



Including values in evidence-based policy making for breast screening: An empirically grounded tool to assist expert decision makers



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ABSTRACT

Values are an important part of evidence-based decision making for health policy: they guide the type of evidence that is collected, how it is interpreted, and how important the conclusions are considered to be. Experts in breast screening (including clinicians, researchers, consumer advocates and senior administrators) hold differing values in relation to what is important in breast screening policy and practice, and committees may find it difficult to incorporate the complexity and variety of values into policy decisions. The decision making tool provided here is intended to assist with this process. The tool is modified from more general frameworks that are intended to assist with ethical decision making in public health, and informed by data drawn from previous empirical studies on values amongst Australian breast screening experts. It provides a structured format for breast screening committees to consider and discuss the values of themselves and others, suggests relevant topics for further inquiry and highlights areas of need for future research into the values of the public. It enables committees to publicly explain and justify their decisions with reference to values, improving transparency and accountability. It is intended to act alongside practices that seek to accommodate the values of individual women in the informed decision making process for personal decision making about participation in breast screening.

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1. Introduction

After several decades of organised breast screening, leading experts in the field continue to disagree about aspects of its policy and practice [1–5]. There is particularly strong debate about whether or not the benefits of breast screening outweigh the harms amongst certain population groups, and the level of information detail to provide for women. Reasons for disagreement are often attributed to disputes about the epidemiological evidence [6–11] or to conflicts of interest [6,12–14], and there have been calls to deliver better epidemiological education for experts [11,15], provide clearer communication of trial results [14,16,17], and focus on independent analysis of quantitative data [6,12,17,18]. Despite implementing at least some of these ideas, disputes continue: that is, even when capable, well-meaning experts agree about numbers they may still disagree about one or more aspect of breast screening [2,7,12,19]. Thus it appears that epidemiological misunderstandings, epistemic differences and conflicts of interests may not entirely explain expert disagreement. In light of this, and recog-

nising the self-evident concept that health policy decisions depend not only on analysis of epidemiological evidence but also on what is valued in relation to that evidence [20–22], it seems likely that different values (views about what is right and wrong [23]) may be at least partly responsible for disagreements in relation to breast cancer screening.

There has been growing acceptance of the need to explicitly consider values in the process of evidence-based healthcare decision making. For example, the GRADE framework for producing evidence-based guidelines incorporates assessments of values regarding benefits and harms, in particular, the extent to which intervention outcomes are generally regarded as being desirable or undesirable. GRADE authors recommend that decision-making committees should use the perspective of patients when thinking about benefits and harms [24], and should be transparent about their estimates or assumptions regarding these typical patient values [25,26]. The GRADE framework is widely endorsed, although the (limited) empirical evidence about its usability and effectiveness suggests there may be room for improvement [27–30]. This may be especially relevant to the field of public health, where value judgements about benefits and harms may be more complex, and

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where other relevant principles (such as supporting autonomy) might be prioritised by some [31].

There is less endorsement of the idea that values held by informed experts are relevant and important to the policy decision-making process. Some writers have proposed that values of committee members have no role in decision making, arguing for a so-called “objective” interpretation of “raw evidence” [32], p. 956, implying that this is possible, that it would yield a value-free view of breast screening, and would resolve disagreement. Others, including myself, contend that it is unrealistic and unhelpful to suggest that an expert’s personal values can be removed from decision making [19,21,33]. Evidence is vital in answering questions about breast screening policy and practice but evidence is not value-free. Values are inherent in the type of questions that are asked, the methods that are used to address those questions, the ways that results are interpreted and communicated, and the importance that is placed upon the conclusions [34]. Thus the collection and analysis of evidence is fundamentally driven by what is considered to be important, meaning that values, rather than “massed files of scientific evidence” [32], p. 310 lie at the heart of decision making.

Accepting that values are an integral part of evidence-informed policy making is an important first step; the next challenge is to think about how they might best be incorporated. Much of the literature that refers to values in the context of breast screening tends to concentrate on selected dominant interpretations of what is important, often discussing the pros and cons of two apparently competing ethical principles (rules that guide moral action, [35], p. 124), such as ‘maximising benefit’ or ‘supporting autonomy’, conceptualised in a particular way [36–40]. (Conceptualisation of values refers to the way that a particular ethical principle is interpreted: for example, conceptualisation of what it means to respect a woman’s autonomy in this context might include one or more of: unfettered access to breast screening on demand; strong encouragement to attend breast screening in order to maximise a woman’s knowledge about her breast anatomy and pathology; detailed information about screening benefits and harms [41].)

