



# Informing about mammographic screening: Ethical challenges and suggested solutions

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## Abstract

Providing high quality and user oriented information about mammographic screening is no easy task, as screening has been subject to heated professional and public debates. Although the information has to be developed and provided in context for each screening program, the basic challenges are very much the same for all programs. Accordingly, the objective of this article is to analyze key ethical challenges in informing about mammographic screening, and based on these, to suggest some guiding principles for practical solutions. A literature review identifies five crucial issues with respect to informing women about mammographic screening. By analyzing and addressing these issues, five guiding principles are suggested: the content and the form of information should be developed through open and transparent processes with strong stakeholder involvement. Facts should be presented in a balanced way and uncertainties should be acknowledged, e.g., by presenting outcomes in ranges. Information should be layered without attempts to frame information. Attending mammographic screening should be as easy as not attending. Although apparently trivial, the suggested principles can be useful for elaborating specific information material about mammographic screening in a field of great ethical controversy.

## KEYWORDS

benefit, harm, information, mammographic screening

## 1 | SUMMARY POINTS

- Mammographic screening has been subject to vast and vivid debates and screening programs have been heavily criticized for providing biased information.
- Informing well about controversial health services is difficult, but crucial for trust, autonomy, and beneficence.
- Various screening programs have different information strategies, but the basic challenge is the same: providing information that promotes and assures informed choice and trust.
- Five guiding principles are suggested for elaborating specific information material about mammographic screening in order to reach sound practical solutions in a field of controversy.

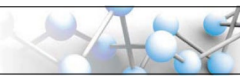
## 2 | BACKGROUND

Mammographic screening is provided for early detection of breast cancer in many countries.<sup>1</sup> However, information material about such

<sup>1</sup>Council of the European Union. (2003). *Council Recommendation of 2 December 2003 on Cancer Screening (2003/878/EC)*. OJ L 327 (Dec 16, 2003), Office for Official Publications of the European Communities; Brussels, 34–38; Tonelli, M., Connor Gorber, S., Joffres, M., Dickinson, J., Singh, H., Lewin, G., ... Liu, Y. Y. (2011). Recommendations on screening for breast cancer in average-risk women aged 40–74 years. *Canadian Medical Association Journal = journal de l'Association medicale canadienne*, 183(17), 1991–2001; Basu, P., Ponti, A., Anttila, A., Ronco, G., Senore, C., Vale, D. B., ... Dillner, J. (2018). Status of implementation and organization of cancer screening in the European Union Member States - summary results from the second European screening report. *International Journal of Cancer*, 142(1), 44–56; Siu, A. L. (2016). Screening for breast cancer: US Preventive Services Task Force recommendation statement. *Annals of Internal Medicine*, 164(4), 279–296; Dimitrova, N., Parkinson, Z. S., Bramesfeld, A., Ulutürk, A., Bocchi, G., López-Alcalde, J., ... Donata, L. (2016). *European Guidelines for Breast Cancer Screening and Diagnosis—the European Breast Guidelines; EUR 28360 EN*. doi:10.2788/503032; International Agency for Research on Cancer. (2016). *Breast cancer screening. IARC handbooks of cancer prevention*, Vol. 15. Lyon, France: IARC Press. <https://publications.iarc.fr/Book-And-Report-Series/IARC-Handbooks-Of-Cancer-Prevention/Breast-Cancer-Screening-2016>

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screening has been criticized for ignoring harms<sup>2</sup> and for making unwarranted bold claims about benefits.<sup>3</sup> Information has been shaped to “ensure screening uptake more than autonomous decisions among the women involved”.<sup>4</sup> Studies of invitation letters, leaflets and other information related to mammographic screening concluded that many of these lacked sufficient and balanced information.<sup>5</sup> A National Community Survey from Australia found that women reported that they were not properly informed about potential harms, which they think they should be.<sup>6</sup> Several studies also document significant misconceptions about the outcomes of mammography screening.<sup>7</sup> On the other hand, the information material is not always crucial to women's choice.<sup>8</sup> A randomized study in Spain showed that only 23% of women made an informed choice even when using a balanced decision aid.<sup>9</sup>

The lack of sufficient, unbiased, and balanced information resulted in worries about trust<sup>10</sup> and consent.<sup>11</sup> While previous information strategies were preoccupied with uptake, newer approaches have focused on

informed choice and risk stratification.<sup>12</sup> Guidelines and elaborate recommendations were developed to help professionals to understand the complexities of screening communication and to use effective information strategies.<sup>13</sup> Different decision aids were developed, tested, and implemented<sup>14</sup> and several screening programs have revised their information.

Although the information has to be developed and provided in context, the ethical challenges with informing about screening in order to obtain an informed choice are very much the same. So is the aim, as succinctly expressed by the Independent UK Panel on Breast Cancer Screening: “Information should be made available in a transparent and objective way to women invited to screening so that they can make informed decisions.”<sup>15</sup> As providing information in a transparent and objective way has been such a difficult task, it would be helpful to have some general guiding principles for elaborating information for specific mammographic screening programs. This study identifies and analyses some ethical issues with informing about mammographic screening in terms of five specific questions, and in analyzing and addressing these, suggests five guiding principles for informing about screening. Although they are developed for mammographic screening, they may also be relevant to other screening programs.

### 3 | APPROACH

In order to identify ethical challenges with informing about mammographic screening a literature search was performed in PubMed (January 8, 2018) to identify (a) existing information about mammography screening; (b) evaluations and reports on such information; and (c) examples of existing information material. The logic of the initial search string was: “information” AND (“mammography” OR “breast cancer” OR “screening”) AND (“choice” OR “consent” OR “motivation” OR “understanding” OR “voluntariness” OR “obligation” OR “trust” OR “risk

<sup>2</sup>Croft, E., Barratt, A., & Butow, P. (2002). Information about tests for breast cancer: What are we telling people? *The Journal of Family Practice*, 51(10), 858–860; Zapka, J. G., Geller, B. M., Bulliard, J. L., Fracheboud, J., Sancho-Garnier, H., & Ballard-Barbash, R. (2006). Print information to inform decisions about mammography screening participation in 16 countries with population-based programs. *Patient Education and Counseling*, 63(1–2), 126–137; Heleno, B., Thomsen, M., Rodrigues, D., Jorgensen, K., & Brodersen, J. (2013). Quantification of harms in cancer screening trials: Literature review. *BMJ*, 347, f5334; McPherson, K. (2010). Screening for breast cancer—balancing the debate. *BMJ*, 340, c3106.

<sup>3</sup>Blennerhassett, M. (2013). Breast cancer screening: An ethical dilemma, or an opportunity for openness? *Quality in Primary Care*, 21(1), 39–42.

<sup>4</sup>Østerlie, W., Solbjør, M., Skolbekken, J. A., Hofvind, S., Saetnan, A. R., & Forsmo, S. (2008). Challenges of informed choice in organised screening. *Journal of Medical Ethics*, 34(9), e5; Raffle, A. E. (2001). Information about screening – is it to achieve high uptake or to ensure informed choice? *Health Expectations*, 4(2), 92–98; Champion, V., Skinner, C. S., Hui, S., Monahan, P., Juliar, B., Daggy, J., & Menon, U. (2007). The effect of telephone v. print tailoring for mammography adherence. *Patient Education and Counseling*, 65(3), 416–423; Camilloni, L., Ferroni, E., Cendales, B. J., Pezzarossi, A., Fumari, G., Borgia, P., ... Rossi, P. G. (2013). Methods to increase participation in organised screening programs: A systematic review. *BMC Public Health*, 13, 464–464.

