

## ETHICAL ASPECTS OF CANCER SCREENING

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### Abstract

Screening for cancer or cancer risk is well-established in high-income countries. This article considers ethical aspects of cancer screening. Ethical evaluation of screening depends on a contested evidence base, interacts with people's fear of cancer, and their enthusiasm for technology in general and screening in particular. Cancer screening is both a clinical and a public health activity, and so the often-conflicting frameworks from both clinical ethics and public health ethics are relevant to its evaluation. Cancer screening is an intrusion by health services into the lives of well individuals and so requires strong justification. Cancer screening can and should prevent harms to physical health, but its ability to do so is contingent on many factors and finely balanced; screening can also affect psychological wellbeing. When communicating about screening programs, care must be taken to support rather than undermine the autonomy of people considering participation. The benefit offered by cancer screening programs should be large enough to justify the opportunity costs of screening and the consequent cascade of intervention. Treatment should be offered in a way that avoids creating financial strain for individuals. Other relevant ethical issues include equity of opportunity and outcome in screening and accountability to communities. It is not clear how population-level and individual-level outcomes and interests in cancer screening should be balanced; future work should focus on resolving these difficult issues.

Screening for cancer or cancer risk is well-established in high-income countries. In Australia this includes organised population-based screening programs for breast cancer, cervical cancer risk and colorectal cancer risk. In addition, prostate specific antigen (PSA) testing to detect prostate cancer risk in asymptomatic men is done so frequently that it has become a de-facto screening program. This article considers ethical aspects of cancer screening.

Screening is the application of a test (which for practical reasons must generally be affordable and easy to use) to large, normal-risk populations of asymptomatic people – people who appear to be well. This testing is generally initiated by health authorities rather than individuals. Screening aims to separate people at higher risk from those at low risk. Higher risk people then receive diagnostic testing, and treatment if disease is present.<sup>1,2</sup>

Ethics addresses the question of what, in any given situation, is the right or good thing to do, and why those actions are more justifiable than alternatives. An ethical evaluation of cancer screening is an analysis of whether screening for a particular cancer in a certain way is the right thing to do, and if so, why.

### Ethically-relevant contextual issues

An analysis of the ethics of cancer screening occurs in a context: it depends both on the evidence about screening and on the culture in which screening occurs.

#### **Screening is usually not initiated by the person being screened**

In ordinary clinical medicine, a patient approaches a health professional seeking resolution of a symptom or problem.

In contrast, in screening, health authorities encourage apparently well people to be tested, an act that may turn them into a sick patient.<sup>2</sup> This intrusiveness suggests the need for a strong justification for screening programs – perhaps stronger than for treatments for symptomatic disease.

#### **Ethics depends on evidence, but evidence is contested**

Ethical evaluation depends on good evidence, in this case, epidemiological evidence about the benefits and harms that screening offers. Unfortunately, the evidence-base for even for the best-established programs is contested.<sup>3-5</sup> It has developed in disparate contexts, and its coherence and generalisability is often unclear. Experts disagree on the quality of studies and potential screening harms are often not studied. These uncertainties hamper ethical evaluation of screening programs.<sup>4</sup>

#### **Public perceptions and cultural meanings interact with moral judgements**

Perceptions about cancer can affect people's moral judgements about screening. Cancer is an especially-feared disease, strongly associated with death.<sup>6,7</sup> Screening offers a solution to the problem of cancer led by technological development, which may increase its appeal.<sup>8,9</sup> There is general enthusiasm for cancer screening. A US study found that 87% of respondents believed screening was almost always a good idea and 32-41% believed that an 80 year-old who did not participate in screening was irresponsible.<sup>10</sup> (Note that an 80 year-old would not ordinarily be screened for cancer: the investigators asked this question to test how strong

respondents' commitment to screening was, even in the absence of the possibility of benefit.) In an Australian study, 80% of participants believed early detection saved lives most or all of the time, and 70% wanted to be tested even for a cancer that could not be effectively treated.<sup>11</sup> This combination (frightening cancer, high-tech solution, enthusiasm for screening) may make people generally vulnerable to misperceiving cancer risk, or to taking up offers of unproven screening tests, and suggests a heightened responsibility for those who offer screening to healthy populations.<sup>3</sup>

## Ethical issues in screening activities

### **Both clinical ethics and public health ethics are relevant to screening**

Cancer screening is both a public health and a clinical activity.<sup>2</sup> It is 'public' in that it is used as a tool to improve the health of the general population, supported by public funds, organised into national programs that include public communication campaigns, and is standardised (e.g. the target group, the test used, the quality of pathology or radiology services). Although organisation varies enormously between jurisdictions,<sup>12</sup> the resulting standardisation and improvements in service quality are important potential shared benefits of organising screening. This 'public' character of screening programs suggests that frameworks for public health ethics are likely to be relevant.<sup>13</sup> Public health ethics frameworks emphasise values and principles such as: reasoning at the level of the population, working for common good, maximising utility through effective interventions, distributing opportunities or outcomes fairly, acting in ways that promote trust in the health system (e.g. communicating honestly, facilitating public participation), ensuring that interventions are necessary and proportional to the problem, and avoiding coercion or restrictions on important liberties.<sup>14-18</sup>

