

2015

## Values in breast cancer screening: an empirical study with Australian experts

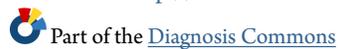
Lisa Parker

Lucie Rychetnik

University of Notre Dame Australia, lucie.rychetnik@nd.edu.au

Stacy Carter

Follow this and additional works at: [http://researchonline.nd.edu.au/med\\_article](http://researchonline.nd.edu.au/med_article)



This article was originally published as:

Parker, L., Rychetnik, L., & Carter, S. (2015). Values in breast cancer screening: an empirical study with Australian experts. *BMJ Open*, 5 (5:e006333).

<http://doi.org/10.1136/bmjopen-2014-006333>

This article is posted on ResearchOnline@ND at

[http://researchonline.nd.edu.au/med\\_article/685](http://researchonline.nd.edu.au/med_article/685). For more information, please contact [researchonline@nd.edu.au](mailto:researchonline@nd.edu.au).



# BMJ Open Values in breast cancer screening: an empirical study with Australian experts

Lisa Parker,<sup>1</sup> Lucie Rychetnik,<sup>2</sup> Stacy Carter<sup>1</sup>

**To cite:** Parker L, Rychetnik L, Carter S. Values in breast cancer screening: an empirical study with Australian experts. *BMJ Open* 2015;**5**:e006333. doi:10.1136/bmjopen-2014-006333

► Prepublication history and additional material is available. To view please visit the journal (<http://dx.doi.org/10.1136/bmjopen-2014-006333>).

Received 8 August 2014  
Revised 30 March 2015  
Accepted 29 April 2015



CrossMark

<sup>1</sup>Centre for Values, Ethics and the Law in Medicine (VELiM), Sydney School of Public Health, The University of Sydney, Sydney, New South Wales, Australia

<sup>2</sup>Auburn Clinical School, School of Medicine Sydney, The University of Notre Dame (Australia), Auburn, New South Wales, Australia

## Correspondence to

Dr Lisa Parker;  
[lisa.parker@sydney.edu.au](mailto:lisa.parker@sydney.edu.au)

## ABSTRACT

**Objective:** To explore what Australian experts value in breast screening, how these values are conceptualised and prioritised, and how they inform experts' reasoning and judgement about the Australian breast-screening programme.

**Design:** Qualitative study based on interviews with experts.

**Participants:** 33 experts, including clinicians, programme managers, policymakers, advocates and researchers selected for their recognisable influence in the Australian breast-screening setting.

**Setting:** Australian breast-screening policy, practice and research settings.

**Results:** Experts expressed 2 types of values: ethical values (about what was good, important or right) and epistemological values (about how evidence should be created and used). Ethical values included delivering benefit, avoiding harm, promoting autonomy, fairness, cost effectiveness, accountability, professionalism and transparency. Epistemological values informed experts' arguments about prioritising and evaluating evidence methodology, source population and professional interests. Some values were conceptualised differently by experts: for example, delivering benefit could mean reducing breast cancer mortality, reducing all-cause mortality, reducing mortality in younger women, reducing need for aggressive treatment, and/or reassuring women they were cancer free. When values came into conflict, experts prioritised them differently: for example, when experts perceived a conflict between delivering benefits and promoting autonomy, there were differences in which value was prioritised. We explain the complexity of the relationship between held values and experts' overall views on breast cancer screening.

**Conclusions:** Experts' positions in breast screening are influenced by evidence and a wide range of ethical and epistemological values. We conclude that discussions about values should be a regular part of breast-screening review in order to build understanding between those who hold different positions, and provide a mechanism for responding to these differences.

## INTRODUCTION

Mammographic breast screening was first performed in the mid-20th century and became

## Strengths and limitations of this study

- This is the first application of empirical ethics to breast-screening policy and practice outside of consumer studies.
- The study has a wide reach, using data from a broad selection of key players in breast screening and covering all important stakeholder groups across the country.
- The rich data set and detailed analysis provides a comprehensive picture of how values guide thinking and influence experts' opinions on mammographic screening.
- Experts in other jurisdictions, with different organisational structures and different societal values, may express different views. However, since the Australian programme shares much in terms of rationale, purpose and implementation with counterpart programmes in the UK and many European countries, it seems likely that our results will be at least partially transferable to these contexts.
- There may have been differences between experts who agreed to participate and those who did not. However, we purposely interviewed experts from a range of backgrounds and public opinions about breast cancer screening.

widespread in the 1980s. Public and professional debate about mammography screening began immediately,<sup>1–3</sup> and intensified after publication of controversial meta-analyses of breast screening randomised controlled trials that suggested lower benefits than originally calculated<sup>4–6</sup> and significant overdiagnosis.<sup>7–9</sup> (Throughout this paper, we use overdiagnosis to mean: diagnosis of non-progressive or slowly progressive breast cancer through screening, a diagnosis that does not produce a net benefit for the women diagnosed. We use the term overtreatment to mean the treatment of overdiagnosed cancers, treatment which is, by definition, unnecessary<sup>10–12</sup>). It was widely hoped<sup>13</sup> that the recently updated review of the evidence by Marmot *et al*<sup>14</sup> would put an end to the controversy, but disagreements between experts about breast screening persist, particularly around the amount of benefit and the risk of overdiagnosis.<sup>15</sup> Such disagreements can be a challenge

for policy and practice, particularly if they persist and seem intractable. Relatively little is known about how breast screening experts develop different interpretations of the evidence on the benefits and harms of breast cancer screening. There have been a number of suggestions. Some attribute the differences to variable epidemiological understanding of potential biases.<sup>12 16 17</sup> Others acknowledge the possible effect of professional bias or vested interests,<sup>6 12 17–19</sup> or differing historically based assumptions about the biology or inevitability of cancer growth.<sup>20</sup> While these are all potentially relevant, it is likely that there are also deeper differences underlying the variation in experts' positions: that is, these experts may have different ideas about what is important and what matters with regard to breast screening<sup>21 22</sup> and/or the evaluation of evidence.<sup>6</sup> Well-meaning, thoughtful and epidemiologically competent experts may hold a range of views and ideas about breast cancer screening owing to differences in how they prioritise certain values or principles.

