

# The use of citizens' juries in decision-making processes in screening mammography

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*Many women in the general public but also health professionals tend to overestimate the benefits of the early detection of breast cancer and to underestimate the potential disadvantages of the techniques, such as screening mammography, used to achieve this aim. In Spain, women invited to participate in screening mammography programmes generally do not receive information about the possible downsides associated with such participation. To rectify this, initiatives with the aim of facilitating informed decision-making by women considering screening mammography have been welcomed. This article summarizes the results of a recently published study evaluating the use of "citizens' juries" in the decision-making processes involved in the screening mammography program currently operating in Andalusia, Spain.*

Several studies of the technique known as "deliberative democracy" and its application to the overall prevention of cancer have been carried out in countries such as Australia, New Zealand, & the United Kingdom. The results of such studies support the use of the approach as a tool to facilitate the participation of the general population in influencing health policies in general and as a way to increase knowledge of health questions and enable meaningful decisions to be taken on the part of the individual.

## CONTROVERSIES ON THE REAL BENEFITS OF SCREENING MAMMOGRAPHY

As in many aspects of medicine, there are no black and white absolute truths about the pros and cons of screening mammography — the available data are always relative.

The predominant and prevailing belief regarding screening mammography is based on the intuitively appealing idea that, the earlier cancer is detected the better since this gives an improved chance of less aggressive treatment and better outcomes. This belief is in fact founded on the results of clinical trials and systematic reviews [1-4]. Since the 1960s, ten randomized trials have been carried out, involving a total of some 600,000 women in which a cohort who did not undergo mammography was compared with another group which did. In addition to these trials, four systematic reviews have been carried out: Cochrane, American, Canadian and British Collaboration.

Taken together, these studies indicated that screening mammography reduces mortality from breast cancer by 20%, with a relative risk (RR) around 0.80.

However the estimates of the number of women aged 50-69 years who would have to be invited over a period of 10 years to avoid a single death from breast cancer vary considerably. Thus, according to the British review [4], to prevent one death due to breast cancer, 235 women would have to be screened whereas the Nordic Cochrane Center [2] found that the participation of at least 2000 women would be necessary.

The part of the scientific community supporting screening mammography believes that the benefits in reducing mortality outweigh the disadvantages such

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as false positives and overdiagnosis of breast cancer.

However critics of screening mammography also have their point of view. For example although the American [3] and British [4] reviews considered that the trials were of acceptable quality, the Cochrane and Canadian reviews considered that only four out of the ten trials did not have irregularities in the number of women recruited to ensure adequate randomization. In five trials it was considered that the two cohorts of women were not adequately randomized or that there were inconsistencies in the number of women assigned to one group or the other. Therefore, any differences in mortality rates between the groups could not reliably be ascribed to mammography, since they could be simply due to other differences between the groups. In the methodologically more rigorous trials, specific mortality reduction was not shown. In addition, critics of screening mammography attribute more value to the reduction of global mortality and less to that of breast cancer-specific mortality. No trial or systematic review has shown that overall mortality is reduced by subjecting women to screening mammography.

The part of the scientific community which is critical of mammographic screening believes that the benefits in reducing mortality are outweighed by the disadvantages such as a level of false positives of 10% of women participants over 10 years [2] and overdiagnosis that, from a population perspective affects 11% of women, and, from the perspective of women invited to the screening, can reach 19% [4].

### **RECOMMENDATIONS FOR SCREENING MAMMOGRAPHY IN ANDALUSIA, SPAIN**

The Public Health Service of Andalusia implemented a screening mammography program in 1995, in which women between 50 and 69 years of age were invited to have mammograms every two years (in some districts of the region women between 45 and 69 years of age were

invited), There was an enrolment rate of 86.1%. A report was subsequently issued [5] standardizing the age range for screening mammography to be between 50 and 69 years, i.e. women between 45 and 49 years of age were no longer invited to participate. In the program, women in the 50 - 69 age range receive a letter by mail inviting them to participate. The letter contains the date of the appointment and basic instructions to follow.

