Online information about mammography screening in Italy from 2014 to 2021

Francesco Attena*, Lucia Abagnale and Angela Avitabile

Abstract

Background: Many studies have reported that the information women receive about the risk-to-benefit ratio of breast cancer screening is still scarce and biased toward benefit. In a study we conducted in 2014, we analysed online documents about breast cancer screening that were addressed to the general female public. In the present study, we used the same methodology to verify if the information provided to women was improved.

Methods: We evaluated documents addressed to the general female public and posted on the Internet by the Italian national and regional public health services. False-positive and false-negative screening results, biopsy-proven false-positive results, interval cancer, overdiagnosis, radiation exposure, and decrease in risk of mortality were analysed. In addition, quantitative data were searched.

Results: In 2021, the most frequently reported information was reduction in breast cancer mortality (58.2%). The most frequently reported risk was a false-positive mammogram (42.5%). Similar frequency rates were reported for interval cancer, false-negative result, and radiation exposure (35.8%, 31.3%, and 28.3%, respectively). Overdiagnosis and biopsy-proven false-positive result were the less reported risks (20.1% and 10.4%). Thirteen documents provided quantitative data about reduction of mortality risk (16.7%), and only 19 provided quantitative data about risks or harms (8.4%). Almost all organisations sent letters of invitation to women (92.5%) and provided screening free of charge (92.5%). The most recommended was biennial screening for women aged between 50 and 69 years (48.5%). Compared with the information in 2014, that in 2021 showed some improvements. The most marked improvements were in the numbers of reports on overdiagnosis, which increased from 8.0 to 20.1%, and biopsy-proven false-positive result, which increased from 1.4 to 10.4%. Regarding the benefits of breast cancer screening, reduced mortality risk became increasingly reported from 2014 (34.5%) to 2021 (58.2%). Conversely, quantitative data remained scarce in 2021.

Conclusions: Moderate improvements in information were observed from 2014 to 2021. However, the information on breast cancer screening in documents intended for women published on Italian websites remain scarce.

Keywords: Website, Breast cancer prevention, Mammography, Information

Introduction

Breast cancer screening is one of the most debated scientific topics, with many issues that are still controversial and divisive. Its usefulness is probably the most important issue because some studies still consider breast cancer screening as a scarcely effective or ineffective tool for reducing breast cancer mortality or to have an unfavourable benefit-to-risk ratio [1–6]. The debate among women is equally intense and mainly concerns the degree of information they receive. Despite the current era of transparent communication and informed consent, many recent studies have reported that the information women receive on the risk-to-benefit ratio of breast cancer screening is still scarce and biased toward benefit [7–11].

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Women can obtain information about breast cancer prevention in many ways. When women request or are invited to undergo breast cancer screening, the health operators involved should support them in achieving a shared decision making [12–16]. This informed participation in the decision making implies that health operators must provide women with correct and comprehensive information about the benefits and risks of breast cancer screening to help them decide in accordance with their personal values. When women try to find out about mammography on their own, information about breast cancer screening is accessible from various sources (websites, journals, television, oncological centres, or other health organisations) and is provided in various formats (leaflets, booklets, brochures, pamphlets, and technical reports). Among these sources, Internet-based information on health concerns has become increasingly important.

In a previous study we conducted in 2014, we analysed documents about breast cancer screening specifically addressed to the general female public and posted online by the Italian national and regional health services, local health authorities, and major hospitals [17]. The aim was to evaluate the type and completeness of information about the risk-to-benefit ratio of mammography screening. In the present study, we used the same methodology to verify any improvement in the information provided to women during a 7-year period.

Methods
We reported below the same methodology of our previous study [17].

Types of web page
We analysed web pages specifically addressed to the general female public and published by the Italian national and regional health services, local health authorities, or major hospitals. We excluded technical documents specifically directed to health-care personnel but included a few documents addressed to an unclear audience.

Search strategy
Although Italy has a national health service (Servizio Sanitario Nazionale), each Italian region has its own regional health service (Servizio Sanitario Regionale). Therefore, the organisation of and communication about mammography services vary throughout Italy. Furthermore, each region has local health authorities (Aziende Sanitarie Locali [ASL]), major hospitals (Aziende Ospedaliere [AO]) and local hospitals (Presidi Ospedalieri [PO]) affiliated with ASL. Therefore, our search strategy included national, regional, and local levels hierarchically.