Values are integral to public health programme planning and are emphasised in the aims of many national breast-screening programmes including those of the UK,<sup>23</sup> Australia<sup>24</sup> and many European countries,<sup>25</sup> which refer to concepts such as delivering benefit, avoiding harm, accountability and recently, transparency and respect for autonomy. Many authors also see values as being important in the creation and interpretation of evidence.<sup>26 27</sup> Our commitment to different values may be expressed overtly, via debates and discussions about these values; but debates around such issues are rare in the literature on breast screening. This sidesteps important conversations about what is important and gives limited acknowledgement to the role of these values in determining breast-screening policy and practice decisions.

The idea that values are important in healthcare is not new. There has been considerable interest in paying attention to: patients' values in clinical practice<sup>28</sup> and health technology assessment;<sup>29–31</sup> citizens' values in healthcare policy;<sup>32 33</sup> and health practitioners' values in clinical practice.<sup>34 35</sup> This way of looking at healthcare not only assumes the importance of values in healthcare,<sup>36</sup> but also accepts a plurality of values among different stakeholders, and emphasises the need to explore and work through values' differences during healthcare decision-making.<sup>35</sup> With these ideas in mind, we aimed to investigate experts' values in breast screening, with a view to identifying new means by which persistent disagreements in this field might be understood or mitigated.

This study is part of a larger Australian National Health and Medical Research Council-funded project examining ethics and evidence in cancer screening. In this paper, we report on one component of a substudy focused on ethics and evidence in screening for breast cancer. Our aim in this paper is to empirically examine the values or principles that Australian experts employ when evaluating the Australian breast cancer screening programme.<sup>37</sup> We reasoned that by developing a clearer

understanding of the values employed by these experts, we could move towards a better understanding of the debate about this changing and sometimes difficult topic. We focused on experts because (1) they are well-informed relative to the general population of citizens, policymakers or researchers; (2) disagreement between experts has been a central feature of breast screening, so mapping experts' values should assist in understanding this disagreement and (3) these experts have influenced breast-screening policy and practice, both directly through decision-making bodies, and indirectly by influencing consumer groups and other policymakers.

Our research questions were:

- ▶ What are the values expressed in the talk of Australian experts about breast screening in Australia?
- ▶ What are the implications for policy and practice of experts holding particular values?

## METHOD

### Methodology

This study employed a qualitative methodology, with sampling, data collection and analysis strategies designed to best answer our research questions.<sup>38</sup> We used open qualitative methods because there was little pre-existing knowledge about the topic and because we sought to access the values of participants on their own terms. We were motivated by our commitment to empirical bioethics, in particular to the view that practice and theory must exist in a symbiotic relationship, where each has the potential to alter the other.<sup>39 40</sup> We undertook this study in that spirit, expecting that existing ethical theory would inform our analysis, but also that our data and analysis could make a useful contribution to ethical theorising in the area of breast screening. We have considerable experience and knowledge of grounded theory methodology, which informed our study design,<sup>41 42</sup> but this was not strictly a 'grounded theory study'.<sup>43 44</sup>

### Participants and sampling

We selected participants from the population of 'influential experts', individuals who had engaged in frequent media commentary, publications, senior administration or management, advice to government or professional committees, or senior advocacy on breast screening. We sampled purposively for maximum variation<sup>45</sup> of ideas, deliberately inviting participants with strongly divergent opinions (table 1). We also reasoned that perspectives may be associated with professional responsibilities and experiences, so contacted participants with a range of professional roles.

We identified potential interviewees by scanning academic and popular media publications on breast screening, and personnel lists on websites of organisations involved in breast screening. We also followed up on suggestions from colleagues and previously interviewed experts. As experts, all participants were able to be contacted via information in the public domain.

**Table 1** Characteristics of experts**Participants 33 (brackets contain number of experts who were invited but did not participate; 13)**

Professional role*	
Clinicians† 15 (3)	Oncologists 3 (1) Surgeons 4 (0) Breast physicians 1 (2) Radiologists 2 (0) Radiation oncologists 2 (0) Pathologists 3 (0) Not otherwise specified 0 (1)
Non-clinical researchers 14 (3)	Epidemiologists/biostatisticians 9 (1) Not otherwise specified [NOS] 5 (1)
Administrators/managers	Administrators/ managers 6 (2)
Advocacy leaders 6 (7)	Consumers working in advocacy 3 (6) Clinicians/researchers working in advocacy 3 (1)
Public stance on breast screening‡	
Supportive 16 (9)	
Mostly supportive§ 3 (1)	
Critical 6 (0)	
Unknown to researchers 8 (3)	

\*Note that some experts held more than one professional role.