<sup>5</sup>Croft et al., op. cit. note 2; Jorgensen, K. J., Zahl, P. H., & Gotzsche, P. C. (2009). Overdiagnosis in organised mammography screening in Denmark. A comparative study. *BMC Women's Health*, 9(1), 36; Thornton, H., Edwards, A., & Baum, M. (2003). Women need better information about routine mammography. *BMJ*, 327(7406), 101–103; Luqmani, Y. A. (2014). Breast screening: An obsessive compulsive disorder. *Cancer Causes & Control*, 25(10), 1423–1426.

<sup>6</sup>Moynihan, R., Nickel, B., Hersch, J., Beller, E., Doust, J., Compton, S., ... McCaffery, K. (2015). Public opinions about overdiagnosis: A national community survey. *PLoS ONE*, 10(5), e0125165.

<sup>7</sup>Webster, P., & Austoker, J. (2006). Women's knowledge about breast cancer risk and their views of the purpose and implications of breast screening—a questionnaire survey. *Journal of Public Health*, 28(3), 197–202; Gigerenzer, G., Mata, J., & Frank, R. (2009). Public knowledge of benefits of breast and prostate cancer screening in Europe. *Journal of the National Cancer Institute*, 101(17), 1216–1220; Chamot, E., & Perneger, T. (2001). Misconceptions about efficacy of mammography screening: A public health dilemma. *Journal of Epidemiology and Community Health*, 55(11), 799–803.

<sup>8</sup>Østerlie et al., op. cit. note 4; Jepson, R. G., Hewison, J., Thompson, A., & Weller, D. (2007). Patient perspectives on information and choice in cancer screening: A qualitative study in the UK. *Social Science & Medicine*, 65(5), 890–899; Martinez-Alonso, M., Carles-Lavila, M., Perez-Lacasta, M. J., Pons-Rodriguez, A., Garcia, M., & Rue, M. (2017). Assessment of the effects of decision aids about breast cancer screening: A systematic review and meta-analysis. *BMJ Open*, 7(10), e016894.

<sup>9</sup>Perez-Lacasta, M. J., Martinez-Alonso, M., Garcia, M., Sala, M., Perestelo-Perez, L., Vidal, C., ... Rue, M. (2019). Effect of information about the benefits and harms of mammography on women's decision making: The InforMa randomised controlled trial. *PLoS ONE*, 14(3), e0214057.

<sup>10</sup>Blennerhassett, op. cit. note 3; Perez-Lacasta et al., op. cit. note 9; McCartney, M. (2018). Margaret McCartney: Can we now talk openly about the risks of screening? *BMJ*, 361. <https://doi.org/10.1136/bmj.k2055>

<sup>11</sup>Baines, C. J. (2003). Mammography screening: Are women really giving informed consent? *Journal of the National Cancer Institute*, 95(20), 1508–1511; Marshall, T., & Adab, P. (2003). Informed consent for breast screening: What should we tell women? *Journal of Medical Screening*, 10(1), 22–26; General Medical Council. (2015). *Seeking patients' consent: The ethical considerations*. London, UK: General Medical Council.

<sup>12</sup>Martinez-Alonso et al., op. cit. note 8.

<sup>13</sup>Geller, B. M., Zapka, J., Hofvind, S. S., Scharpantgen, A., Giordano, L., Ohuchi, N., & Ballard-Barbash, R. (2007). Communicating with women about mammography. *Journal of Cancer Education: The Official Journal of the American Association for Cancer Education*, 22(1), 25–31; Giordano, L., Rowinski, M., Gaudenzi, G., & Segnan, N. (2005). What information do breast cancer screening programmes provide to Italian women? *European Journal of Public Health*, 15(1), 66–69; Giordano, L., Cogo, C., Patrick, J., & Paci, E. (2012). Communicating the balance sheet in breast cancer screening. *Journal of Medical Screening*, 19(Suppl. 1), 67–71; Hersch, J., Jansen, J., Barratt, A., Irwig, L., Houssami, N., Jacklyn, G., ... McCaffery, K. (2014). Overdetection in breast cancer screening: Development and preliminary evaluation of a decision aid. *BMJ Open*, 4(9), e006016; Entwistle, V., Carter, S., Trevena, L., Flitcroft, K., Irwig, L., McCaffery, K., & Salkeld, G. (2008). Communicating about screening. *BMJ*, 337, a1591; Forbes, L. J., & Ramirez, A. J. (2014). Communicating the benefits and harms of cancer screening. *Current Oncology Reports*, 16(5), 382.

<sup>14</sup>Martinez-Alonso et al., op. cit. note 8; Hersch et al., op. cit. note 13; Abhyankar, P., Volk, R. J., Blumenthal-Barby, J., Bravo, P., Buchholz, A., Ozanne, E., ... Stalmeier, P. (2013). Balancing the presentation of information and options in patient decision aids: An updated review. *BMC Medical Informatics and Decision Making*, 13(Suppl. 2), S6; Coulter, A. (2001). Patient-centered decision making: Empowering women to make informed choices. *Women's Health Issues*, 11(4), 325–330; Hersch, J., Barratt, A., Jansen, J., Irwig, L., McGeehan, K., Jacklyn, G., ... McCaffery, K. (2015). Use of a decision aid including information on overdetection to support informed choice about breast cancer screening: A randomised controlled trial. *The Lancet*, 385, 1642–1652; Barratt, A., Howard, K., Irwig, L., Salkeld, G., & Houssami, N. (2005). Model of outcomes of screening mammography: Information to support informed choices. *BMJ*, 330(7497), 936; Hersch, J. (2017). *Breast cancer screening: It's your choice*. Sydney, Australia: University of Sydney; Reeder, M., & Kolip, P. (2017). Does a decision aid improve informed choice in mammography screening? Results from a randomised controlled trial. *PLoS ONE*, 12(12), e0189148.

<sup>15</sup>Independent UK Panel on Breast Cancer Screening. (2012). The benefits and harms of breast cancer screening: An independent review. *The Lancet*, 380(9855), 1778–1786.

perception" OR "bias"). The identified references were assessed on the basis of title, abstract, and keywords. Publications were excluded when the title, abstract, or keywords made it clear that they were not about information handling in mammographic screening. Eighty-one publications were investigated in detail. Publications were *included* if the publication addressed (a) challenges with informing about mammographic screening; (b) strategies or methods for informing about such screening; or (c) reasons or arguments for such strategies or methods. *Exclusion criteria* were (a) the publication only mentions challenges, strategies, or reasons, but gives no substantial insight; (b) the publication adds nothing new compared to previously included publications (and is not a more seminal article); and (c) a more elaborate or seminal publications addressing the same identified challenges, strategies, or reasons (than the previously identified publication) has been found.