At the national level, we searched official websites of the four main national health institutions, namely Ministero della Salute, Istituto Superiore di Sanita, Agenas (Agenzia Nazionale per i Servizi Sanitari), and Osservatorio Nazionale Screening. For regional and local information, we examined the health services section of the official website of each region and all ASL and AO official websites in each region. The search on all these websites was performed with the Google search engine. We thought this is the main search strategy used by Italian women. We excluded private health organisations, as a complete list was not available and as mammography screening is almost exclusively supported by the SSN.

Keywords
On each official website, we performed a search using the following terms: mammografia (mammography), prevenzione dei tumori (cancer prevention), tumore della mammella (breast cancer), screening tumore della mammella (breast cancer screening), and prevenzione (prevention).

When no documents appeared in the search using these terms, we performed additional searches in the websites.

Assessment of health information
Two medical researchers, who were residents in public health, epidemiology, and hospital organisation, analysed the websites independently and in a blinded manner to evaluate information on potential risks and harms, including false-positive and false-negative results, biopsy-proven false-positive results (i.e. a false positive on mammography confirmed as false positive even after biopsy), interval cancer, overdiagnosis, and radiation exposure, and on potential benefits, including reduced risk of mortality and increased chance of survival. In addition, quantitative data (e.g. percentages, relative risk reduction, number needed to screen) were searched. After the evaluation for each region, the results were compared, and minor discrepancies were discussed and resolved.

Other collected data included information on whether the examination was free of charge or not (yes/no), justification for absence at work (yes/no), whether a letter of invitation was given to each woman (yes/no), age range, and frequency. The websites were accessed between February and May 2021. Ethics committee approval was not required for this study because it did not involve patients.

Results
In accordance with the search strategy, we examined 166 websites (Table 1). Among these websites, 134 (80.7%) had web pages addressed to the general female public and 73 (54.5%) reported at least one risk of breast cancer. Therefore, almost half of these sites didn't give any
information about risk/benefit of screening. Overall, the mean number of reported risks in each document was 1.7 (226/134 websites). In 2014, more websites were found (255 vs 166) because after this period, significant mergers occurred between health organisations. However, the number of documents on breast cancer screening that were addressed to women is similar between 2014 and 2021. In general, more documents discussed at least one risk (54.5% vs 43.4%) and more risks were reported in 2021 than in 2014 (226 vs 152).

The most reported information was the reduction in breast cancer mortality (58.2%; Table 2), with false-positive result being the most frequently reported risk (42.5%). Similar rates were reported for interval cancer, false-negative screening result, and radiation exposure (35.8%, 31.3%, and 28.3%, respectively). Overdiagnosis and biopsy-proven false-positive result were the less frequently reported risks (20.1% and 10.4%, respectively). Of the 226 risks reported, only 19 were supported with quantitative data (8.4%), and more than half (11) were overdiagnosis. Thirteen documents had quantitative data about reduced risk of mortality (16.7%).

Compared with the information in 2014, the information in 2021 had moderate improvements for all single items. The most marked improvements were in the numbers of reports on overdiagnosis, which increased from 8.0% to 20.1%, and biopsy-proven false-positive result, which increased from 1.4% to 10.4%. Regarding the benefits of breast cancer screening, reduced risk of mortality was increasingly reported from 2014 (34.5%) to 2021 (58.2%). Conversely, quantitative data remained scarce, with the exception of those for overdiagnosis (11 vs 3).

Almost all organisations sent letters of invitation to women (92.5%) and provided screening free of charge (92.5%). Some women also received justified absence from work (14.2%). The age group recommended for screening was highly variable; the most common was biennial screening, for women aged between 50 and 69 years (48.5%). However, 34 documents (25.4%) anticipated screening at the age of 45 years; and 2, at the age of 40 years (Table 3).

### Discussion

The level of information provided to women on the benefit-risk balance of breast cancer screening is still low. However, comparing with data collected in 2014, we found some improvements in the information in 2021.

The most frequently reported risk of breast cancer screening was a false-positive result, although not all the reported information was clear. The following are two examples of unclear reporting of false-positive results: 1. ‘If the test is not legible or any changes are detected, the

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**Table 1** Documents that reported information on breast cancer screening and at least one risk of breast cancer screening

|                      | 2021 n | 2014 n |
|----------------------|--------|--------|
| Web pages searched   | 166    | 255    |
| Documents addressed to the female public | 134    | 136    |
| Documents discussing at least one risk | 73     | 59     |
| Total risk reported  | 226    | 152    |