### **GENERAL PRINCIPLES OF "DEMOCRATIC DELIBERATION" BY POPULAR JURY**

The technique of deliberative democracy is used to involve citizens in formal dialogue with the authorities or public institutions, in order to reach agreement on complex problems and policies. The methodology includes the use of a popular jury, consensus conferences, deliberative surveys, study circles, citizen assemblies and new online options. The overall objective is to bring the opinion and values of citizens closer to the political decision-making process [6]. The approach is particularly useful for issues where personal values, ethics and existing evidence on the subject matter are important. In such situations, citizens need time to fully understand and consider all relevant aspects [7]. The method can thus also be considered as an "informed consent" representative of the community [8].

### **FEASIBILITY STUDY OF THE CITIZENS' JURY APPROACH IN ANDALUSIA, SPAIN**

A sample of 13 women between 50 and 69 years old, of medium or higher education was selected from the invitation lists of the screening mammography program to act as a jury.

Two expert epidemiologists put forward the views for and against screening mammography. The principal investigator of the study was a neutral moderator. The jury met on three occasions for four hours.

On the first day the moderator informed the jury how to evaluate the key benefits of the screening program

such as overall reduction of breast cancer mortality, the main drawbacks (e.g. overdiagnosis, overtreatment and false positives) and other pros and cons. The presentation and the accompanying documentation were aimed at enabling an understanding of the arguments "for and against" to be presented the next day.

On the second day, the experts duly gave further presentations and were thereupon questioned by the jury, with the moderator chairing the debate and the discussion.

On the final day, the jury deliberated between themselves, without the presence of the experts or the moderator and came to their own conclusions.

The jury then issued its decision on the question as to whether the Andalusian Public Health System should continue to offer screening mammography to women between 50 and 69 years old. The jury recorded their conclusions in writing and submitted their suggestions to the political authorities. All sessions were recorded, a transcription of the deliberation session was made and analyzed.

### **OUTCOME OF THE DELIBERATION PROCESS**

After the deliberation eleven women voted "yes" and two voted "no" to the proposition that the Andalusian Public Health System should continue screening mammography. The reasons for continuing screening could be grouped into three categories, namely health, the nature of the procedure and individual freedom. However differing opinions were also noted: some members of the jury valued the universal nature of the screening program while others thought that it should be offered on demand.

However, a minority of the jury members focussed on the perceived lack of effectiveness and the high cost of screening mammography to recommend that the screening mammography program be discontinued.

After a joint discussion, the jury drew up a list of recommendations addressed to the health authorities

with the aim of improving the screening mammography program. The recommendations included on the improvement of available information, the need for psychological support to women participating in the program and the promotion of research on breast cancer screening.

## DISCUSSION

The process of deliberative democracy was thus shown to be feasible in a group of Andalusian women discussing the pros and cons of whether to continue or not the screening mammography program and resulted in a majority of the jury recommending continuation of screening program, although a minority of the jurors (2 out of 13, 15%) disagreed. From the analysis of the discussions, it could be seen that the participants generally increased their knowledge of the issues involved so that they could take a meaningful position for or against, could evaluate the universal or optional demand for mammography and could give an opinion about the efficacy of the screening mammography program in terms of reducing mortality, its cost and different aspects of overdiagnosis [9].

There is no consensus about the best way for women to be informed about screening mammography and their ability to make informed decisions [10], but the current reality is that most women have a very poor knowledge level of the subject and have an enthusiastically positive attitude towards screening mammography [11].

To reflect the scientific controversy about the subject, it is recommended that the various sources of information on screening mammography that are available from health professionals, the media, including information documents and websites should be improved. Health professionals, especially primary care physicians, should change the informative / educational model they use so that it is based on truthful, objective and complete information that enhances the critical capacity of women to make their own decisions. Full and truthful information material should be made readily available (not just a letter of invitation) as real tools to help decision-making.