When using content analysis<sup>16</sup> to investigate the publications a wide range of ethical challenges with informing about mammographic screening were identified. These challenges were grouped under five specific issues (here formed as questions):

1. Which facts should be presented? Should the information stem from the specific country or results from reviews? How should variation in outcomes due to different study designs or scientific methods be handled and presented?
2. What is "good quality information?"
3. What should be the extent and format of information? How elaborate and how detailed should the information be? How do we assure that the language is "honest, respectful, plain, non-prescriptive, up to date?"<sup>17</sup> When are other non-text formats useful?
4. (How) should the information address misconceptions and bias?
5. How should the information provided to potential participants balance the goal of screening programs (population health) and the individuals' rights to make informed choices?

To address these specific questions additional literature searches with snowballing technique were performed. Twenty-seven additional references were included.

## 4 | ETHICAL ISSUES WITH INFORMING ABOUT MAMMOGRAPHIC SCREENING

The five questions above were addressed by applying the content of the identified references.

### 4.1 | Which facts should be presented?<sup>18</sup>

A number of the identified publications dealt with the issue of which facts about mammographic screening should be presented to

invitees. It was widely recognized that while there are numerous studies documenting the effectiveness and efficacy of organized mammographic screening,<sup>19</sup> the results and thus, the benefit-to-harm ratio, are debated.<sup>20</sup> It was also pointed out that information stems from studies with different reference populations, follow-up time, study designs,<sup>21</sup> and from researchers with different professional interests.<sup>22</sup> Accordingly, it is suggested that studies used to inform about mammographic screening should pass specific quality requirements,<sup>23</sup> that facts about outcome should be presented in ranges, and that controversies should be explicitly explained in order to avoid biases.<sup>24</sup> Moreover, it has been recommended that information about outcomes should refer to the effect for screening participants (from per protocol analysis) instead of for the invited (intention to treat analysis).<sup>25</sup>

Moreover, several studies underscored that the way numbers are presented should be carefully considered. Cognitive testing has shown that UK women found numbers overwhelming, hindering their understanding of the information.<sup>26</sup> Numeracy is demonstrated to have an impact on graphical risk estimates and patient understanding,<sup>27</sup> and experts encourage the presentation of numbers in formats like X per 1000 instead of 1 to X format.<sup>28</sup> Risk estimates can be provided<sup>29</sup> and tailored to the individual woman, but they may not be efficient, as women tend

<sup>19</sup>International Agency for Research on Cancer, op. cit. note 1; Gotzsche, P. C., & Jorgensen, K. J. (2013). Screening for breast cancer with mammography. *The Cochrane Database of Systematic Reviews*, 6, Cd001877; Paci, E. (2012). Summary of the evidence of breast cancer service screening outcomes in Europe and first estimate of the benefit and harm balance sheet. *Journal of Medical Screening*, 19(Suppl. 1), 5–13; Rossi, P. G. (2014). Screening: The information individuals need to support their decision: Per protocol analysis is better than intention-to-treat analysis at quantifying potential benefits and harms of screening. *BMC Medical Ethics*, 15(1), 28.

<sup>20</sup>Paci, op. cit. note 19; Paci, E., Broeders, M., Hofvind, S., Puliti, D., Duffy, S. W., & Group, E. W. (2014). European breast cancer service screening outcomes: A first balance sheet of the benefits and harms. *Cancer Epidemiology Biomarkers & Prevention*, 23(7), 1159–1163; Welch, H. G. (2010). Screening mammography—a long run for a short slide. *The New England Journal of Medicine*, 363(13), 1276–1278; Broeders, M., & Paci, E. (2015). The balance sheet of benefits and harms of breast cancer population-based screening in Europe: Outcome research, practice and future challenges. *Women's Health*, 11(6), 883–890; Heath, I. (2014). Back to back: Breast cancer screening causes more harm than good: Yes. *Journal of Primary Health Care*, 6(1), 79–80; Quanstrum, K. H., & Hayward, R. A. (2010). Lessons from the mammography wars. *The New England Journal of Medicine*, 363(11), 1076–1079.

<sup>21</sup>Jorgensen, K. J., Kalager, M., Barratt, A., Baines, C., Zahl, P. H., Brodersen, J., & Harris, R. P. (2017). Overview of guidelines on breast screening: Why recommendations differ and what to do about it. *The Breast*, 31, 261–269.

<sup>22</sup>Hofmann, B. (2018). The gene-editing of super-ego. *Medicine, Health Care and Philosophy*, 21(3), 295–302.

<sup>23</sup>Carter, J. L., Coletti, R. J., & Harris, R. P. (2015). Quantifying and monitoring overdiagnosis in cancer screening: A systematic review of methods. *BMJ*, 350, g7773.

<sup>24</sup>Welch, H. G., & Passow, H. J. (2014). Quantifying the benefits and harms of screening mammography. *JAMA Internal Medicine*, 174(3), 448–454.

<sup>25</sup>Giorgi Rossi, op. cit. note 19.

<sup>26</sup>Forbes & Ramirez, op. cit. note 13; Forbes, L. J., & Ramirez, A. J. (2014). Offering informed choice about breast screening. *Journal of Medical Screening*, 21(4), 194–200.

<sup>27</sup>Brown, S. M., Culver, J. O., Osann, K. E., MacDonald, D. J., Sand, S., Thornton, A. A., ... Weitzel, J. N. (2011). Health literacy, numeracy, and interpretation of graphical breast cancer risk estimates. *Patient Education and Counseling*, 83(1), 92–98.

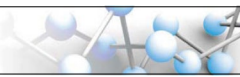
<sup>28</sup>Zikmund-Fisher, B. J. (2011). Time to retire the 1-in-X risk format. *Medical Decision Making: An International Journal of the Society for Medical Decision Making*, 31(5), 703–704; Barratt, A., Trevena, L., Davey, H. M., & McCaffery, K. (2004). Use of decision aids to support informed choices about screening. *BMJ*, 329(7464), 507–510.

<sup>29</sup>Marshall & Adab, op. cit. note 11.

<sup>16</sup>Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15(9), 1277–1288.

<sup>17</sup>Giordano et al. (2012), op. cit. note 13.

<sup>18</sup>It is important to notice that this study does aim to develop *specific content* of the information, but only aims at developing basic principles for elaborating such information. Hence, it focuses on the *form, basic elements*, and the *process* of providing transparent and balanced information on mammographic screening.



to disbelieve tailored breast cancer risk statistics.<sup>30</sup> Whether specific outcomes are considered to be beneficial or harmful varies, and caution with such labeling is recommended.<sup>31</sup> It was also pointed out that it can be important to take practical aspects into consideration when deciding on which facts should be presented, such as that lay people define and conceptualize informed choice differently from policy makers<sup>32</sup> and that they understand and assess information differently than healthcare providers<sup>33</sup> and that women targeted by screening tend to seek information about the screening process and the disease before information about benefits and risks.<sup>34</sup> Moreover, time differences with respect to when benefits and harms occur may also result in bias and calls for attention.

On the challenges with which facts should be presented, there seems to be fair agreement in the literature that the following information elements are considered to be important:

- The aim of the screening program.
- A description of breast cancer and stages of the disease.
- Practical aspects of the screening examination.
- Procedures related to a negative and a positive screening exam.
- Possible outcome including prospective benefits and harms.
- Administrative matters (how and when participants will be invited and receive the informed about result of the screening examinations).
- The economic costs for the women (and for the provider).
- Ethical, legal, and social aspects of screening.