†Most clinicians engaged in research to a greater or lesser extent.

‡We loosely categorised potential interviewees as being 'supportive', 'mostly supportive' or 'critical' about breast screening based on publicly available commentary.

§Broadly supportive of breast screening but with selected concerns about one or more elements of the programme.

We approached 46 experts via email, and interviewed 33 (17 male and 16 female). Thirteen people either refused (3), or were unable to participate (1), or did not respond to emails (9). We had a particularly low response rate from volunteers who were on public record as holding senior roles in consumer advocacy organisations. This may have been due to a higher turnover of people in these positions than in other professional roles: they may no longer have been working as advocates when we sent our email. Our sampling evolved as analysis progressed, ensuring that we had enough representation of positions and roles to give us confidence in our findings.<sup>41</sup> We continued to sample until we reached thematic saturation.<sup>38</sup>

### Data collection

LP conducted semistructured interviews face to face in the expert's or LP's workplace, or by telephone, if unavailable to meet in person, from October 2012 to October 2013. Interviews lasted 39–105 min (average 66 min). In keeping with reports from the literature, we found that face-to-face and telephone interviews were of comparable quality and length.<sup>46</sup> Utilising telephone interviews enabled us to interview experts across the country.

Interviews were designed to elicit experts' views and opinions on breast screening in Australia. LP described her interest in the topic as a medical practitioner undertaking doctoral studies in cancer-screening ethics. She noted aloud that there was an obvious range of opinions among experts despite, and often about, the large evidence base, and suggested that she was interested in exploring this further. The aim of the interviews was to ensure that participants could speak freely without

experiencing any judgement regarding their views. We did not ask direct questions about abstract values or principles, instead we asked about interviewees' experience of the breast-screening programme and their views on what was good or bad and why (see online supplementary appendix). Interviews were digitally recorded, transcribed by a professional service, and de-identified.

### Analysis

Analysis focused on developing a set of categories that captured the most important values in experts' talk. Our goal was not to develop a theory, but to identify mid-range ethical concepts being used by participants, and understand what those concepts meant in use. Interviews were read repeatedly and coded in detail to capture values-in-use. From codes, more abstract categories were developed; these evolved iteratively as the data collection and analysis progressed. LP wrote analytic memos throughout, and shared these with other authors for discussion. Coding, categorisation and memo writing were closely informed by Charmaz's iteration of the constant comparative method.<sup>41</sup>

All participants gave individual written or verbal consent, were assured of confidentiality, and were free to withdraw from the study at any stage.

## RESULTS

### Experts disagreed as to whether, or to what degree, values influenced their thinking

Although all experts discussed value-laden concepts in relation to breast screening, they varied in how much

they considered values to be important in shaping their opinions. Many experts suggested that values influenced their thinking, volunteering that “ideology” (#15 epidemiologist), “values” (#17 researcher, not otherwise specified (NOS)) or “judgements” (#13 consumer advocate), as well as evidence, influenced how they and others formed opinions about breast screening. Others denied the influence of values, contrasting value-based reasoning (characterised by use of “intuition, judgement, political trickery, [and attending to] those with the loudest voice” (#29 epidemiologist) against scientific reasoning (in which, ‘the figures cannot lie’ #21 epidemiologist). For these experts, using values meant being biased or unscientific, and as such, should be avoided: “I’m a scientist, I look at the available evidence and I try and evaluate that impartially” (#9 oncologist).

A single expert presented a unique argument against using values when reasoning about breast screening. Using values, they argued, required deep, philosophical reflection. They saw themselves as a person of action rather than reflection, which meant values thinking was

not relevant to them. This view suggested that values thinking was only for philosophers or academics, not for practitioners, and implied that practitioners could maintain a value-free position.

### Experts invoked ethical and epistemological values in their talk

At the most abstract level, experts’ value-talk about breast screening could be categorised into two main groups: ethical and epistemological (table 2). Ethical values related to ideas about the right thing to do:

There [is] disagreement amongst experts about what we should do. Even if you had a room full of people agreeing on the evidence, you would still get different ideas about screening. I think it’s values ... that is responsible for those differences. (#17 researcher NOS)

Epistemological values related to preferred sources of knowledge, including the nature of evidence-based reasoning:

**Table 2** Experts’ views on values that are important in breast cancer screening

Ethical values	The range of meanings-in-use of this value* ( <i>common conceptions of values are in italics</i> )
Delivering benefits†	Breast cancer-related benefits (mortality: <i>reducing population breast cancer mortality</i> ; reducing breast cancer mortality in non-elderly women. Morbidity: <i>enabling less aggressive treatments; providing reassurance; reducing population burden of disease—incidence of total/advanced breast cancer</i> ) Non-breast cancer-related benefits (reducing all-cause mortality; improving health for communities with the poorest health outcomes)
Avoiding harms†	<i>Low overdiagnosis rate; low false positive rate; minimal overtreatment</i> ; minimal pain and inconvenience; low false negative rate (false reassurance)
Respecting autonomy†	<i>Providing information; facilitating informed choice</i> ; providing screening to women in the target age range; providing screening upon request for older women beyond the target age; maximising breast screening participation so that women will have the knowledge to make decisions about their future
Equity	<i>Providing equal access to breast screening</i> ; contributing to equal health outcomes for all
Economic efficiency	Cost effective relative to other health interventions; minimising inefficiencies
Accountability	Regular audit and evaluation
Professionalism	Performing well at required tasks of job; providing individualised and patient-centred care to consumers
Fair process for policy decision-making	<i>Including all stakeholders</i> ; excluding those with possible vested interests; asking public opinion on worthiness of breast screening; asking public opinion about breast-screening policy if the scientific evidence is uncertain
Transparency	Ensuring that underlying values that guide breast-screening policy are clear to consumers
Epistemological values	The range of meanings-in-use of this value
Evidence-based knowledge†	Randomised controlled trial evidence; all relevant scientific studies; scientific studies that have been rigorously analysed for bias; preference for local and recent service studies; must include evidence about harms; avoiding modelling studies; including modelling studies; evidence as evaluated by expert methodologists; evidence as evaluated by impartial scientists without vested interests; including studies of ‘uninformed’ consumer opinions; excluding studies of ‘uninformed’ consumer opinions
Other knowledge sources	Clinical experience; logical reasoning; personal stories; government endorsement; include those with extreme opinions; assume truth is in the middle