*4 national, 20 regional, 41 AO, 101 ASL

**Table 2** Information about the risks and benefits of breast cancer screening by Italian public health organisations in 2021 and 2014

|                      | 2021 n | 2014 n |
|----------------------|--------|--------|
|                      | q      | %      |
|                      | q      | %      |
| Risks                |        |        |
| False-positive result| 57     | 42.5   |
| Biopsy-proven false-positive result | 14     | 10.4   |
| False-negative result| 42     | 31.3   |
| Interval cancer      | 48     | 35.8   |
| Overdiagnosis        | 27     | 20.1   |
| Radiation exposure   | 38     | 28.3   |
| Total risk           | 226    |        |
| Total quantitative data on risks | 19     | 8.4    |
| Benefits             |        |        |
| Reduced breast cancer mortality | 78     | 58.2   |
| Quantitative data on Reduced breast cancer mortality | 13     | 16.7   |

q = number of sites that offered quantitative information about the indicated risk or benefit.
This seems surprising because overcoming the paternalistic physician–patient relationship has long been universally accepted and, in our case, because the scientific literature has continued over the years to emphasise the importance of an informed choice for women [12–16].

The persistent lack of information is also a common finding in other countries, both from the website search [8, 24–27] and written documents [9, 28–30].

Information about overdiagnosis showed a notable increase in 2021 compared with 2014. However, the frequency of this information in the documents aimed at women was still low, probably because it is both the most recent and harmful risk for women. Therefore, not all health operators are aware of overdiagnosis, and if they are aware of it, they might avoid reporting the information in public documents for fear of dissuading women from undergoing screening [20, 21]. Moreover, we considered many reports of overdiagnosis unclear. For example, ‘it is also possible that mammography reveals very small but slow-growing tumors (about 10%) that are not harmful for the woman’s health’ [22]. Considering that overdiagnosis is the most important risk for women, the main scientific efforts on this screening are directed toward reducing overdiagnosis by understanding tumour heterogeneity and how indolent cancers evolve and progress [23].

Table 3 General information about breast cancer screening by Italian public health organisations

| General characteristics | n   | %   |
|-------------------------|-----|-----|
| Documents/websites       | 134 | 80.7|
| Justified absence at work| 19  | 14.2|
| Free-of-charge test      | 124 | 92.5|
| Letter of invitation     | 124 | 92.5|

**Screening programs by age group**

| Age group                  | n   | %   |
|----------------------------|-----|-----|
| 50–69 y.o., annual*        | 65  | 48.5|
| 50–74 y.o., biennial       | 18  | 13.4|
| 45–49 y.o., annual/50–69 y.o., biennial | 1   | 0.74|
| 40–49 y.o., annual/50–69 y.o., biennial | 2   | 1.5 |
| 45–69 y.o., biennial       | 4   | 2.9 |
| 45–49 y.o., annual/50–74 y.o., biennial | 19  | 14.2|
| 45–49 y.o., annual/50–69 y.o., biennial/70–75 y.o., biennial | 10  | 7.5 |
| No information             | 45  | 33.6|

y.o. = years old
*Guidelines of Italian Ministry of Health

This condition persists for many reasons. One of the most frequently reported justifications is that providing information on potential harms could reduce adherence to screening. Scientific literature reports contradictory data, as some studies have shown a reduction in adherence [31], whereas others more often showed that correct information only slightly reduced [36] or did not reduce adherence to screening [7, 32–34]. Whatever the causes of this lack of information for women, the main way to overcome them is the training of operators. If operators are not up to date, they will receive the correct update on the risks/benefits ratio of mammography. If the operators are aware of this ratio, they will receive the correct update to provide, in Italy through informed consent form, women with complete information on the risks and benefits of mammography. However, from an ethical point of view, preventing reduction in adherence cannot justify the lack of information.

Other reasons for the scarce information is the gap between research and practice, which has resulted in many breast cancer practitioners being not well updated about the controversial risk-to-benefit ratio of breast cancer screening [35]. Major propensities towards breast cancer screening, with risk minimisation, may depend on professional interests. Radiologists, breast cancer specialists, and other involved health workers may have distorted judgments due to their professions [36]. Then, explaining risk/benefit in a simple and short way takes time and patience for the operators. Furthermore, breast cancer screening is strictly incorporated in women’s struggle for emancipation and thus has become a red flag for criticism, as any criticism is considered by women’s movements as an anti-feminist attack on their health and freedom. This is the paradox of breast cancer screening: for women to be fully in control of their own body, they receive less information on breast cancer screening than on any other health topic.

Much information was unclear perhaps to avoid alarming patients. Instead, a valid explanation is provided for the absence of quantitative information; which is the wide variability of data in the literature and the difficulty of summarising these data in a way that would be accessible to non-experts.

