening professionals understand the methodology which lies behind the balance sheet, in order to make proper use of it in their encounters with women and stakeholders. For example, they should know that the estimates provided are based on the experience of several European countries where screening has been in place for many years.¹⁴ However, estimates have to be based on some assumptions (for example, regular tests every 2 years with 30 years follow-up and 100% compliance) which should be taken into account in any generalization. Given this, the scenario depicted on a balance sheet can be considered a good approximation of what happens across the European states.

WHAT PRINCIPLES OF GOOD (QUANTITATIVE) COMMUNICATION UNDERLIE THE BALANCE SHEET?

A balance sheet should be developed according to some fundamental principles of risk communication: 'be exact', 'make it concrete' and 'keep it simple!' This means that the format of providing information on risk should preferably be numerical (exact), as simple as possible (reducing cognitive complexity), and as concrete as possible (easy to imagine).¹⁵ Such a balance sheet provides:

- Quantified presentation of risk: The numerical estimates are the core of the document, and they are derived from the experience of European programmes.
- Use of natural frequencies: Presenting the data using natural frequencies means that women evaluate it using numbers that can be easily understood. Presenting the data in a more complex form (such as formal probabilities) is not usually intuitive to most people.¹⁶
- Use of a small and constant denominator: Qualitative and quantitative studies have found that the smaller the denominator, the easier it is to understand and to visualize. When a large denominator is used to convey the probability of an event, the readership gains the impression that the event is more likely to occur than if a small denominator is used.¹⁵ Also, it is much easier to compare two probabilities using the same denominator than using the same numerator.
- Use of number needed to treat: In a large systematic review, Covey¹⁷ found strong evidence that differences between risks are generally considered to be greater when they are expressed as relative risks instead of absolute risks. So, while relative risk reductions can be persuasive, they can also be misleading about the actual effects of screening. As for presenting absolute risk reductions, the 'number needed to screen' to prevent one breast cancer has been advocated by some as a good and simple tool for communicating the effectiveness of screening.^{17,18} In this case, the denominator is a single death avoided.

WHAT PRINCIPLES OF GOOD QUALITY INFORMATION SHOULD BE FOLLOWED IN COMMUNICATING THE BALANCE SHEET?

Clarity, accessibility and being up-to-date and evidence-based are key attributes of good quality information. However, there is no such thing as absolute certainty, and good quality information should include any limitations and indicate further sources of information. It must also be relevant to the needs of its target readership. The challenge in producing good quality information is to find and maintain a constant balance between all the above attributes and to avoid losing focus on some principles by overemphasizing others.^{19–21} Good quality information is also tailored to meet the needs of special groups. In the case of breast screening, it is phase specific and multilevel so that it takes into account the needs of women recalled for further investigation in addition to those invited to the initial screen. In order to ensure its comprehension and acceptance, the language of good quality information is clear, honest, respectful, plain, non-prescriptive, up to date and has a logical structure, effective layout and text format.

The information presented in a screening balance sheet should be made available to invitees with their first invitation, usually in leaflet form. Because of the potential complexity of screening information, it is essential to test the accompanying narrative or commentary with the target readership, paying particular attention to how successfully the information is conveyed throughout the text. Those who want a further explanation should be able to get it through a help line or website. Ideally, the information is developed in collaboration with the target readership or feedback from the target readership is sought.

Given the difficulty of some numerical formats, alternative formats might be explored. The use of graphs is appealing because they may allow the illustration of quantitative part-to-whole proportions, make comparisons easier (needing less cognitive effort) and are vivid and attention grabbing. However, although some studies have demonstrated their benefits in increasing risk awareness, there is limited evidence, so far, that graphs substantially improve understanding and decision-making.¹⁸

The readership of a balance sheet is wider than the potential screening participants, as its messages are also relevant to health professionals and other significant stakeholders, such as decision makers and advocacy groups. Any communications strategy must consider different information tools and approaches for different stakeholders. Stakeholdership may also extend to journalists to ensure that media debates are appropriately informed.