Hence, a series of advice on which facts should be presented is available, and strong stakeholder involvement is encouraged<sup>35</sup> avoiding process and participant bias.<sup>36</sup>

## 4.2 | What is good quality information?

While the literature revealed fair agreement that good quality information facilitates the individual woman to make an informed choice in accordance with her own preferences, there is less agreement about how we can measure informed choice<sup>37</sup> or about which methods best

improve informed choices in screening programs.<sup>38</sup> Assessments of information quality also vary between stakeholders.<sup>39</sup> Good quality information was identified as information that is transparent, that empowers women,<sup>40</sup> that improves knowledge about screening,<sup>41</sup> that alters attitudes and decisions,<sup>42</sup> that achieves high uptake,<sup>43</sup> or that facilitates and/or ensures informed choice.<sup>44</sup> Adequate information is also characterized by improving knowledge and promoting informed decision-making, in accordance with women's preferences.<sup>45</sup>

Despite diverging opinions, information based on high quality evidence, according to standard evidence criteria such as GRADE,<sup>46</sup> is widely endorsed. Moreover, procedural criteria were also recommended, e.g., that information is provided through open and transparent processes where stakeholders and independent experts are involved in gathering, assessing, testing, and approving the information.<sup>47</sup> Underneath such pragmatic suggestions lie more fundamental problems of whether informed consent or choice are really obtainable,<sup>48</sup> which will partly be discussed below.

## 4.3 | What extension and format should information have?

The identified literature acknowledged that women have different needs for information, and the opinions about which information is needed vary.<sup>49</sup> It was revealed that while healthcare providers tend to think that too much information is provided, women may think that the information was about the right length.<sup>50</sup> Despite several guidelines and decision aids, no consensus on the best extension and format of information<sup>51</sup> was found, e.g., web-based information,

<sup>30</sup>Scherer, L. D., Ubel, P. A., McClure, J., Green, S. M., Alford, S. H., Holtzman, L., ... Fagerlin, A. (2013). Belief in numbers: When and why women disbelieve tailored breast cancer risk statistics. *Patient Education and Counseling*, 92(2), 253–259.

<sup>31</sup>Barratt et al., op. cit. note 28.

<sup>32</sup>Jepson et al., op. cit. note 8.

<sup>33</sup>Barratt et al., op. cit. note 28.

<sup>34</sup>Jepson et al., op. cit. note 8; Silverman, E., Woloshin, S., Schwartz, L. M., Byram, S. J., Welch, H. G., & Fischhoff, B. (2001). Women's views on breast cancer risk and screening mammography: A qualitative interview study. *Medical Decision Making: An International Journal of the Society for Medical Decision Making*, 21(3), 231–240.

<sup>35</sup>Khor, Z. (2013). *Citizens' jury on information for women about breast screening*. London, UK: Office of Public Management.

<sup>36</sup>Thornton, H. (2012). New citizens' juries in breast screening review are biased. *BMJ*, 345, e7552; Street, J., Duszynski, K., Krawczyk, S., & Braunack-Mayer, A. (2014). The use of citizens' juries in health policy decision-making: A systematic review. *Social Science & Medicine*, 109, 1–9; Hawkes, N. (2012). "Citizens' jury" disagrees over whether screening leaflet should put reassurance before accuracy. *BMJ*, 345, e8047.

<sup>37</sup>Jepson, R. G., Hewison, J., Thompson, A. G., & Weller, D. (2005). How should we measure informed choice? The case of cancer screening. *Journal of Medical Ethics*, 31(4), 192–196.

<sup>38</sup>van Agt, H. M., Korfage, I. J., & Essink-Bot, M.-L. (2014). Interventions to enhance informed choices among invitees of screening programmes—a systematic review. *The European Journal of Public Health*, 24(5), 789–801.

<sup>39</sup>Prinjsa, S., Evans, J., & McPherson, A. (2006). Women's information needs about ductal carcinoma in situ before mammographic screening and after diagnosis: A qualitative study. *Journal of Medical Screening*, 13(3), 110–114.

<sup>40</sup>Coulter, op. cit. note 14.

<sup>41</sup>Fox, R. (2006). Informed choice in screening programmes: Do leaflets help? A critical literature review. *Journal of Public Health*, 28(4), 309–317.

<sup>42</sup>Waller, J., Douglas, E., Whitaker, K. L., & Wardle, J. (2013). Women's responses to information about overdiagnosis in the UK breast cancer screening programme: A qualitative study. *BMJ Open*, 3(4), e002703.

<sup>43</sup>Østerlie et al., op. cit. note 4; Gardner, M. P., Adams, A., & Jeffreys, M. (2013). Interventions to increase the uptake of mammography amongst low income women: A systematic review and meta-analysis. *PLoS ONE*, 8(2), e55574.

<sup>44</sup>Raffle, op. cit. note 4.

<sup>45</sup>Martinez-Alonso et al., op. cit. note 8.

<sup>46</sup>Schünemann, H. J., Oxman, A. D., Brozek, J., Glasziou, P., Jaeschke, R., Vist, G. E., ... Guyatt, G. H. (2008). Grading quality of evidence and strength of recommendations for diagnostic tests and strategies. *BMJ*, 336(7653), 1106–1110.

<sup>47</sup>Giordano et al. (2012), op. cit. note 13; Forbes & Ramirez, op. cit. note 26.

<sup>48</sup>Baines, op. cit. note 11.

<sup>49</sup>Prinjsa et al., op. cit. note 39; Davey, H. M., Barratt, A. L., Butow, P. N., & Houssami, N. (2008). The impact of different criteria for selecting information to be provided to women undergoing diagnostic breast tests. *Patient Education and Counseling*, 71(1), 86–94.

<sup>50</sup>Barratt et al., op. cit. note 28.

<sup>51</sup>Geller, op. cit. note 13; Giordano et al. (2005), op. cit. note 13; Giordano et al. (2012), op. cit. note 13; Hersch et al., op. cit. note 13; Entwistle et al., op. cit. note 13; Sasieni, P. D., Smith, R. A., & Duffy, S. W. (2015). Informed decision-making and breast cancer screening. *Journal of Medical Screening*, 22(4), 165–167.



both as text, illustrations, and video, was considered as attractive alternatives to plain text.<sup>52</sup>

However, despite disagreements, the literature indicates that presenting information in several layers, starting with overall information, and providing more detailed information in subsequent layers may be a good strategy. Moreover, decision aids are strongly recommended, as are opportunities for acquiring additional information, advice, counseling, and assistance in shared decision-making.<sup>53</sup>

#### 4.4 | (How) should the information address misconceptions and bias?

Several identified publications acknowledged that the focus of the information material about mammographic screening previously has been on beneficial aspects<sup>54</sup> and on ensuring uptake.<sup>55</sup> The literature also identifies a general enthusiasm for cancer screening,<sup>56</sup> and significant misconceptions about the effects of screening.<sup>57</sup> The analyzed publications suggest that women frequently overestimate their breast cancer risk<sup>58</sup> as well as the benefits of screening.<sup>59</sup> Moreover, several publications pointed out that the harms of screening are poorly understood by the invited women<sup>60</sup> as well as by the public.<sup>61</sup>

Motivational biases, where attitudes are anchored in affective rather than strictly rational aspects are also documented.<sup>62</sup> It is revealed that the same information can be conceived differently in different countries and in various groups of women in the same country. Despite significant attempts to improve the information, there still is work to do in order to promote informed

choice.<sup>63</sup> As acknowledged in a historical overview: “[m]any women continue to be ‘prescribed’ or encouraged to undergo screening rather than being supported to make an informed choice.”<sup>64</sup> Furthermore, it is pointed out that the efficacy of mammographic screening is overestimated by some women<sup>65</sup> and also sometimes oversold.<sup>66</sup>

Hence, the question of whether such misconceptions and biases ought to be adjusted or compensated for becomes pertinent. Although there is unanimous agreement in the literature that it is important to *correct* misconceptions and biases by providing balanced information presented in a comprehensible manner, no explicit arguments were found for trying to *compensate* for misconceptions and biases. On the contrary, recent research underscored that it is challenging to adjust people’s conceptions.<sup>67</sup> Although it has been shown that the information has been biased (towards screening) and that women are guided by other aspects than information, the identified literature does not argue that this should be counterbalanced or that the information should be framed or counterbiased.<sup>68</sup>

#### 4.5 | How to balance the goal of screening programs (population health) and the individual’s right to make informed choices?