\*Some experts may use more than one meaning simultaneously.

†Most commonly discussed values.

What ... people do with the same evidence and the same statistics is, in the main part, ideologically driven...I don't think that anything is value-free—[that] any scientific statement is particularly value-free. (#15 epidemiologist)

As shown in [table 2](#), the range of ethical values discussed by experts related to familiar concepts from the literature, including the influential Four Principles<sup>47</sup> of clinical medicine (delivering benefit, avoiding harm, respecting autonomy, supporting justice), as well as principles more commonly endorsed in public health practice or public health ethics (economic efficiency, accountability and fair and/or transparent decision-making processes). Experts also valued professionalism.

A range of epistemological values was also expressed ([table 2](#)), with experts describing ways of thinking about knowledge, including views on constructing or reviewing the scientific evidence base and uses of non-evidence-based knowledge.<sup>48</sup>

### Experts had different interpretations of value-related concepts

Although experts' value talk reflected familiar ethical and epistemological concerns, our central finding is this: there was substantial variation in the way experts conceived of each value. This is consistent with the literature, which acknowledges and discusses such distinctions and complexities.<sup>35</sup> The range of ways that experts conceive of each value is shown in [table 2](#). The most commonly discussed values were also the most variably constructed: we discuss this in detail below.

#### Delivering benefits

Experts' conceptions of delivering benefit in breast screening fell into two main categories: breast cancer-specific and non-breast cancer-specific outcomes. All experts talked about breast cancer-specific benefits, including reduced population breast cancer mortality and morbidity. Morbidity was mostly discussed in terms of enabling less aggressive treatment and reducing population breast cancer burden. Two experts (both consumer advocates) also included breast cancer-related reassurance:

Some of that benefit might be just peace of mind, the fact that you don't, as far as they can tell, have breast cancer. (#24 consumer advocate)

Most experts suggested that breast screening delivered modest to substantial population mortality benefits. Many also saw the breast cancer morbidity benefits of screening as substantial, but others saw them as being absent. Participants' conception of morbidity appeared to inform their perception of the presence or absence of this benefit. When participants said, 'screening offers morbidity benefits' they usually meant 'screening reduces the treatment needed, or provides reassurance'. When participants said, 'screening does not offer morbidity benefit' they usually meant, 'screening does not decrease

the burden of breast cancer illness in populations' (generally because of the impact of overdiagnosis).

A small group of experts argued that breast screening did not deliver benefits. When they argued this, they used a broader, non-breast cancer-specific concept of benefits, and meant either that screening did not reduce all-cause mortality, or that screening did not assist the communities with the poorest health outcomes. These experts were concerned that the high cost and attention paid to breast screening meant that other, possibly more worthy, public health programmes were not implemented, meaning that the important public health benefit of improving health outcomes for the most needy was not realised.

#### Avoiding harms

Experts' described (avoiding) harm in a variety of ways ([table 2](#)), with two main patterns and a third minor pattern emerging. One group of experts, comprised mostly of researchers, conceived of harm as being mainly about overdiagnosis. A second group, mostly clinicians, saw significant harms in false-positive diagnoses and/or overtreatment. Not all researchers or clinicians expressed a clear conception of harm, and of those that did, not all described it along these lines. However, these two major patterns were associated with particular professional roles, suggesting some influence of availability bias.<sup>49</sup> Researchers whose work involved calculating overdiagnosis in populations tended to conceptualise harm as overdiagnosis. By contrast, clinicians working with identifiable patients receiving false-positive results and negotiating between appropriate treatment and overtreatment, tended to see harm in these terms. A third, less widely expressed view about harms concentrated on women's experience of the screening process. This view was held by all three consumer advocates and one researcher, who described harm in terms of minor physical discomfort and inconvenience, and denied that overdiagnosis or false positives caused harm:

Women aren't being harmed by breast screening and society isn't being harmed by breast screening. It's ... a little mindset that has developed. (#13 consumer advocate)

As with benefits, we saw correlations between experts' concepts of harm and ideas about levels of harm. Those who viewed harm as overdiagnosis perceived harms as more extensive than those who viewed harm as false positives, overtreatment, or unpleasant experiences.