Likewise, as for the political decision-making process there are of course specific methodologies for the development of summarized evidence to support public health initiatives and policies [12], but for this the political authorities should accept their role as involved actors. Instead of focussing on the fundamental aim of being of benefit to women, political involvement in, and interference with scientific/medical aspects can in fact frequently discourage shared decision-making, increase the perception of the harms of screening and instead sow doubt in the public's mind about the general value and integrity of medical science [13]. A summary of evidence for policy-making can be part of a broader communication strategy with other interested parties, including women, who whether involved either individually or collectively, have a lot to say.

## CONCLUSION

Having carried out this study of deliberative democracy and the role of the popular jury in reaching a position regarding the merits of screening mammography we conclude that the strategy is feasible in practice. The approach did not change the initially favorable positioning of the group with respect to screening mammography, although the process did change the opinion of some women. However, all of the women wanted to be able to make informed decisions and to decide whether to maintain or increase the level of medicalization in their lives.

## REFERENCES

1. Fitzpatrick-Lewia D, Hodgson N, Ciliska D, Peirson L, Gauld M, Yun Liu Y. Breast cancer screening. Canadian Task Force on Preventive Health care, 2011. Disponible en: [http://canadiantaskforce.ca/docs/breast\\_cancer\\_systematic\\_review\\_ENG.pdf](http://canadiantaskforce.ca/docs/breast_cancer_systematic_review_ENG.pdf) [accessed 19-6-2014].
2. Gøtzsche PC, Nielsen M. Screening for breast cancer with mammography. *Cochrane Database Syst Rev*. 2011 Jan 19;(1):CD001877.
3. U.S. Preventive Services Task Force. Screening for breast cancer: U S. Preventive Services Task Force recommendation statement. *Ann Intern Med* 2009; 151 (10): 716–26.
4. Independent UK Panel on Breast Cancer Screening. The benefits and harms of breast cancer screening: an independent review. *Lancet* 2012; 380: 1778–86.
5. Márquez S, Lacalle JR. Beneficios y efectos adversos del cribado de cáncer de mama: revisión de la evidencia científica. Secretaría General de Salud Pública, Inclusión Social y Calidad de Vida. Consejería de Salud y Bienestar Social. Enero 2013.
6. Rychetnik L, Carter SM, Abelson J, Thornton H, Barratt A, Entwistle VA, et al. Enhancing Citizen Engagement in Cancer Screening Through Deliberative Democracy. *J Natl Cancer Inst*; 2013; 105: 380–386.
7. Street J, Duszynski K, Krawczyk S, Braunack-Mayer A. The use of citizens' juries in health policy decision-making: A systematic review. *Soc Sci Med*. 2014; 109: 1-9. doi: 10.1016/j.socscimed.2014.03.005
8. Irwig L, Glasziou P. Informed consent for screening by community sampling. *Eff Clin Pract* 2000;3:47–50.
9. Baena-Cañada JM, Luque-Ribelles V, Quílez-Cutillas A, et al. How a deliberative approach includes women in the decisions of screening mammography: a citizens' jury feasibility study in Andalusia, Spain. *BMJ Open* 2018;8:e019852. doi:10.1136/bmjopen-2017-019852
10. Jimbo M, Rana GK, Hawley S, et al. What is lacking in current decision aids on cancer screening? *CA Cancer J Clin* 2013;63:193–214.
11. Baena-Cañada JM, Rosado-Varela P, Expósito-Álvarez I, et al. Women's perceptions of breast cancer screening. Spanish screening programme survey. *Breast* 2014;23:883–8.
12. Oliver K, Innvar S, Lorenc T, et al. Systematic review of barriers and facilitators of the use of evidence by policymakers. *BMC Health Serv Res* 2014;14:2.6.
13. Lin KW, Gostin LO. A public health framework for screening mammography: Evidence-based vs politically mandated care. *JAMA* 2016;315(10):977-8. DOI: 10.1001/jama.2016.0322