The literature revealed, as already mentioned, that screening programs have been driven by public health goals, where the aim has been to reduce breast cancer mortality in the population, and where uptake has prevailed over free choice.<sup>69</sup> Such strategies have been argued for from various perspectives: paternalism, libertarian paternalism (nudging), and normative recruitment. The challenge of balancing public health interests and those of individual health interests have been addressed along these perspectives.

##### 4.5.1 | Paternalism

As providers consider mammographic screening to be in the best interest for invitees, information has been formed to reinforce the women’s decisions to be screened. To date, a mammographic

<sup>52</sup>Fox, op. cit. note 41.

<sup>53</sup>Abhyankar et al., op. cit. note 14; Coulter, op. cit. note 14; Hersch et al. (2014), op. cit. note 13; Hersch et al. (2015), op. cit. note 14; Reder & Kolip, op. cit. note 14.

<sup>54</sup>Croft et al., op. cit. note 2; Zapka et al., op. cit. note 2.

<sup>55</sup>Østerlie et al., op. cit. note 4; Raffle, op. cit. note 4; Champion et al., op. cit. note 4; Camilloni et al., op. cit. note 4.

<sup>56</sup>Waller, J., Osborne, K., & Wardle, J. (2015). Enthusiasm for cancer screening in Great Britain: A general population survey. *British Journal of Cancer*, 112(3), 562–566.

<sup>57</sup>Webster & Austoker, op. cit. note 7; Gigerenzer et al., op. cit. note 7; Chamot & Perneger, op. cit. note 7.

<sup>58</sup>Silverman et al., op. cit. note 34; Black, W. C., Nease, R. F., & Tosteson, A. N. (1995). Perceptions of breast cancer risk and screening effectiveness in women younger than 50 years of age. *Journal of the National Cancer Institute*, 87(10), 720–731.

<sup>59</sup>Schwartz, P. H. & Meslin, E. M. (2008). The ethics of information: Absolute risk reduction and patient understanding of screening. *Journal of General Internal Medicine*, 23(6), 867–870.

<sup>60</sup>Lewis, C. L., Pignone, M. P., Sheridan, S. L., Downs, S. M., & Kinsinger, L. S. (2003). A randomized trial of three videos that differ in the framing of information about mammography in women 40 to 49 years old. *Journal of General Internal Medicine*, 18(11), 875–883; Nekhlyudov, L., Li, R., & Fletcher, S. W. (2005). Information and involvement preferences of women in their 40s before their first screening mammogram. *Archives of Internal Medicine*, 165(12), 1370–1374; Nekhlyudov, L., Ross-Degnan, D., & Fletcher, S. W. (2003). Beliefs and expectations of women under 50 years old regarding screening mammography. *Journal of General Internal Medicine*, 18(3), 182–189.

<sup>61</sup>Barratt et al., op. cit. note 28.

<sup>62</sup>Nyhan, B. & Reifler, J. (2015). Does correcting myths about the flu vaccine work? An experimental evaluation of the effects of corrective information. *Vaccine*, 33(3), 459–464; Nyhan, B., Reifler, J., Richey, S., & Freed, G. L. (2014). Effective messages in vaccine promotion: A randomized trial. *Pediatrics*, 133(4), e835–e842.

<sup>63</sup>Aschwanden, C. (2015). Why I’m opting out of mammography. *JAMA Internal Medicine*, 175(2), 164–165; Barratt, A. (2015). Overdiagnosis in mammography screening: A 45 year journey from shadowy idea to acknowledged reality. *BMJ*, 350, h867; Ghanouni, A., Meisel, S. F., Hersch, J., Waller, J., Wardle, J., & Renzi, C. (2016). Information on ‘overdiagnosis’ in breast cancer screening on prominent United Kingdom- and Australia-oriented health websites. *PLoS ONE*, 11(3), e0152279.

<sup>64</sup>Barratt, op. cit. note 63.

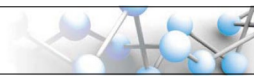
<sup>65</sup>Hoffmann, T. & Del Mar, C. (2015). Patients’ expectations of the benefits and harms of treatments, screening, and tests: A systematic review. *JAMA Internal Medicine*, 175(2), 274–286.

<sup>66</sup>Woloshin, S., & Schwartz, L. M. (2012). How a charity oversells mammography. *BMJ*, 345, e5132; Parker, L., Rychetnik, L., & Carter, S. (2015). Values in breast cancer screening: An empirical study with Australian experts. *BMJ Open*, 5(5), e006333.

<sup>67</sup>Nyhan & Reifler (2015) op. cit. note 62; Nyhan et al. (2014) op. cit. note 62.

<sup>68</sup>Edwards, A., Elwyn, G., & Mulley, A. (2002). Explaining risks: Turning numerical data into meaningful pictures. *BMJ*, 324(7341), 827–830.

<sup>69</sup>Østerlie et al., op. cit. note 4; Raffle, op. cit. note 4.



screening program is only mandatory in Uruguay,<sup>70</sup> and *strong* or *hard paternalism* is very rare (and contested) (see Supporting Information Table S1). However, some of the identified studies also revealed that women may be less likely to choose screening when they are better informed,<sup>71</sup> and information has been biased in invitation letters and pamphlets,<sup>72</sup> which have exaggerated benefits and understated harms.<sup>73</sup> This is a form of *weak paternalism* (Supporting Information Table S1).

Moreover, the literature indicates that women do not make *informed* choices, as they do not apply important information when deliberating on mammographic screening. Self-beliefs, experiences, and stories from friends and relatives have shown to be more important for decisions than well balanced information.<sup>74</sup> Many women tend not to understand crucial information about mammographic screening and to overestimate the benefits.<sup>75</sup> Women may not read, not want to read, or they do not understand the information.<sup>76</sup> Moreover, access to more information does not ensure an informed consent<sup>77</sup> and women's decision about attendance is weakly influenced by information about harms.<sup>78</sup> On the other hand, prescheduled appointments can trigger participation<sup>79</sup> and can give the impression of a recommendation and that the decision has already been made by a trusted institution like by a "caring mother."<sup>80</sup> Indications that women do not use balanced information when deliberating on mammographic screening can be used to argue for *soft paternalism*, i.e., that one needs to make sure that they understand and act voluntarily, e.g., by tests for their understanding before screening (Supporting Information Table S1).