#### Respecting autonomy

Experts expressed differing versions of what respecting autonomy means in breast screening. The dominant view was that respecting autonomy is about providing comprehensive information to women who are offered breast screening. A less common view, described by a smaller number of experts, including all three consumer

advocates, placed respecting autonomy as being about the provision and promotion of breast screening, as this enabled women to “find out whether you have [a cancer] or not” (#24 consumer advocate) early enough to enable less aggressive treatments. For these experts, information was less central to autonomy than the option/encouragement to screen. They advocated limiting information in order to avoid scaring women away.

### Epistemological values

Most experts viewed the scientific evidence as the most important source of knowledge about breast cancer screening. There was a wide spread of ideas, however, about what constitutes ‘good’ scientific evidence (table 2), and this spread was evident across the subgroup of epidemiologists and biostatisticians. For example, some epidemiologists said it was important to consider all studies, others preferred only top-quality studies, some prioritised recent, local service studies, and there were differing opinions about mathematical models. Several experts emphasised their own studies when discussing examples of evidence that they used and trusted.

A smaller number of experts described their lack of understanding of the scientific evidence on breast screening. Some explained that they still viewed this evidence as important and relied on the interpretation of trusted colleagues or opinion leaders. Others, including two who openly stated that they did not trust the scientific evidence, described additional or different sources of knowledge (table 2) including: “intuitive interpretation based on what has changed in breast screening over 30 years ... [and] common sense” (#23 surgeon). We did not find a clear pattern linking experts’ epistemological values and their overall opinion about breast screening, and could not predict, from expressed epistemological values, whether experts would be supportive or critical of breast screening.

### Experts’ awareness about different interpretations

Some experts were aware of variations in how values were conceived, occasionally referring to an alternative conception to their own, mainly in order to reject it. Discussion of such differences was not common, however, most experts expressed values implicitly rather than explicitly, and did not explore alternative meanings of the values they were using. This opens the possibility that experts may sometimes be speaking at cross-purposes about what is important in breast screening, despite using similar terminology.

### Conflicting values

Many experts described a perceived conflict between one or more values in the breast-screening context. They saw certain values as being in tension with each other, such that respecting one value would necessarily entail sacrificing the other. Most experts who discussed conflicting values described tensions between respecting autonomy and delivering benefit. These experts equated respecting

autonomy with providing information, and felt that providing information to consumers might reduce participation rates and, therefore, lower breast cancer mortality and morbidity benefits of screening. Some experts simply described a spectrum of positions that one could take regarding these conflicting values, such as ‘the continuum between individual autonomy and public health’ (#17 researcher NOS). Others openly favoured one value over another, with implications for practice. Those who prioritised delivering benefits, for example, preferred to limit breast-screening information in order to avoid frightening women away. Those who prioritised autonomy were in favour of providing more comprehensive information and encouraging informed choice.

A smaller number of experts discussed conflicting values in terms of avoiding harms and delivering benefits. Their view about the relative importance of these two values had practical implications for whether or not they supported breast screening: those who prioritised avoiding harm were less likely to support screening than those who prioritised delivering benefits. Experts’ conceptions of harm were also important, however, and box 1 describes several examples of ways in which the combination of experts’ conception and prioritisation of ‘avoiding harm’ might affect their level of support for breast screening.

As reported, experts rarely discussed alternative conceptions of a particular value different to their own. By contrast, experts frequently referred to alternative ways other experts might *prioritise* values. Several experts agreed that an important step towards resolving conflict in breast screening was to seek consensus on which values to prioritise.

## DISCUSSION

We have shown that experts’ positions in breast screening are influenced by more than just the evidence<sup>50</sup>; they are also influenced by a wide range of ethical and epistemological values. We have demonstrated considerable variation in how experts conceive of individual values, and how they prioritise certain values over others. These differences, together with a lack of knowledge about how one might, or whether one should, engage in explicit values-based discussions, suggests a vast potential for fundamental disagreement about screening policies and programmes.

Disagreements in breast screening have persisted despite multiple meta-analyses of the breast-screening evidence, including the recent Independent Review led by Marmot.<sup>14</sup> This review made a vital contribution, providing a highly regarded consensus on quantification of mortality reduction and overdiagnosis. Its publication was, however, immediately followed by disputes about both the conclusions and their implications for policy and practice.<sup>15</sup> We noted earlier that differences of opinion of this sort are often attributed to the correctness or incorrectness of evidence interpretations,<sup>12 16 17</sup>

### Box 1 Conception of values and prioritisation of values influences experts' opinions on breast screening

The following three case study examples from the data illustrate how experts' conception and prioritisation of 'avoiding harm' can influence their opinions on breast screening.

*Expert A* (#21 epidemiologist) saw breast-screening harm in terms of overdiagnosis and considered these harms to be substantial. This expert saw both avoiding harms and delivering benefits as being important, but because harms were, in their view, so large, was not supportive of the breast-screening programme.

*Expert B* (#10 epidemiologist) saw breast-screening harms as being limited to those inconveniences that women experienced as a result of attending screening services: thus, they were seen as very minor. Thus, although this expert believed strongly that avoiding harms should take priority over delivering benefits in the context of public health programmes in general, the harms from breast screening were, in their view, so negligible they were strongly supportive of breast screening.