Conversely, screening is frequently implemented in clinic-like situations, either by a person's usual primary care physician as exemplified by PSA testing and cervical screening, or by a specialist technician in the case of mammography. The choice to participate in or refuse cancer screening is largely a matter for individuals. Unlike vaccination, where high participation is needed to sustain herd immunity, there is little common good arising from an individual's participation in cancer screening. Thus the concerns of clinical ethics, such as avoiding harm to individuals and respecting the decision of individuals about whether screening is in their best interests for example, are also relevant.<sup>19-21</sup>

This ethical tension is not yet resolved. It seems likely that the public aspects of screening programs should be assessed according to public health ethics criteria and the clinical aspects according to clinical ethics criteria. How we should adjudicate if these come into conflict - for example, if seeking informed consent to participate

decreases population-level mortality benefit or program cost effectiveness - is not clear.

### **Cancer screening should protect physical health and avoid physical harm**

Preventing harms to physical health is the stated goal of most screening programs. Each Australian cancer screening program, for example, takes as its aim: "to reduce illness and death from [the relevant] cancer."<sup>22</sup>

However, screening alone cannot prevent harms to physical health (that is, prevent morbidity and mortality from cancer). This relies on the cascade of diagnostic testing and treatment that follows screening.<sup>23,24</sup> This cascade can prevent harms that would have been caused by cancer. But it can also cause physical harm, such as pain, disfigurement or functional deficits (for example, impotence and/or incontinence after prostate biopsy and treatment). If cancer could be reliably detected, and if all cancers inevitably and linearly progressed to death, and if early treatment was always more effective than later treatment, the harms of the screening cascade would readily outweigh the harms of cancer.<sup>25</sup> Unfortunately, benefits and harms in the cascade are often delicately balanced.

Screening and the resulting cascade will be more likely to do net harm under the following conditions:

1. When test characteristics are poor, so that large numbers of low risk people are directed to diagnostic testing and/or treatment.<sup>4,26</sup>
2. When treatment for later, symptomatic disease is very effective, so screening is less necessary.
3. When the disease diagnosed is not destined to cause harm i.e. when a disease is present, but not destined to cause symptoms, such that diagnosing and treating it will cause net harm (the problem known as overdiagnosis).<sup>27-29</sup>
4. When the population-level risk of the disease is low, such that more people will need to be screened to save one life and more net harm is likely.<sup>4,25</sup>

What should count as a benefit or a harm of screening is also not clear. Policymakers, clinicians and citizens have different views on what is important.<sup>30,25,31</sup> For example, some may wish to avoid every cancer death at any cost, while others may prioritise avoiding unnecessary treatment. Determining whether screening prevents harm requires deciding which harms matter, finding data about them, and deciding how they should be weighted in analysis.

### **Cancer screening and psychological wellbeing**

Social marketing about screening commonly suggests that screening can provide reassurance that disease is absent.<sup>32,33</sup> If this correct, a negative screening result may

serve the goal of improving psychological wellbeing.<sup>2</sup> However, in population screening, how or when such reassurance should count as a benefit is not clear.

As noted, fear of cancer is common in populations. Cancer was historically difficult to treat, and so was associated with suffering and death. Even after significant improvements in treatment, cancers are leading causes of death in middle age in Australia and directly experienced by many, so some fear of cancer is not unreasonable.<sup>34,35</sup> However, fear or anxiety may also arise from public health communication campaigns designed to encourage people toward screening or other health behaviour change.<sup>36,37</sup> That is, at least some anxiety about cancer may effectively be iatrogenic. If this is the case, it seems dubious to count the relief of this anxiety as a benefit of a screening program. In addition, screening itself produces some psychological harms. False positives in particular, which cumulate across a lifetime of participation,<sup>38</sup> have been shown to have lasting detrimental effects on psychological wellbeing of a similar magnitude to a cancer diagnosis.<sup>39</sup>

## **Supporting autonomy in screening**

Screening can, in itself, promote or support autonomy by providing information.<sup>2</sup> On the surface, this seems relatively straightforward. A person enters screening knowing little about their cancer risk, and exits knowing a great deal more. There are certainly situations in which this will allow people to make better decisions about their health care, consistent with their own values.

However, communication within screening programs also has the potential to undermine autonomy.<sup>40</sup> Screening communication and social marketing sometimes seems designed to secure high participation rates - even to coerce participation - rather than support autonomy.<sup>33,41</sup> Information is often incomplete because harms are rarely described and relative instead of absolute risks are often used.<sup>26,33,36,42-44</sup> Relative risks are known to discount harms and inflate benefits in people's perceptions, and such systematic biasing of people's perceptions has been criticised as a form of unethical manipulation.<sup>45</sup> System incentives for high screening rates including performance payments and key performance indicators may encourage this bias.<sup>25,33,46</sup> Concern has also been expressed that screening communications that emphasise a responsibility to screen may make people who decide to refuse screening feel guilty.<sup>37</sup>