Although various forms of paternalism have been used to defend framed information in mammographic screening before, no arguments have been found in the recent literature that argue for or justify paternalism in screening programs aiming at promoting and assuring informed choice.

#### 4.5.2 | Nudging (libertarian paternalism)

Several types of nudging were identified in the literature. Nudging is defined as a way to steer people to choose in ways that will increase their welfare without obstructing or stalling their choice.<sup>81</sup> Imposing trivial costs, framing options, and institutional default rules are common strategies in nudging. As nudging tries to reconcile paternalism and free choice it is sometimes called "libertarian paternalism."<sup>82</sup> Telephone reminders and letters from physicians,<sup>83</sup> as well as pre-scheduled appointments and special requirements, such as filling out forms if one does not want to attend,<sup>84</sup> can be nudging,<sup>85</sup> as they push the person towards attending screening, but the person is still free to refrain. Implicit consent may also be a kind of nudging, e.g., when merely showing up is interpreted as consenting, whereas in fact women may show up aiming to seek more information to help them make a decision.

Moreover, Ploug, Holm, and Brodersen found that some mammographic screening programs nudge by framing information by (a) emphasizing some information, leaving out other information; (b) providing misleading risk information; and (c) by "unequivocal recommendation" provided in weighing up pros and cons.<sup>86</sup> They also found that choosing not to participate generates a feeling of guilt, as most women feel bound by norms of courtesy and trust in the health care provider.<sup>87</sup> Further, in many screening programs it seems to be easier to opt in than to opt out.<sup>88</sup>

Although Ploug and colleagues conclude that nudging is not warranted in mammography screening, as it is not "unequivocally welfare-enhancing for the individual" they do accept that it could be justified from a liberty-enhancing perspective.<sup>89</sup>

<sup>70</sup>Carter, S. M., Rogers, W., Heath, I., Degeling, C., Doust, J., & Barratt, A. (2015). The challenge of overdiagnosis begins with its definition. *BMJ*, 350, h869.

<sup>71</sup>Hersch et al. (2015), op. cit. note 14.

<sup>72</sup>Slaytor, E. K., & Ward, J. E. (1998). How risks of breast cancer and benefits of screening are communicated to women: Analysis of 58 pamphlets. *BMJ*, 317(7153), 263–264; Jorgensen, K. J., & Gotzsche, P. C. (2006). Content of invitations for publicly funded screening mammography. *BMJ*, 332(7540), 538–541.

<sup>73</sup>Croft et al., op. cit. note 2; Jorgensen et al., op. cit. note 5; Jorgensen, K. J., Klahn, A., & Gotzsche, P. C. (2007). Are benefits and harms in mammography screening given equal attention in scientific articles? A cross-sectional study. *BMC Medicine*, 5(1), 12.

<sup>74</sup>Takechi, M. (2008). Construction of knowledge and perception of mammography in the UK. *Ecancermedicalscience*, 2, 98.

<sup>75</sup>Hoffmann & Del Mar, op. cit. note 65; Schwartz & Meslin, op. cit. note 59; Domenighetti, G., D'Avanzo, B., Egger, M., Berrino, F., Perneger, T., Mosconi, P., & Zwahlen, M. (2003). Women's perception of the benefits of mammography screening: Population-based survey in four countries. *International Journal of Epidemiology*, 32(5), 816–821; Hudson, B., Zarifeh, A., Young, L., & Wells, J. E. (2012). Patients' expectations of screening and preventive treatments. *Annals of Family Medicine*, 10(6), 495–502.

<sup>76</sup>Jepson et al., op. cit. note 8,

<sup>77</sup>Reyna, V. F. (2008). A theory of medical decision making and health: Fuzzy trace theory. *Medical Decision Making: An International Journal of the Society for Medical Decision Making*, 28(6), 850–865.

<sup>78</sup>Hersch, J., Barratt, A., Jansen, J., Houssami, N., Irwig, L., Jacklyn, G., ... McCaffery, K. (2014). The effect of information about over-detection of breast cancer on women's decision-making about mammography screening: Study protocol for a randomised controlled trial. *BMJ Open*, 4(5), e004990; Van den Bruel, A., Jones, C., Yang, Y., Oke, J., & Hewitson, P. (2015). People's willingness to accept over-detection in cancer screening: Population survey. *BMJ*, 350, h980.

<sup>79</sup>Sin, J. P., & St Leger, A. S. (1999). Interventions to increase breast screening uptake: Do they make any difference? *Journal of Medical Screening*, 6(4), 170–181.

<sup>80</sup>Østerlie et al., op. cit. note 4.

<sup>81</sup>Ploug, T., Holm, S., & Brodersen, J. (2012). To nudge or not to nudge: Cancer screening programmes and the limits of libertarian paternalism. *Journal of Epidemiology and Community Health*, 66(12), 1193–1196.

<sup>82</sup>Vallgarda, S. (2012). Nudge: a new and better way to improve health? *Health Policy*, 104(2), 200–203.

<sup>83</sup>Richardson, A., Williams, S., Elwood, M., Bahr, M., & Medicott, T. (1994). Participation in breast cancer screening: Randomised controlled trials of doctors' letters and of telephone reminders. *Australian Journal of Public Health*, 18(3), 290–292; Hayes, C., O'Herlihy, B., Hynes, M., & Johnson, Z. (1999). The impact of reminder letters on attendance for breast cancer screening. *Irish Journal of Medical Science*, 168(1), 29–32.

<sup>84</sup>Jorgensen & Gotzsche, op. cit. note 72.

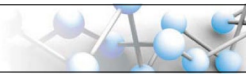
<sup>85</sup>Gigerenzer, G. (2015). On the supposed evidence for libertarian paternalism. *Review of Philosophy and Psychology*, 6(3), 361–383.

<sup>86</sup>Ploug et al., op. cit. note 81.

<sup>87</sup>Ploug et al., op. cit. note 81.

<sup>88</sup>Østerlie et al., op. cit. note 4; Manjer, Å. R., Zackrisson, S., & Emilsson, U. M. (2014). On women's ambivalence about mammography screening: Support in the decision-making process a potential role for health care social workers? *The British Journal of Social Work*, 46(2), 480–497.

<sup>89</sup>Ploug et al., op. cit. note 81.



### 4.5.3 | Normative recruitment

A third alternative approach to balance health promotion and respecting individual choice, which is found in the literature, is normative recruitment, i.e., to appeal to a moral duty to participate. Mammographic screening is recommended by health authorities in several countries and women feel a duty to participate.<sup>90</sup> The duty may also be felt towards their family or their group. A study from Norway showed that many women trust the health care system and their provided services.<sup>91</sup>

Accordingly, it can be argued that women have a duty to participate in screening in the same way as when invited to take part in research or vaccination programs,<sup>92</sup> which is considered to be good for the public health. However, no such explicit arguments are found in the recent scientific literature, and there are relevant differences between screening and vaccination, such as “herd effects.”

### 4.6 | Framing, bias, and the informed choice model

Before moving from analyzing the literature to suggesting solutions, one important issue has to be settled: should informing about mammographic screening assume rational decision-makers?

As we have seen, the issue of informing about screening touches on general debates on irrational aspects of decision-making,<sup>93</sup> cognitive and affective biases and heuristics,<sup>94</sup> and free will. It has also been argued that nudging can be acceptable<sup>95</sup> and even commendable for some types of screening<sup>96</sup> (although not for mammographic screening).