*Expert C* (#9 oncologist) saw breast-screening harm in terms of overdiagnosis. This expert was uncertain as to the level of overdiagnosis harm: "you don't know how much to worry about that" but assumed it was, "probably lower than in some of the other screening programs." They thought delivering benefits should take priority over avoiding harms: "[Some] professionals may put a higher weight and value on 'first do no harm'. It's a point of view. It's not my point of view." Their overall opinion was, like Expert B but via a very different route, highly supportive of breast screening.

but our findings suggest that evidence interpretations may also be related to variations in epistemological values. Other authors attribute disagreements to vested interests.<sup>6 12 17–19</sup> Although we did not explore experts' financial or commercial interests in this study, many participants had direct clinical and/or research interests in breast screening. Their familiarity with and trust in their own work may have led them to ignore or discount evidence that presented an alternative view. More significantly, our study suggests another, potentially more subtle set of reasons to explain differing opinions: experts may hold quite different values, or different versions of the same values. Even epidemiologically competent and non-conflicted experts may disagree about breast cancer screening because of deep value commitments. They may be working from very different understandings of what is good or bad about breast screening, what its goals should be, and what matters.

### Strengths and limitations

The strengths of this study are its empirical nature and the completeness of its reach. This is, to the best of our knowledge, the first empirical ethics study with breast-screening policymakers and practitioners. We were able to interview a wide selection of key players in breast screening in Australia, and so could provide a comprehensive picture of experts' values and reasoning. Possible limitations include the focus on Australia, as experts from

other jurisdictions may hold different values. However, since the Australian programme shares much in terms of rationale, purpose and implementation with counterpart programmes in the UK and many European countries, it seems likely that our results will be at least partially transferable. Note, that we were not seeking to demonstrate the prevalence of particular values (which would require a survey in a population-based sample), rather, we aimed to capture the range and variety of values. By continuing our sampling and analysis until we reached thematic saturation we are confident that we have achieved this aim.<sup>38</sup> Finally, it is possible that experts who agreed to take part were somehow different from those who did not, however, we sought to minimise such potential bias by ensuring that we interviewed experts from a range of backgrounds and professed opinions about screening.

### Implications for practice, policy and research

Our findings have strong implications for practice and policy, as both the way experts conceive of values, and the types of values they prioritise, directly influence the positions they take regarding breast screening. The current situation where values are rarely explicitly considered or discussed is not ideal. We do not presume that all experts should adhere to one set of 'correct' public health values, or even that such a thing exists. Rather we argue for a closer, more explicit examination of the values underpinning breast-screening service provision and policy by individual experts, in expert decision-making bodies, and in the public domain.<sup>51 52</sup> Our findings highlight several issues suitable for specific examination by breast-screening decision-makers, the public and researchers (box 2).

If stakeholders are able to be more transparent about values, this may enable people with seemingly divergent positions to recognise points of agreement, or at least improve their understanding of why others think the way they do, helping to build bridges between opposing viewpoints. It should also assist with the justification of breast-screening policy, and wider debate about concordance or discordance between the values of influential experts and the considered judgements of the community.<sup>39 53</sup> Empirical investigation of citizens' values regarding breast screening was beyond the scope of this project, but is an important issue for future research. Broad engagement regarding what is important to experts and citizens (eg, by using a citizen's jury model<sup>32</sup>) could support the development of an explicit framework of values to guide future decision-making on breast screening.<sup>54</sup> This would not be straightforward: the plurality and apparent incommensurability of values in communities is well recognised, such that it may be best not to expect or force a consensus, but rather to focus on the fairness of the decision-making process.<sup>55</sup> Regardless, Weed<sup>56</sup> reminds us that more engagement with and knowledge about ethics and values has a tendency to lead to more ethically appropriate decisions, and that this is a worthy aim in provision of healthcare and public health services.

## Box 2 Examples of value-related topics that warrant further research and public debate

- ▶ *Plurality of experience influencing values:* Our study suggested a likely impact of availability bias on some experts' conceptions of values. Experts are likely to understand concepts such as harm, benefit and autonomy differently depending on what they encounter day to day (eg, population-level data, or individual women experiencing disease or the consequences of screening). We suggest that conversations and attempted definitions about values in breast screening should endeavour to include a plurality of professional roles and experiences in order to cover the likely range of conceptions of relevant values.
- ▶ *Focus of population health programmes:* Some participants in our study concentrated on the impact of breast screening on all-cause mortality or on the health of vulnerable populations, expressing concern that, in their view, breast screening had minimal impact on these, and that the programme was associated with substantial opportunity costs. This raises questions about the aim or focus of population health programmes, and indicates that there may be differences between people's opinions about exactly where that focus should lie. It would be useful to elucidate the range of relevant values on this issue.
- ▶ *Breast cancer consumers' view of screening:* Consumer advocates in this study presented a very particular view of breast screening. They emphasised morbidity benefits including reassurance; tended to suggest that harms were minimal; and argued that the best way to respect women's autonomy was to provide them with, and promote, screening services, as this allowed them to access information about their personal breast cancer risk. It seems possible that these ways of thinking about screening may risk generating 'too much medicine'<sup>10</sup> for women. We were only able to interview three consumer advocates, and as such our findings may not be indicative of the entire range of opinion in the breast cancer consumer movement. However, the experts that we spoke to were in senior consumer advocacy roles, and expressed remarkably consistent positions on each of these three important values. Further research is needed to explore the range of values held by consumer advocates. If our findings are transferable to breast cancer consumer advocacy more generally, it seems possible that these values may promote and protect screening activity, but provide little avenue for adjustment or improvement in line with new evidence and technologies.
- ▶ *Professional ethics education:* Opportunities to participate in training in thinking explicitly about ethics and values may assist experts in the difficult task of decision-making.<sup>51</sup> Thinking and talking about values is not easy, not least because—as we have shown—the same terminology can be used to communicate very different meanings. Explicit training has the potential to increase the robustness and contextualisation of reasoning about breast screening, both by individuals and in decision-making bodies.<sup>39 53</sup>