THE BACKDROP TO GOOD QUALITY INFORMATION: THE EVIDENCE-BASED APPROACH

Good quality information must be correct and based on the best available evidence. Regular updating, expert scrutiny and good methodology are key points of evidence-based information. It has been argued that research on benefits and harms of screening should be carried out by independent, external parties²² rather than by those who work or have research experience in mammographic screening.² It

has also been advocated that information materials should be developed by 'third parties'.²³ Would this ultimately imply that scientists from a specific sector could neither conduct research nor produce information related to the field they are familiar with? In fact, expertise in the subject is required to effectively collate and communicate the appropriate information, and the 'screening industry' has been extremely cautious not to set up any screening programme before having clear evidence that it would bring more benefits than harms, a major issue in the case of prostate and lung cancers.^{24,25}

Good quality information should also be clear about benefits and harms, since no health intervention is ever free of side-effects. In her 1999 paper about informed consent for screening, Austoker wrote, '[yet] it is not clear what information should be given, how much information should be given, and how this should be framed... The effectiveness and efficiency of different ways of presenting information requires research'. This is, perhaps, still true.²⁶

Finally, although a communication may be transparent, it cannot be 'neutral'. Screening professionals are duty-bound to set up initiatives that are effective, and screening programmes are established on this basis. The breast-screening balance sheet here reflects a review of a substantial body of evidence on screening in Europe. The results show that screening is effective and brings more benefits than harms.

A key message of the breast-screening balance sheet is directed towards the scientific community, re-affirming the effectiveness of the methodology, but drawing attention to its limitations. At the same time, the balance sheet cannot be a tool that changes after the publication of every study. It is appropriate that health professionals should not make important decisions on the basis of a single or occasionally even a few studies, especially when a topic is controversial. Until a common understanding of these issues has been reached, such a new balance sheet could be rejected as biased or prejudiced.

EVIDENCE-BASED INFORMATION: IS IT ENOUGH?

Receiving more information on procedures, risks and benefits does not seem to affect women's participation in breast screening.²⁷ Additionally, giving more balanced information does not necessarily imply that women will consider it in making their choices.²⁸ It is not clear that there is public demand for detailed quantitative information. Factors such as trust, gratitude, and convenience may play a more important role than benefits and harms.^{29,30} Such findings may challenge the rather narrow vision of informed participation in which choices are thought to be made in a quantitative way after carefully weighing up advantages and disadvantages,³¹ even though the social sciences have, for many years, emphasized that 'risk is multidimensional – and its mathematical size (its hazard) is only one of the dimensions'.³² It is not intended that these considerations lessen the importance of balanced information. However, if the responsibility of screening professionals is not simply to respond to criticism³³ but also to produce information that can be utilized in making an informed choice, it is essential to understand the role played by non-numerical factors.³⁴ For example, invitation letters with a fixed appointment appear to be correlated with a higher attendance rate.²⁷ It

has been claimed that while information materials 'are aimed at enabling women to make a free and autonomous choice, the prescheduled appointment undermines the option of not participating. When receiving the invitation, women may thus be facing a classic situation of double communication'.²⁹ Is this really the case? To what extent can any public health information be completely neutral and any choice totally autonomous?

To some extent, trust is involved in any choice: choices are taken by decision-makers to finance screening programmes, are taken by associations to support them and, given the mounting and conflicting sources of risk information, are taken by health professionals, too. In a health system, trust is constructed on what services and professionals have been able to build (or not) over time. 'Trust is a function of both care and competence... So, the professional values of competence, expertise, empathy, honesty, and commitment are all relevant to communicating risk: getting the facts right and conveying them in an understandable way are not enough'.³⁵ If trust is involved in the screening decision-making process,³⁶ should we reject trust due to its connection with the paternalistic approach²⁹ or should we build on it?

FUTURE DIRECTIONS

In recent years, several balance sheets have been produced,^{24,37-39} with a variety of decision-making scenarios and outcome measures. Most of the estimates derive from the randomized controlled trial experience. The components used for the decision-making scenarios and the underlying methodology are extremely important, as they can strongly influence final outcomes. Different lengths of follow-up, different population definitions, and different numbers of women used as denominators can result in very different estimates. It is important to continue the effort to promote a frank and open discussion in all settings, including the impact in terms of communication and women's awareness.

Several surveys of communication materials for service screening have been made in European countries. The materials significantly differ in terms of readability, comprehensibility, accessibility, and completeness. New research is needed in order to discover barriers to communication and any weak points of communications strategy.

There is also need for research into the availability of country-specific recommendations on communications issues, in particular those related to the presence of balanced information.