Certainly, there are several arguments for paternalism, nudging and normative recruitment in mammographic screening. One is that soft paternalism is accepted in the promotion of health, e.g., in informing about consumer products, such as cigarettes. The point of the argument is that we need to make sure that the women understand and act voluntarily. Accordingly, it can be maintained that soft paternalism is warranted when informing about mammographic screening, especially when trying to level out socioeconomic differences in attendance.

It can also be argued that women should be able to attend screening based on trust (in the system) and belief (in its beneficence), and that such trust is a good thing that should be stimulated

in the information. Moreover, the informed choice model, based on an individual rational agent, has been criticized from different perspectives (feminists, social scientists, neuroscientists, and psychologists).<sup>97</sup> Accordingly, one could argue for paternalism by undermining informed choice in order to obtain public health goals. While nudging may be warranted in screening, as choice design is hardly ever neutral,<sup>98</sup> the arguments for specific nudging in mammographic screening do not appear to be convincing.

Moreover, arguments appealing to a duty to participate based on analogies with duties to vaccinate or to participate in research do not hold either. If a woman does not attend mammography screening she hardly harms others (directly), and she cannot be considered to be a free rider.<sup>99</sup>

Despite general debates about choice architecture, the literature on informing about mammographic screening is firmly focused on the informed choice model. As pointed out already, trends on informing about mammographic screening appears to have gone from the paternalism of assuring uptake to assure and support informed choice.<sup>100</sup> However tempting or convincing the arguments for framing, nudging, or paternalism may appear, any way of informing that undermines the women's informed voluntary decision undermines an informed choice, and counters health legislation in most countries today. Assuming that women invited to mammographic screening are irrational decision-makers is not a valid starting point when aiming at practical solutions for informing about mammographic screening at present.

## 5 | FROM ETHICAL ISSUES TO SUGGESTED SOLUTIONS

Reviewing the ethical issues makes it possible to address them and suggest some specific solutions. Again, the suggestions are not for armchair or ideal-world conditions, but for real-world circumstances here and now. In particular they are meant for information-development processes as they are organized by many mammographic screening programs. In the following each main issue identified above will be addressed and result in explicit suggestions.

### 5.1 | Facts (on outcomes) should be presented in ways that acknowledge the uncertainties

The findings indicate that information based on facts from the service provider's own screening program should be presented if available, and that the facts should be assessed by independent experts (see below). Additionally, results from studies from comparable settings that fulfil quality criteria and are performed by researchers not directly involved in the actual screening program, should also be

<sup>90</sup>Østerlie et al., op. cit. note 4; Manjer et al., op. cit. note 88.

<sup>91</sup>Østerlie et al., op. cit. note 4.

<sup>92</sup>Harris, J. (2005). Scientific research is a moral duty. *Journal of Medical Ethics*, 31(4), 242–248; Chan, S., & Harris, J. (2009). Free riders and pious sons – why science research remains obligatory. *Bioethics*, 23(3), 161–171; Rhodes, R. (2005). Rethinking research ethics. *The American Journal of Bioethics*, 5(1), 7–28.

<sup>93</sup>Ariely, D. (2008). *Predictably irrational*. New York, NY: HarperCollins.

<sup>94</sup>Blumenthal-Barby, J., Cantor, S. B., Russell, H. V., Naik, A. D., & Volk, R. J. (2013). Decision aids: When 'nudging' patients to make a particular choice is more ethical than balanced, nondirective content. *Health Affairs*, 32(2), 303–310; Blumenthal-Barby, J. S., & Krieger, H. (2015). Cognitive biases and heuristics in medical decision making: A critical review using a systematic search strategy. *Medical Decision Making*, 35(4), 539–557.

<sup>95</sup>Hofmann, B., & Stanak, M. (2018). Nudging in screening: Literature review and ethical guidance. *Patient Education and Counseling*, 101(9), 1561–1569.

<sup>96</sup>Blumenthal-Barby et al., op. cit. note 94.

<sup>97</sup>Ariely, op. cit. note 93.

<sup>98</sup>Hofmann & Stanak, op. cit. note 95.

<sup>99</sup>Harris, op. cit. note 92.

<sup>100</sup>Martinez-Alonso et al., op. cit. note 8.



presented. Although presenting estimates in ranges can be confusing,<sup>101</sup> information should be available in ways that acknowledge and reveal the uncertainty, in addition to information about the age groups and the follow-up time used in the estimates. Information should be presented from the perspective of the women screened. The information needs to be updated continuously.

Numbers should be presented in X per 1000 and color illustrations including all outcomes ought to be provided. Some caution with respect to labeling “benefits” and “harms” is warranted. For example, it may be better to use the term “overdiagnosis” (and describe what it means) than to bluntly label it as “harm.” Decision aids should be offered, and opportunities for additional information, advice, counseling, and assistance for shared decision-making is recommended.

## 5.2 | Information elaborated through an open and transparent process where professionals and stakeholders are involved in gathering, assessing, and approving the information

From the findings it is reasonable to recommend that information should be elaborated through an open and transparent process. Experts in mammographic screening may provide a first draft of the information. However, due to strongly polarized evidence,<sup>102</sup> professionals not involved in mammographic screening need to assess the information. In particular, external experts in risk perception, communication, and competent health professionals not involved in mammographic screening should assure the relevance and quality of the information. This is important, as there are extensive debates on which studies and which numbers are to be trusted.

The women in the target group should test the information, and it is important to include both women who would attend and women who would not. The final decision about the content of the information should be taken in consensus by an interdisciplinary group with strong representation of the target group.

## 5.3 | Layered information

In order to respect the individual women’s needs, information should be layered, starting with the most important information (purpose, potential benefits and harms). Each layer should be balanced in order to reduce bias. Information about the complete screening process, including recall examination, and diagnosis of screen detected and interval breast cancer should be available.

Information should also be available in different languages in different formats, e.g., both on paper and electronically. Illustrations should be used on each layer, where appropriate.

<sup>101</sup>Longman, T., Turner, R. M., King, M., & McCaffery, K. J. (2012). The effects of communicating uncertainty in quantitative health risk estimates. *Patient Education and Counseling*, 89(2), 252–259.

<sup>102</sup>Hofmann, op. cit. note 22.

## 5.4 | Balanced information

According to the present analysis, it is important to *correct* misconceptions and biases by providing balanced information presented in a comprehensible manner. However, it is not warranted to try to *compensate* for misconceptions and biases by framing information, as such compensations may have paternalistic premises and unexpected outcomes. Paternalistic approaches breach traditional norms such as transparency and openness, as well as with accepted goals, such as participation and empowerment. In deliberative democracies, paternalism requires consensus, explicit justifications, and firm evidence, which is presently not available. Moreover, the conception of *bias* in “correcting bias” also presupposes a “correct view,” which may be hard to establish or which presupposes paternalism. Hence, information should be as balanced as possible through processes described in 2.

## 5.5 | The decision about attendance should be entirely up to the invited women

Corresponding to the increased emphasis on informed choice in general and informed consent in health legislation in particular, it is crucial that the decision to attend is open and entirely up to the women invited to screening.