Engagement with values in breast screening—or any other area of health intervention—cannot be a once-only activity, as values change over time in expert and lay communities. For example, since organised breast screening began, consumer leaflets have become increasingly detailed and information rich, reflecting the generally increasing value given to promoting the autonomy of healthcare consumers.<sup>57</sup> Changes in epistemological

values have also occurred, including the introduction of evidence-based medicine,<sup>58</sup> changed thinking about study quality,<sup>59</sup> and the growing attention to impartial reviews by independent experts.<sup>13 14</sup> Growing evidence about overdiagnosis has changed the way we think about and prioritise the value of avoiding harm. Research about values, and processes to incorporate values in policy setting and decision-making, will need to evolve and continue to reflect this ongoing change. Debates around ethical and epistemological values should sit alongside the regular discussions of evidence, as part of ongoing processes for planning the future of breast screening.

**Contributors** LP initiated and performed the study, and prepared the first and subsequent drafts of the paper. LR and SC assisted with study planning and data analysis, trained and supported LP in data collection and analysis methods, and made substantial contributions to draft revisions throughout. LP is the guarantor.

**Funding** The study was funded by the Australian National Health and Medical Research Council (project grant 1023197). LP is supported by a National Health and Medical Research Council PhD scholarship (1038517). SC is supported by a National Health and Medical Research Council Career Development Fellowship (1032963).

**Competing interests** None declared.

**Ethics approval** Cancer Institute NSW Population & Health Services Research Ethics Committee (HREC/12/CIPHS/46) and the University of Sydney Human Research Ethics Committee (#15245).

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data sharing statement** No additional data are available.

**Open Access** This is an Open Access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>

## REFERENCES

1. Warren R. The debate over mass mammography in Britain. The case for. *BMJ* 1988;297:969–70.
2. Skrabanek P. The debate over mass mammography in Britain. The case against. *BMJ* 1988;297:971–2.
3. Roberts MM. Breast screening: time for a rethink? *BMJ* 1989;299:1153–5.
4. Gotzsche PC, Olsen O. Is screening for breast cancer with mammography justifiable? *Lancet* 2000;355:129–34.
5. Jackson VP. Screening mammography: controversies and headlines. *Radiology* 2002;225:323–6.
6. Quanstrum K, Hayward R. Lessons from the mammography wars. *N Engl J Med* 2010;363:1076–7.
7. Jorgensen KJ, Gotzsche PC. Overdiagnosis in publicly organised mammography screening programmes: systematic review of incidence trends. *BMJ* 2009;339:b2587.
8. McPherson K. Screening for breast cancer: balancing the debate. *BMJ* 2010;340:233–5.
9. Bewley S. The NHS breast screening programme needs independent review. *BMJ* 2011;343:d6894.
10. Carter SM, Rogers W, Heath I, et al. The challenge of overdiagnosis begins with its definition. *BMJ* 2015;350:h869.
11. Welch G, Schwartz LM, Woloshin S. *Overdiagnosed. Making people sick in the pursuit of health*. Boston: Beacon Press, 2011.
12. Plutynski A. Ethical issues in cancer screening and prevention. *J Med Philos* 2012;37:310–23.
13. Richards M. An independent review is under way. *BMJ* 2011;343:d6843.
14. Independent UK Panel on Breast Cancer Screening. The benefits and harms of breast cancer screening: an independent review. *Lancet* 2012;380:1778–86.