However, our findings could be underestimated as we have investigated only one of the three moments where it is possible to inform women. In addition to active web searching, most Italian women receive at home a letter of invitation to undergo screening. Furthermore, if they go
for screening, they must sign an informed consent. It is the task of each care facility to best distribute information among these three documents.

Our study has limitations. As just said, one is that it did not analyse invitation letters, brochures or informed consent forms given to women before undergoing mammography, which could contain more information than the corresponding websites. We excluded private treatment centres and did not know whether they offer more or less information than public centres. The comparison between 2014 and 2021 could be biased mainly because the health operators who searched the websites were different.

Conclusions
In conclusion, our results showed moderate improvements in the information about the risks and benefits of breast cancer screening from 2014 to 2021. However, the documents posted on Italian websites were still lacking, as these did not provide correct and complete information to women who wanted to undergo breast cancer screening, preventing them from making fully informed choices about their health.

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Author contributions
FA conceived the study, analyzed data and wrote the article. AA and LA collected data, created database and contributed to analyse data. All authors read and approved the final manuscript.

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Availability of data and materials
All visited Links are available on request from the corresponding author.

Declarations
Ethics approval and consent to participate
Not applicable.

Consent for publication
Not applicable.

Informed consent
Informed consent was not required because the study did not involve any people.

Approval
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Competing interests
The authors declare that they have no competing interests.

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References
1. Geitzcche PC, Jørgensen KJ. Screening for breast cancer with mammography. Cochrane Database Syst Rev. 2013;2013(6):CD001877.
2. Schmidt H. The ethics of incentivizing mammography screening. JAMA. 2015;314:995–6.
3. Lannin DR, Wang S. Are small breast cancers good because they are small or small because they are good? N Engl J Med. 2017;376:2286–91.
4. Autier P, Boniol M. Mammography screening: a major issue in medicine. Eur J Cancer. 2018;90:34–62. https://doi.org/10.1016/j.ejca.2017.11.002. PubMed.
5. Maller MH, Lousdal ML, Kristiansen IS, Stavring H. Effect of organized mammography screening on breast cancer mortality: a population-based cohort study in Norway. Int J Cancer. 2019;144:697–706.
6. Jatoi I, Pinsky PF. Breast cancer screening trials: endpoints and over-diagnosis. J Natl Cancer Inst. 2021;113:1131–5.
7. Jacklyn G, Howard K, Iwig L, Houssami N, Hersch J, Barratt A. Impact of extending screening mammography to older women: information to support informed choices. Int J Cancer. 2017;141:546–50.
8. Martucci J, Schmidt H. Towards more effective online information support for mammography screening decisions. Prev Med. 2018;111:423–8.
9. Hoffmann B. [Do women receive enough information to make informed choices about breast cancer screening?] Tidsskr Nor Laegeforen. 2020;140.
10. Monticciolo DL. Current guidelines and gaps in breast cancer screening. J Am Coll Radiol. 2020;17:1269–75.
11. Kissné DR, Gede N, Szakács Z, Kiss I. Breast cancer screening knowledge among Hungarian women: a cross-sectional study. BMC Womens Health. 2021;21:69.
12. DuBenske LL, Schrager SB, Hitchcock ME, Kane AK, Little TA, McDowell HE, et al. Key elements of mammography shared decision-making: a scoping review of the literature. J Gen Intern Med. 2018;33:1805–14.
13. Croes KD, Jones NR, Dubenske LL, Schrager SB, Mahoney JE, Little TA, et al. Core elements of shared decision-making for women considering breast cancer screening: results of a modified Delphi survey. J Gen Intern Med. 2020;35:1668–77.
14. Eden KB, Ilevi J, Bensching KL, Franta G, Hersh AR, Case J, et al. Use of an online breast cancer risk assessment and patient decision aid in primary care practices. J Womens Health (Larchmt). 2020;29:763–9.
15. Hild S, Johanan M, Valenza A, Thabaud M, Laforest F, Ferrat E, et al. Quality of decision aids developed for women at average risk of breast cancer eligible for mammographic screening: systematic review and assessment according to the International Patient Decision Aid Standards instrument. Cancer. 2020;126:2765–74.
16. Roberto A, Colombo C, Candiani G, Satolli R, Giordano L, Jaramillo L, et al. A dynamic web-based decision aid to improve informed choice in organised breast cancer screening: A pragmatic randomised trial in Italy. Br J Cancer. 2020;123:714–21.
17. Attena F, Cancellieri M, Pelullo CP. Scarce information about breast cancer screening: an Italian websites analysis. Medicine (Baltimore). 2016;95:e5615.
18. “Se l’esame non è ben leggibile o vi si rilevano delle alterazioni, l’interessata viene contattata direttamente dal personale competente per ripetarlo o per eseguire ulteriori accertamenti diagnostici”. http://www.aslonisto.it/index.php?xsl=7&v=108208&v=2&v=2982.
19. “Le utenti risultano positivi al test verranno contattate telefonicamente dagli operatori del Centro Screening che le invieranno a sottoporsi ad ulteriori accertamenti (quali esame clinico, ecografia, risonanza magnetica, esame citologico, biopsia, ecc) con indicazione dell’appuntamento (esame di 2° livello)”. http://www.aslcaribonia.it/index.php?xsl=15&v=7&v=9&v=3568&esn=primo+piano&an=1&v=108http://www.aslcaribonia.it.
20. Nagler RH, Franklin Fowler E, Gollust SE. Women’s awareness of and responses to messages about breast cancer overdiagnosis and overtreatment: results from a 2016 national survey. Med Care. 2017;55:879–85.
21. Striggelbaut A, Copp T, Jacklyn G, Jansen L, Liefers GJ, McCaffery K, et al. [Women’s Acceptance of Overdetection in Breast Cancer Screening: Can We Assess Harm-Benefit Tradeoffs?]. Med Decis Making. 2020;40:42–51.
22. “E’ anche possibile che con la mammografia si scoprono tumori molto piccoli ma a lenta crescita (circa il 10%) non dannosi per la salute della donna”. https://www.ausl.fe.it/home-page/news/allegati-news/2016/screening-a4-2015-web.
23. Srivastava S, Koay EJ, Borowsky AD, De Marzo AM, Ghosh S, Wagner PD, Kramer BS. Cancer overdiagnosis: a biological challenge and clinical dilemma. Nat Rev Cancer. 2019;19:349–58.