A more ethically justifiable screening program might focus on improving people's understanding of why they might choose to screen, preserving voluntariness, rather than pushing people towards participation.<sup>19,25,47</sup> Empirical work shows that people choose differently when they are better informed;<sup>48</sup> informed choosing may also improve psychological wellbeing by increasing people's sense of mastery and self-authorisation.<sup>49</sup> The benefit-harm trade-offs of screening are complex. Supporting people

to understand them is no small task and understanding should not be assumed.<sup>43,50</sup> Sustaining valid consent to screen may require re-contacting people at intervals, offering opportunities to reconsider prior decisions and be informed about changes to screening practices and evidence.<sup>50</sup> While some have argued against providing citizens with quantitative information about screening on the grounds that they cannot understand it,<sup>51</sup> this is difficult to justify, and is inconsistent with what informed citizens consider reasonable.<sup>52</sup> Particular care needs to be taken however, when working with people who are educationally or socioeconomically disadvantaged,<sup>49</sup> and work is ongoing regarding the provision of appropriate decision assistance to people with limited literacy and numeracy.<sup>53,54</sup>

## **Other relevant ethical considerations**

Screening programs carry large opportunity costs because they are expensive to run well, so it is important to periodically assess whether they are providing adequate health benefit and/or improvements in health equity to justify that cost.<sup>23,26,29,55</sup> Concern has been expressed that screening may divert funding away from forms of primary prevention that would have a larger effect on all-cause mortality and morbidity,<sup>56</sup> or away from providing necessary care to those who are acutely ill.<sup>57-59</sup>

Financial strain is a particular problem in user-pays health systems, where cancer can readily cause bankruptcy. In some user-pays health systems, people may receive a positive screening result from a free screening service, and then not be able to access affordable treatment.<sup>60,61</sup> Conversely, unregulated private fee-for-service screening can generate large cost burdens for public or insurance-funded follow-up services.<sup>29</sup> Knowing that one is at high risk of developing cancer may, in some contexts, make one less employable or insurable.<sup>62</sup> This is just one reason why confidentiality and privacy are important ethical issues for screening programs.<sup>47</sup>

Screening tends to have differential uptake among people of higher and lower socioeconomic status and people from different cultural backgrounds.<sup>49</sup> An ethical judgement about this depends on whether or not it is considered to be in people's best interests to participate in a particular kind of screening. It also depends on how justice is conceived. For example, if screening programs aim to provide the greatest possible health improvement for the least well off, they will be designed very differently than if they are intended to achieve the largest and most efficient improvement in aggregated population health.<sup>49</sup>

As with any health service, there are important issues to consider regarding how best to involve, and be accountable to, communities,<sup>34</sup> and how to ensure that screening is provided in a way that is respectful and culturally appropriate.<sup>63</sup>

## Does cancer screening serve individual or common interests?

Decisions about whether screening serves the interests of a population are distinct from decisions about whether screening serves the interests of a particular individual.<sup>5,25,64</sup> It is not yet clear how to balance these distinct population and individual-level dimensions of screening activities.<sup>2,41,65</sup> There are advantages to a public approach to screening, particularly in ensuring standardisation and quality in service provision. However, from a more individual perspective, to coerce or manipulate citizens to subject themselves to invasive procedures for the sake of achieving a participation target, or changing a population-level mortality statistic, seems questionable. Different individuals have different goals and values, and so will - if they understand an offer of screening - make different choices. Even expert policymakers disagree on what the goals of screening should be, and so what values should be prioritised in decision making.<sup>66</sup> Anya Plutynski summed up the tension this way:

*"Although a narrow utilitarian or expected utility perspective might simply attach values to lives saved, and so use any strategy (including representing risk deceptively, or discounting or hiding cost to patients due to unnecessary biopsies or overdiagnosis), there are broader issues at stake. Questions of risk and benefit need to be supplemented by some discussion of the reasonable variability in values patients attach to different risks, the norms of clinician-patient relationships, and what respect for autonomy and informed consent requires. Questions about risk and benefit can be better answered once we know how sensitive or specific are our screening tools, how prevalent the disease, and thus what the risks are of false positives. However, we also need to assess the values behind general versus individually tailored recommendations, and arguments for and against individual consultation with clinicians, versus general recommendations that may benefit some, but not most patients."*<sup>25</sup>

The literature regarding the ethics of cancer screening is relatively new, and still in development. This review suggests that there are at least two central questions that need resolution if the field is to advance. The first is to determine how the competing potential goals of screening should be prioritised and balanced against one another. The second related question is the extent to which cancer screening is an individual clinical service, to which the principles of clinical ethics apply, and/or a public health service, to which the principles of public health ethics apply. These questions provide important challenges to future research on the ethics of cancer screening.

## Acknowledgments

This work was funded by NHMRC Project Grant 1023197 and the author was supported by NHMRC Career Development Fellowship 1032963. Sincere thanks to the project grant team on 1023197 for four years of fruitful

discussion, analysis, provocation and hard work - Prof Alexandra Barratt, Assoc Prof Lucie Rychetnik, Dr Chris Degeling, Lisa Parker, Jane Williams, Kristen Pickles and Gemma Jacklyn.

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