15. Donzelli A. The benefits and harms of breast cancer screening. *Lancet* 2013;381:799–800.
16. Kopans DB. Why the critics of screening mammography are wrong. *Diagn Imaging* 2009;31:18–24.
17. Gotzsche PC. *Mammography screening: truth, lies and controversy*. London: Radcliffe Publishing, 2012:43.
18. Norris SL, Burda BU, Holmer HK, *et al*. Author's specialty and conflicts of interest contribute to conflicting guidelines for screening mammography. *J Clin Epidemiol* 2012;65:725–33.
19. Guyatt G, Akl EA, Hirsh J, *et al*. The vexing problem of guidelines and conflict of interest: a potential solution. *Ann Intern Med* 2010;152:738–41.
20. Aronowitz RA. Do not delay: breast cancer and time, 1900–1970. *Milbank Q* 2001;79:355–86.
21. Weed DL, McKeown RE. Science, ethics, and professional public health practice. *J Epidemiol Community Health* 2003;57:4–5.
22. Weed DL. Precaution, prevention, and public health ethics. *J Med Philos* 2004;29:313–32.
23. Department of Health Breast Screening Programme. *Public health functions to be exercised by NHS England: service specification no 24*. England: NHS, 2013.
24. BreastScreen Australia. *Aims and objectives of BreastScreen Australia*. Canberra: Australian Government Department of Health, 2013.
25. Perry N, Broeders M, de Wolf C, *et al*. *European guidelines for quality assurance in breast cancer screening and diagnosis*. 4th edn. Luxembourg: European Commission, 2006.
26. Greenhalgh T, Howick J, Maskrey N. Evidence based medicine: a movement in crisis? *BMJ* 2014;348:g3725.
27. Kahan D. Fixing the communications failure. *Nature* 2010;463:296–7.
28. Entwistle V, Firmigl D, Ryan M, *et al*. Which experiences of health care delivery matter to service users and why? A critical interpretive synthesis and conceptual map. *J Health Serv Res Policy* 2012;17:70–8.
29. European network for health technology assessment (eunetha). HTA core model for screening technologies. 2012. [https://eunetha.fedimbo.belgium.be/sites/5026.fedimbo.belgium.be/files/HTACoreModelForScreeningTechnologies1%200Final\\_0.pdf](https://eunetha.fedimbo.belgium.be/sites/5026.fedimbo.belgium.be/files/HTACoreModelForScreeningTechnologies1%200Final_0.pdf)
30. Hofmann B. On value-judgements and ethics in health technology assessment. *Poiesis Praxis* 2005;3:277–95.
31. Williams JH, Carter SM, Rychetnik L. Information provision in cervical screening in Australia. *Med J Aust* 2014;201:295–7.
32. National Institute for Health and Clinical Excellence (NICE). Citizens council report 2014—Societal values in trade-offs between equity and efficiency. <https://www.nice.org.uk/get-involved/citizens-council/citizens-council-report-2014>
33. Muir Gray JA. Evidence based policy making. *BMJ* 2004;329:988–9.
34. Little M, Gordon J, Markham P, *et al*. Virtuous acts as practical medical ethics: an empirical study. *J Eval Clin Pract* 2011;17:948–53.
35. Fulford KW. The value of evidence and evidence of values: bringing together values-based and evidence-based practice in policy and service development in mental health. *J Eval Clin Pract* 2011;17:976–87.
36. Little M, Lipworth W, Gordon J, *et al*. Values-based medicine and modest foundationalism. *J Eval Clin Pract* 2012;18:1020–6.
37. BreastScreen Australia. *BreastScreen Australia national policy*. Canberra: Australian Government Department of Health, 2013.
38. Mason J. *Qualitative researching*. 2nd edn. London: SAGE Publications, 2002.
39. Frith L. Symbiotic empirical ethics: a practical methodology. *Bioethics* 2012;26:198–206.
40. Carter SM. Beware dichotomies and grand abstractions: attending to particularity and practice in empirical bioethics. *Am J Bioethics* 2009;9:76–7.
41. Charmaz K. *Constructing grounded theory: a practical guide through qualitative analysis*. London: SAGE Publications, 2006.
42. Sbaraini A, Carter S, Evans RW, *et al*. How to do a grounded theory study: a worked example of a study of dental practices. *BMC Med Res Methodol* 2011;11:128.
43. Carter SM. Enacting internal coherence as a path to quality in qualitative inquiry. In: Higgs J, Cherry N, Macklin R, *et al*. eds. *Researching practice: a discourse on qualitative methodologies, vol 2 practice, education, work and society series*. Rotterdam: Sense Publishers, 2010:143–52.
44. Carter SM, Little M. Justifying knowledge, justifying method, taking action: epistemologies, methodologies and methods in qualitative research. *Qual Health Res* 2007;17:1316–28.
45. Miles MB, Huberman AM. *Qualitative data analysis*. 2nd edn. SAGE Publications, 1994:27–33.
46. Sturges J, Hanrahan K. Comparing telephone and face-to-face qualitative interviewing: a research note. *Qual Res* 2004;4:107–18.
47. Beauchamp T, Childress J. *Principles of biomedical ethics*. 7th edn. Oxford University Press, 2012.
48. Tonelli MR. Integrating evidence into clinical practice: an alternative to evidence-based approaches. *J Eval Clin Pract* 2006;12:248–56.
49. Tversky A, Kahneman D. Judgment under uncertainty: heuristics and biases. *Science* 1974;185:1124–31.
50. Barratt A, Irwig L, Glasziou P, *et al*. Users' guides to the medical literature—XVII. How to use guidelines and recommendations about screening. *JAMA* 1999;281:2029–34.
51. Fulford KWM. Ten principles of values-based medicine. In: Radden J. ed. *The philosophy of psychiatry: a companion*. New York: Oxford University Press, 2004:205–34.
52. Petrova M, Dale J, Fulford BK. Values-based practice in primary care: easing the tensions between individual values, ethical principles and best evidence. *Brit J Gen Pract* 2006;56:703–9.
53. Rychetnik L, Carter SM, Barratt A, *et al*. Expanding the evidence on cancer screening: the value of scientific, social and ethical perspectives. *Med J Aust* 2013;198:536–9.
54. Lee LM. Public health ethics theory: review and path to convergence. *J Law Med Ethics* 2012;40:85–98.
55. Daniels N, Sabin JE. *Setting limits fairly: learning to share resources for health*. 2nd edn. Oxford: Oxford University Press, 2008.
56. Weed DL. Towards a philosophy of public health. *J Epidemiol Community Health* 1999;53:99–104.
57. Informed choice about cancer screening. *NHS breast screening: helping you decide*. London: NHS, 2013.
58. Sackett DL, Rosenberg WM, Gray JA, *et al*. Evidence based medicine: what it is and what it isn't. *BMJ* 1996;312:71–2.
59. Guyatt GH, Oxman AD, Vist GE, *et al*. GRADE: an emerging consensus on rating quality of evidence and strength of recommendations. *BMJ* 2008;336:924–6.