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Current Perspective

Avoiding harm and supporting autonomy are under-prioritised in cancer-screening policies and practices

Lisa Parker [a,*], Stacy Carter [a], Jane Williams [a], Kristen Pickles [a], Alexandra Barratt [b]

[a] *Sydney Health Ethics, Sydney School of Public Health, Medical Foundation Building, University of Sydney, NSW 2006, Australia*

[b] *Sydney School of Public Health, University of Sydney, NSW 2006, Australia*

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Abstract The ethical principles of avoiding harm and supporting autonomy are relevant to cancer-screening policy. We argue that more attention needs to be given to implementing them. Cancer screening may deliver excessive harms due to low-value or outdated screening programs and from poorly communicated screening options that leave people with heavy burdens of decision-making. Autonomy is inadequately supported due to limited opportunities for people to understand downsides of screening and because of institutional and societal pressures in favour of screening.

Members of screening policy committees may have differing ideas about the goals of screening or have conflicts of interest that prevent them from addressing policy questions in a neutral way. We recommend the following: 1. Committees should be required to discern and discuss the values of individual members and the wider public; 2. Committee membership and voting procedures should be more carefully constructed to reduce the likelihood that committee members' interests are placed above public interests; 3. Committees should explain their policy decisions with reference to values as well as evidence, so that values considered in decision-making can be interrogated and challenged if necessary. These changes would increase the likelihood that cancer-screening policy decisions are in keeping with public views about what is important.

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[*] *Corresponding author*. Fax: +61 2 9036 3436.

E-mail addresses: lisa.parker@sydney.edu.au (L. Parker), stacy.carter@sydney.edu.au (S. Carter), jane.h.williams@sydney.edu.au (J. Williams), kristen.pickles@sydney.edu.au (K. Pickles), alexandra.barratt@sydney.edu.au (A. Barratt).

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1. Introduction

In this article, we argue that the ethical principles of avoiding harm and supporting autonomy should have more influence on cancer screening policies and practice. It is well established that health policy and practice decisions are influenced by the values of decision-makers, regarding matters such as likely outcomes of intervention, the means of achieving outcomes and processes of decision-making [1,2]. We extend this to propose that avoiding harm and supporting autonomy are currently heavily under-prioritised in cancer-screening policy and practice. We present this proposal for debate, informed both by ethical reasoning and empirical evidence from cancer-screening research conducted by ourselves and others.

2. Avoiding harm is under-prioritised in cancer screening

It is well recognised that, in addition to providing benefits, cancer screening causes harms [3], including physical, psychological and financial harms, arising from false-positive tests and overdiagnosis.

2.1. Why we argue that avoiding harm is under-prioritised?

2.1.1. Low-value cancer screening is readily available and often publicly funded [4]

Some screening activities return disproportionately small benefits for the harms incurred. The list of low-value cancer screening is contentious but is likely to include the following:

- Prostate-specific antigen (PSA) testing in asymptomatic men at average risk of prostate cancer [5].
- Mammography screening of women aged <50 years at average risk and women with limited life expectancy [4].
- Pap smear screening in women aged <25 years, human papilloma virus (HPV) testing in women aged <30 and frequent cervical screening in women greater than these ages (more often than once every 3 years for Pap testing, once every 5 years HPV testing) [6].

Low-value cancer screening is generally not recommended but may nevertheless be readily available and may be subsidised by governments or via mandatory insurance laws (see Appendix A). Low-value screening and the policies that allow it result in many more individuals suffering harm than receiving benefit, the inverse of the population benefit to harm ratio that should be achieved in screening programs.

2.1.2. People potentially carry a heavy burden of decision-making about whether or not to participate in screening

People are often asked to decide for themselves whether to participate in cancer screening [7], particularly in ‘grey areas’, where the balance of population-level benefits and harms is so close that experts cannot make a strong recommendation. Providing opportunities for individuals to be involved in their own health care decisions is generally considered best practice, but it is especially challenging in cancer screening. People are rarely equipped to interpret conflicting expert opinion or analyse the meaning of uncertainty in the evidence base, particularly if they have limited education. Many individuals experience decisional anxiety about cancer screening [8] and those who experience an undesirable outcome after their screening choice may suffer decisional regret [9]. The complexity of decision-making about cancer screening has been recognised for many years, but despite a growing literature about how to reduce associated harms and burdens [7,10], recommendations have not been widely implemented. The public remains confused and uncertain [11].

2.1.3. There are few formal disinvestment strategies in cancer-screening programs

The balance of benefits and harms in cancer-screening programs depends on factors that affect cancer incidence (e.g. prevalence of HPV vaccination and average age of child bearing) and cancer-related morbidity and mortality (e.g. cancer awareness and stage distribution of self-referred patients, availability of effective treatment and average population longevity) [2]. These factors may vary with time and place, meaning that, for example, a population with a falling underlying cancer incidence and recently improved treatment program may derive little benefit from a cancer-screening program, even if there is evidence of its effectiveness in previous decades or in other populations. Cancer-screening programs should be regularly evaluated in the context of up-to-date evidence about incidence and treatment, using pre-agreed indicators to trigger review, change or disinvestment to screening. This would be a strong reminder that cancer screening causes harms and requires ongoing evaluation and justification. It is likely to be particularly important in large, institutionalised programs, for which disinvestment may prove difficult [12], even if harms begin to outweigh benefits. These kinds of triggers or conditions for disinvestment are rarely provided in formal cancer-screening programs.

3. Supporting autonomy is under-prioritised in cancer screening

Autonomy can be a difficult concept to pin down. Our view of autonomy in the context of cancer screening draws on the work of Mackenzie [13], who identifies three common understandings of the word and advocates for the broader concept of relational autonomy. Very briefly, autonomy is often understood as (i) freedom from constraint of any kind (libertarian autonomy) or (ii) having information and support to make a decision, (decisional autonomy). Mackenzie [13]