Such head-on comparisons leave little space for decision makers and others to reach an understanding of how and why others think the way they do, or recognise points of agreement. In addition, my previous empirical work mapping the broad range of values in use amongst those who influence breast screening policy and practice [41], suggests that these “either/or” kinds of values-based policy discussion are too narrowly focused for a complex topic such as breast screening, as they fail to recognise the plurality of ways to conceptualise and prioritise ethical principles and thus ignore a multitude of potentially relevant ethical considerations. (Combining a particular conceptualisation and prioritisation of values delivers a view about what is considered to be most important in breast screening: for example one individual might focus on delivering benefit, conceptualised as high breast screening participation rates, while another might be particularly concerned about avoiding harm, conceptualised as reducing participation amongst those less likely to benefit from mammographic screening.) The impact of these simplified forms of values-based discussions is likely to be success for those with the loudest or most influential voice rather than endorsement of what is most ethically correct, or to a stalemate position with experts unwilling to be persuaded of alternative points of view.

The rationale for this study was to facilitate values-based discussions amongst breast screening policy makers in a way that (1) would encourage decision makers to consider the broad range of relevant values and the wide variety of ways that values are conceptualised and prioritised, and (2) would enable committees to explain their decisions to the public using the language of values in order to facilitate transparency and accountability. Ultimately

Table 1
Decision-making tool explanation and instructions for use.

The decision-making tool consists of a tabled list of ethical principles that are relevant to breast screening policy and practice. Column One lists a range of conceptualisations for each principle. Subsidiary information in Columns Two and Three provide commentaries and questions for further research

- Instructions for use:*
- Look at the list of principles (maximising health benefits; minimising harms; delivering more benefits than harms; maintaining cost-efficiency; supporting autonomy; distributing benefits and harms justly; communicating honestly; making policy with a transparent process; upholding reciprocal obligations to the public; facilitating connections between community members). Add any other principles that are relevant to your particular breast screening context.
 - Read the list of conceptualisations for each principle (Column One). Discuss which one or more is used by each member of the group uses, and which are used by others, including consumers and citizens. Add any other relevant conceptualisations that are not provided.
 - Using the notes in Column Two as a guide, consider the strengths and weaknesses of each conceptualisation (e.g. what a given conceptualisation might miss; whether or not there are inconsistencies or inaccuracies in a given conceptualisation.) Discuss which conceptualisations the group wishes to endorse most strongly and why. If a widely held conceptualisation is held to be inadequate or problematic in some way, consider engaging in wider public debate and discussion about this.
 - Using the questions in Column Three as a guide, write a list of topics that require further research and/or discussion in order to determine the relevance and importance of each concept for the current breast screening context. Obtaining answers to these questions should assist the group in making ethically justified decisions about breast screening policy and practice.

this will deliver breast screening policies and practices that are more ethically sound and appropriate for the given context and population group. The specific objective was to develop a concrete tool to assist decision makers discuss and incorporate values into evidence-based decision making for breast screening policies and practices. The tool provided here is intended as a preliminary draft, to provide some guidance and to stimulate further conversation in this arena. While the tool development was informed by empirical work, it has not yet been formally tested and there is scope for ongoing research in this area.

2. Methods

The tool draws on existing frameworks that provide general guidance for ethical decision making in public health by listing the kinds of ethical principles that are likely to be relevant [30,42–44]. The ethical framework model was modified by expanding out relevant abstract ethical principles into concrete values, and including a wide range of conceptualisations of each value. This was informed by the results of prior empirical qualitative research involving long interviews with 33 influential Australian breast screening experts including consumers, clinicians, researchers and administrative personnel, which demonstrated the broad range of ways that values were conceptualised and prioritised amongst this group [41]. (Further detail on the methods for this empirical work are available in Supplementary Appendix A.) Commentary and questions about each value were drawn from extensive reading on the topic of ethics in breast cancer screening, undertaken as part of a larger project on cancer screening ethics in Australia (cancerscreeningethics.org).

3. Results

The study resulted in a tool to assist policy makers incorporate values into evidence-based breast screening decision making. (See Tables 1 and 2) The tool is an empirically informed framework of relevant values that enables and prompts a deep and rich discussion

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