Narratives accompanying balance sheets should be tested and adapted for different stakeholder groups, and different communication formats should be tested, including those for the Web and electronic communication. The balance sheet, with its implications on communication is not an event that should occur only once, but rather a continuous process, where regular, but not too frequent, updates are planned. Thoughts should continue on the best communication strategy to adopt to convey balance sheet information.

CONCLUSIONS

In medicine, communication of quantitative estimates is a challenge. Despite its difficulties, there is a moral responsibility

to provide women with the best estimates of benefits and harms. The balance sheet we propose attempts to do so. It can be viewed as an opportunity to reaffirm some basic principles of good evidence-based communication. Because 'few things make risk communication more difficult than conflicts or public disagreements with other credible sources'³² the balance sheet can also be an opportunity to strengthen partnerships and alliances with professional and advocacy groups. Moreover, the balance sheet could be a starting point for a broader vision of informed decision-making in screening, which should also 'recognize the hidden agendas, symbolic meanings, and broader social, cultural, economic or political considerations that often underlie and complicate the task of risk communication'.³²

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REFERENCES

- Giordano L, Rowinski M, Gaudenzi G, Segnan N. What information do breast cancer screening programmes provide to Italian women? *Eur J Public Health* 2005;**15**:66–9
- Thornton H, Edwards A, Baum M. Women need better information about routine mammography. *BMJ* 2003;**327**:101–3
- Raffle AE. Information about screening – is it to achieve high uptake or to ensure informed choice? *Health Expect* 2001;**4**:92–8
- Croft E, Barratt A, Butow P. Information about tests for breast cancer: what are we telling people? *J Family Practice* 2002;**51**:858–60
- Coulter A. Patient-centered decision making: Empowering women to make informed choices. *Womens Health Issues* 2001;**11**:325–30
- Deber R. Physicians in Health Care Management: 7: The patient–physician partnership: changing roles and the desire for information. *Can Med Assoc J* 1994;**151**:171–6
- Quill TE, Brody H. Physician recommendations and patient autonomy: Finding a balance between physician power and patient choice. *Ann Intern Med* 1996;**125**:763–9
- Giordano L, Webster P, Segnan N, Austoker J. Guidance on breast screening communication. In: Perry N, Broeders M, de Wolf C, *et al.*, eds. *European guidelines for quality assurance in breast cancer screening and diagnosis, 4th edn.* Luxembourg: European Communities, 2006:379–94
- Giordano L, Webster P, Anthony C, *et al.* Guidance on communication in cervical screening. In: Arbyn M, Anttila A, Jordan J, *et al.*, eds. *European guidelines for quality assurance in cervical cancer screening, 2th edn.* Luxembourg: European Communities, 2008:243–66
- Austoker J, Giordano L, Hewitson P, Villain P. Communication. In: Segnan N, Patnick J, von Karsa L, eds. *European guidelines for quality assurance in colorectal cancer screening and diagnosis, 1th edn.* Luxembourg: European Communities, 2010:301–39
- Department of Health, NHS Cancer Screening Programmes. Breast screening: the facts. 2006. Available at: www.cancerscreening.nhs.uk/breastscreen/publications/ia-02.html
- Edwards A, Elwyn G, Mulley A. Explaining risks: Turning numerical data into meaningful pictures. *BMJ* 2002;**324**:827–30
- Euroscreen Working Group. Summary of the evidence of breast cancer service screening outcomes in Europe and first estimate of the benefit and harm balance sheet. *J Med Screen* 2012 (in press)