24. Jørgensen KJ, Gøtzsche PC. Presentation on websites of possible benefits and harms from screening for breast cancer: cross sectional study. BMJ. 2004;328:148.

25. Ferreira D, Carreira H, Silva S, Lunet N. Assessment of the contents related to screening on Portuguese language websites providing information on breast and prostate cancer. Cad Saúde Pública. 2015;29:2163–76.

26. Ballesteros-Perla S, Gavilán-Moral E. Content of official addressed to women informative documents about breast cancer screening in Spain. Rev Esp Salud Publica. 2018;92: e201810076.

27. Spagnoli L, Navaro M, Ferrara P, Del Prete V, Attena F, the Collaborative Working Group. Online information about risks and benefits of screening mammography in 10 European countries: an observational Web sites analysis. Medicine (Baltimore). 2018;97: e10957.

28. Gümürsenbach E, Piccoliori G, Zerbe CO, Altiner A, Othman C, Rose C, et al. Are women getting relevant information about mammography screening for an informed consent: a critical appraisal of information brochures used for screening invitation in Germany, Italy, Spain and France. Eur J Public Health. 2010;20:409–14.

29. Kurzenhäuser S. What kind of information do German health information pamphlets provide on mammography screening? Z Arztl Fortbild Qualitatsch. 2003;97:53–7.

30. Gøtzsche PC, Jørgensen KJ. The breast screening programme and misinforming the public. J R Soc Med. 2011;104:361–9.

31. Waller J, Whitaker KL, Winstanley K, Power E, Wardle J. A survey study of women’s responses to information about overdiagnosis in breast cancer screening in Britain. Br J Cancer. 2014;111:1831–5.

32. Goto Y, Tsugawa K, Furuya Y, Maeszato M, Tagami Y, Ogawa Y, Saisu M, Yamazaki M, Kuramochi F. Behavior of Japanese women after being informed about the benefits and disadvantages of breast cancer screening: a questionnaire survey. Breast Cancer. 2020;27:739–47.

33. Hersch J, Barratt A, McGeachan K, Jansen J, Houssami N, Dhillon H, Jacklyn G, Irving L, McCaffery K. Informing women about overdetection in breast cancer screening: two-year outcomes from a randomized trial. J Natl Cancer Inst. 2021;113:1523–30.

34. Montero-Moraga JM, Román M, Burón A, Sala M, Castells X, Macià F. Effect of an information leaflet on breast cancer screening participation: a cluster randomized controlled trial. BMC Public Health. 2021;3(21):1301.

35. Wegwarth O, Gigerenzer G. The barrier to informed choice in cancer screening: statistical illiteracy in physicians and patients. Recent Results Cancer Res. 2018;210:207–21.

36. Hofmann B. Fake facts and alternative truths in medical research. BMC Med Ethics. 2018;19:4.

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