A woman making an informed choice not to attend may feel a significant pressure to participate, and to reject may require more reflection and active deliberation than to participate.<sup>103</sup> An invitation with a suggested appointment may be conceived of as a decision or an obligation, and ignoring it may be conceived of as rude by the women. Conversely, requiring women actively to make an appointment themselves may make it more challenging to attend than not to attend. It can be conceived of as nudging in one direction or the other. Nevertheless, to attend mammographic screening requires action (travelling to mammography site, undressing etc.) compared to non-attendance. In general, to take action in order to accept an offer or invitation is the default.

The point is that attending and not attending mammographic screening should be made equally easy. If the target group does not conceive a fixed appointment as a decision or an obligation, then such appointments are acceptable. However, if women take them as recommendations or obligations, then they are not. Hence, empirical knowledge and strong stakeholder involvement is crucial.

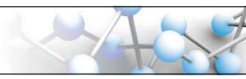
## 5.6 | Summary of suggested solutions

Based on the analysis and considerations described above, the following principles for informing women to facilitate informed choice about whether to attend mammographic screening or not are suggested:

1. Facts (on outcomes) should be presented in ways that acknowledge the variation and uncertainty, e.g., in ranges. Externally

<sup>103</sup>Østerlie et al., op. cit. note 4; Ploug et al., op. cit. note 81; Manjer et al., op. cit. note 88.





- assessed facts from own screening programs should be provided, if available. The information should be continuously updated.
2. Information should be elaborated through an open and transparent process. Stakeholders, but also independent health experts and public health persons should be involved in the process and critically revise the information. Women in the target group should test the information.
  3. Information should be presented in several layers. The information should be presented in an easily understandable way, starting with overall information, and providing more detailed information in subsequent layers. Illustrations should be used to increase the understanding of benefits and risks.
  4. Information should be presented in a balanced way in order to avoid misconceptions or biases. If present, misconceptions should be corrected by adequate information, but compensation for such misconceptions should be avoided. Paternalistic approaches, nudging, and normative recruitment should also be avoided or minimized. The women's right to decide whether they want to participate should be openly and clearly stated. The information should be presented in a manner easy to understand for all invitees. Nonetheless, health illiteracy should be given special attention, and special information aimed at subgroups may be warranted.
  5. It should be clear from the information that the decision about attendance is entirely up to the invited women. Choosing to attend screening should be as easy as a choice not to attend.

## 6 | DISCUSSION

Altogether, five specific guiding principles for elaborating information about mammographic screening have been suggested to promote and facilitate informed choice. The guiding principles are neither exhaustive, nor exclusive. They only give guidance on how to proceed when developing information material for women. The content of this information has to be developed in context. However, while the context is different, the challenges with informing about mammographic screening are the same. This warrants a common strategy, although it does not mandate the same information material.

Moreover, other issues and questions than addressed here exist, and there are overlaps between the questions above. For example, there is an overlap with respect to what is considered to be good quality information (content) and the best way to present the information (format).

Furthermore, the principles ought to be viewed from a wide range of perspectives that need balancing: public health, screening program administration, legal, health care, and other perspectives. Although acknowledging other perspectives, the main focus here has been the perspective of healthy women who are invited to mammographic screening. However, as is evident from the history of mammographic screening, information to the target group is crucial for the trust in and uptake of health services, and, hence, of great importance to health policy.

Altogether, the principles are not radical, and it may be argued that they are quite commonsense. However, with the backdrop of the polarized and heated debates about mammographic screening and the history of biased information, the principles certainly can play an important role in finding practical solutions.

It may be argued that the "mammography war"<sup>104</sup> is so harsh and entrenched that there is no space for middle ground solutions. In fact mammography screening is an area where facts appear to be constructed and directed by strong polarized interests.<sup>105</sup> Nonetheless, women have to be informed about mammography screening when invited. Many countries also have laws demanding informed consent or informed choice for health services. This is especially relevant for preference-sensitive services such as breast cancer screening. Therefore, the task of providing as good information as possible in order for women to make as informed choices as possible appears unavoidable—even if one accepts that there may not be consensus. In fact, this is an example of where (normative) ethics can play an important role in finding practical solutions to pressing problems.

Moreover, it can be argued that women do not, and do not wish to, make rational choices about mammographic screening. Accordingly, one should provide information that supports their choice architecture. Such a claim has wide-reaching implications well beyond mammographic screening and is well beyond the scope of this article. Here, I have taken as a point of departure that women should be provided information that facilitates informed choice, which is encoded in most countries' legislation.

There are of course also several *methodological limitations* with this study. First, the elaboration of the suggestions is not based on a systematic review of the literature as classified by guidelines (e.g., PRISMA). The reason for this is that the study did not aim at comprehensiveness with respect to all the references, but with respect to content. Many relevant references were omitted because they added nothing new (in content) to already identified references. However, as with all qualitative analysis, there may be some issues that are not covered even though saturation was reached.

Second, the search was only performed in one database (PubMed), which has some well-known shortcomings. This may have resulted in some important issues being ignored. However, reviewing reports and guidelines on informing about screening programs did not reveal any such missing issues. Neither did discussions in an expert group (see Acknowledgments). It does not seem likely that a systematic review of the literature would have added anything to this study. Here it is important to note that the goal is not a comprehensive review the ethical issues with informing about mammographic screening, but to elaborate on guiding principles.

Third, other types of content analysis may have given different categories of challenging issues, and even other research questions. Although this is certainly true, it does not follow from this that the suggested principles would differ (and vice versa). Fourth, it is clearly a

<sup>104</sup>Quanstrum & Hayward, op. cit. note 20.

<sup>105</sup>Hofmann, op. cit. note 22.

weakness that the content analysis was only performed by one person. However, the results of the analysis were exposed to an expert group who were able to provide critical responses (see Acknowledgments).

Fifth, this study is based on the premises that openness, transparency, informed choice, and trust in health care providers are core values for screening programs. It should be acknowledged that not all share this premise. However, these values are sufficiently widespread to warrant the study. As argued, many countries have informed consent or informed choice stated in their health legislation. One may think that informed choice is irrelevant (for screening), but then one would have to change health regulation and basic values in liberal democracies. At least until this is obtained, the suggested principles may be of value to screening program providers and health policy makers.

Sixth, others may come to different conclusions from the same analysis of the literature. This is certainly true, and this fact is the very reason for this publication, where these suggestions are presented to peers as part of an ongoing scholarly debate. Accordingly, criticism is most welcome and will hopefully contribute to improvement of the principles—and foremost—to ascertain good information about mammographic screening program.

## 7 | CONCLUSION

In conclusion, informing about mammographic screening is a challenging task with a troubled history. This article has addressed the question about how to inform women about mammographic screening in order to promote and facilitate informed choice and trust in public health programs. Through identifying and addressing specific issues, five guiding principles have been suggested: 1) facts should be presented in ways that acknowledge variation and uncertainties, e.g., by presenting outcomes in ranges; 2) the content and the form of information should be developed through open and transparent processes with strong stakeholder involvement; 3) information should be layered, 4) and balanced without attempts to frame information, and 5) attending mammographic screening should be as easy as not attending. Given the history and controversies of mammographic screening, the five specific, analyzed, and justified principles may be of practical value in handling the challenges with informing about mammographic screening.

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## CONFLICT OF INTEREST

The author declares no conflict of interest.

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## SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

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