- 14 Giordano L, von Karsa L, Tomatis M, *et al.* Mammographic screening programmes in Europe: organization coverage and participation. *J Med Screen* 2012 (in press)
- 15 Timmermans DR, Ockhuysen-Vermeij CF, Henneman L. Presenting health risk information in different formats: the effect on participants' cognitive and emotional evaluation and decisions. *Patient Educ Couns* 2008;**73**:443–7
- 16 Gigerenzer G, Gaissmaier W, Kurz-Milcke E, Schwartz LM, Woloshin S. Helping doctors and patients make sense of health statistics. *Psychol Sci Public Interest* 2007;**8**:53–96
- 17 Covey J. A meta-analysis of the effects of presenting treatment benefits in different formats. *Med Decis Making* 2007;**27**:638–54
- 18 Kristiansen IS, Gyrd-Hansen D, Nexoe J, Nielsen JB. Number needed to treat: Easily understood and intuitively meaningful? Theoretical considerations and a randomized trial. *J Clin Epidemiol* 2002;**55**:888–92
- 19 How to write medical information in plain English. Plain English campaign 2001. Available at: <http://www.plainenglish.co.uk/free-guides.html>
- 20 D. Charnock. The DISCERN Handbook. Quality criteria for consumer health information on treatment choices. Radcliffe Medical Press. © 1998 University of Oxford and The British Library. Available at: <http://www.discern.org.uk/index.php>
- 21 National Cancer Institute (NCI). Designing print materials: A communications guide for breast cancer screening. Bethesda (MD): NIH, 2007. NHI Publication No 07–6100 Available at: <http://appliedsearch.cancer.gov/icsn/manual.pdf>
- 22 McPherson K. Screening for breast cancer—balancing the debate *BMJ* 2010;**340**:c3106
- 23 Gøtzsche P, Hartling OJ, Nielsen M, Brodersen J, Jørgensen KJ. Breast screening the facts—or maybe not. *BMJ* 2009;**338**:b86
- 24 NHS cancer screening programmes. Prostate Cancer Risk Management Programme. Available at: <http://www.cancerscreening.nhs.uk/prostate/index.html>
- 25 International workshop on randomized lung cancer screening trials. State of the art in Europe after early conclusion of the US National Lung Screening Trial. The European Lung Cancer Trials. The PISA Position Statement. Pisa, Italy, March 4th 2011. Available at: http://www.osservatorionazionale screening.it/ita/images/stories/pisa_position_statement_english.pdf
- 26 Austoker J. Gaining informed consent for screening. Is difficult—but many misconceptions need to be undone. *BMJ* 1999;**319**:722–3
- 27 Giordano L, Stefanini V, Senore C, *et al.* The impact of different communication and organizational strategies on mammography screening uptake in women aged 40–45 *Eur J Public Health* 2011
- 28 Jepson RG, Hewison J, Thompson A, Weller D. Patient perspectives on information and choice in cancer screening: a qualitative study in the UK. *Soc Sci Med* 2007;**65**:890–9
- 29 Østerlie W, Solbjør M, Skolbekken JA, Hofvind S, Sætnan AR, Forsmo S. Challenges of informed choice in organised screening. *J Med Ethics* 2008;**34**:e5
- 30 Cogo C, Grazzini G, Iossa A. Analysis of health information within Italian Cervical Screening Programmes Osservatorio Nazionale Screening, Terzo Rapporto. Available at: <http://win.osservatorionazionale screening.it/eng-select.php>
- 31 Alaszewski A, Horlick-Jones T. How can doctors communicate information about risk more effectively? *BMJ* 2003;**327**:728–31
- 32 Covello V, Sandman P. "Risk communication: evolution and revolution," in Wolbarst A. *Solutions to an Environment in Peril*. Baltimore, MD: John Hopkins University Press, (2001):164–78. Available at: <http://www.psandman.com/articles/covello.htm>
- 33 Gøtzsche PC, Jørgensen KJ. The breast screening programme and misinforming the public. *J R Soc Med* 2011;**104**:361–9
- 34 Peters RG, Covello VT, McCallum DB. The determinants of trust and credibility in environmental risk communication: An empirical study. *Risk Analysis* 1997;**17**:43–54
- 35 Edwards A. Communicating risks. Means that patients too have to learn to live with uncertainty. Editorial. *BMJ* 2003;**327**:691–2
- 36 European Centre for Disease Prevention and Control. A literature review of trust and reputation management in communicable disease public health, Stockholm: ECDC; 2011 Available at: http://ecdc.europa.eu/en/publications/Publications/Forms/ECDC_DispForm.aspx?ID=763
- 37 Welch HG, Black WC. Overdiagnosis in cancer. *J Natl Cancer Inst* 2010;**102**:605–13
- 38 Duffy SW, Tabar L, Olsen AH, *et al.* Absolute numbers of lives saved and overdiagnosis in breast cancer screening, from a randomized trial and from the Breast Screening Programme in England. *J Med Screen* 2010;**17**:25–30
- 39 Puliti D, Zappa M, Miccinesi G, Falini P, Crocetti E, Paci E. An estimate of overdiagnosis 15 years after the start of mammographic screening in Florence. *Eur J Cancer* 2009;**45**:3166–71