



## ETHICS AND CANCER

### Ian Olver

Sansom Institute for Health Research

University of South Australia

Email: Ian.Olver@unisa.edu.au

There are ethical issues to consider across the whole spectrum of cancer control. This forum considers topics spanning the issue from prevention to end of life care. Some issues are generic to medicine in general because they encompass principles like the centrality of respect for each patient, which translates to the provision of sufficient information to allow autonomous decision-making, or ensuring equitable distribution of health resources and the attempted elimination of disparities in health care opportunities. Others are more specifically related to cancer, such as ethical issues around public health messaging about cancer risk, or the recognition of over-diagnosis and its consequences when recommending a cancer screening program.

### Public health messaging about cancer prevention and screening

Muhlack et al discuss how alcohol consumption is a known modifiable risk factor for cancer and yet an entrenched widespread social practice.<sup>1</sup> It is a good example for studying whether legislation requiring mandatory public health warnings about the health risk of alcohol would be justified. Specifically, health warning labels on alcohol products are being used as the example because this has been proposed as a strategy to reduce alcohol consumption. Such warnings had an impact on tobacco control. Alcohol health warning labels have been defended on the grounds of such warnings providing information only, but the real goal is behavioural change that will result in harm reduction. However, knowledge alone may not change behaviour and society may value the principle of individuals making autonomous choices without government interference. A balance must be struck between the utilitarian nature of public health interventions and liberalism in a society in which interventions are proposed.

Carter explains that there are three established screening programs for each of, cancers of the cervix, breast and bowel in Australia.<sup>2</sup> Evidence of efficacy is judged on a population basis. Does routinely testing a healthy population to attempt to detect cancer earlier than when symptoms develop result in a decreased mortality from that cancer without causing harm? The difficulty is that even if a population may benefit, not every individual will benefit. In some, cancer may be detected but never cause harm, a situation referred to as over-diagnosis, which often leads to invasive further

testing, treatment and emotional distress. It can be difficult to judge whether a screening program has a net benefit over harm if different studies yield opposing results. Individuals at least should be fully informed of the potential benefits and risks to them and be able to make their own judgement about whether to participate in a population screening program.

### Population data linkage in indigenous health

In a multicultural society, different groups may have different perspectives on data collection to inform health messaging, screening and treatment. For example, 'big data' enables new information to be gleaned from linking large population datasets. Garvey et al highlight some of the complexities of working with and linking such data sets in the context of indigenous health.<sup>3</sup> Firstly, many such datasets may not identify indigenous patients, and being identified as indigenous has not previously had positive outcomes. There can be barriers to accessing state-based data to gain a national perspective in a federated structure, despite the fact that the data collection is often publicly funded, raising an ethical dilemma for data custodians. This dilemma finds expression in Indigenous communities as well, where central ethical approval of a data linkage study would facilitate the research but disempower local communities whose data are included. However, fragmentation of research effort will not be productive either. When formulating public policy in cancer, the cultural differences must be accommodated to achieve the best outcomes across the whole population.

### Ethics and the use of genomics in cancer.

Margaret Otlowski examines the challenges that have arisen as we have progressed from single gene testing to whole of genome sequencing, as we move to an era of personalised medicine.<sup>4</sup> The commercial provision of the ability for people to have their whole genome sequenced has progressed beyond the ability to accurately interpret the data generated. Otlowski examines the issues around privacy and consent, but also discusses emerging issues such as the role of the researcher or clinician in recontacting and reporting incidental findings to patients who are being tested for particular mutations when other unanticipated, but possibly significant, mutations are found. She suggests that cancer panel testing may limit the potential problems at the current state of knowledge.

## Equitable resource allocation and the challenge of high-cost drugs

The introduction of targeted therapies has resulted in high-cost drugs being approved at regular intervals, which is putting pressure on health budgets. Lipworth et al highlight the dilemma of decision-makers in having to balance the emotive issues of individual patients desperate for access to what they see as potentially life-saving new drugs, and the decision-makers' responsibilities to assess cost-effectiveness and opportunity costs across the whole health consumer population.<sup>5</sup> The latter need to ascertain the value of a treatment and whether the evidence-based outcomes of efficacy justify the cost. This is particularly the case because the price at which the drugs are offered is not so much based on efficacy as what the market in high-income countries will pay. To help navigate conflicting values, Lipworth et al propose the development of a framework based upon accountability for reasonableness, which could then be applied to price negotiations and funding decisions.

## Cancer research and consent

In most human research, participants are provided with information so that they can make informed choices about participation. In population-based research, data may have been collected on thousands of patients in cancer registries. Most commonly the results of the analysis of the data in those registries are de-identified. The logistical difficulty of obtaining individual consent may compromise the representativeness of the sample, and therefore the result obtained. Ethics committees have allowed a waiver of consent in this situation, but a more recent option allowed in the *National statement on ethical conduct in human research* of the National Health and Medical Research Council has been opt-out consent.<sup>6</sup> Xafis explores how with opt out consent, information about a study is made publicly available and individuals are then given the opportunity to opt out of having their data included.<sup>7</sup> Although this has been characterised as only presumed consent and it is not clear how many of the population are informed by the public information. The procedure results in high participation rates, which can be important when population data is used, for example to guide cancer policy. The public good is being balanced with any compromise of individual autonomy.

Even when individual consent is obtained for participation in cancer research trials, there is no guarantee that the patient understands what is being presented. Trials measuring the quality of that understanding have confirmed that view.<sup>8</sup> A trial presenting the information by electronic means rather than paper failed to improve recall of the information.<sup>9</sup> However, a randomised study of uniform total disclosure as compared to an individual clinician's discussions, did result in better understanding, though it increased anxiety and decreased willingness to participate

in randomised trials.<sup>10</sup> Tattersall reports on a study audiotaping clinicians' discussions with patients of randomised trials that showed great variation in what was presented to the patient.<sup>11</sup> The consensus was that standard treatment options should be discussed before the trial option was introduced.<sup>12</sup> Phase I studies, where the chance of individual patient benefit is small, are more problematic since patients may equate them with care and be more optimistic about the outcome than their treating clinicians. This optimism may be due to poor communication by the clinician, resulting in a lack of understanding by the patients.<sup>12</sup>

## End of life issues

End of life issues in cancer have often focused on euthanasia and physician-assisted suicide, both of which are theoretical issues in Australia where these procedures are not legal. Gillam raises issues more pertinent to current Australian practice.<sup>13</sup> If a person is dying, then the freedom of choice should focus on comfort and relief of suffering. What if that relief is obtained from a drug that is illegal, like cannabis, where the evidence of benefit is largely from case studies? Similarly, if the only way to achieve symptom control is terminal sedation, is that a reasonable approach, or can that in any way be equated with euthanasia? Although there is a loss of the characteristics of personhood in someone who is treated this way, the evidence is that it doesn't hasten death, nor was killing the intention of this extreme form of symptom control. If this practice is allowed to control symptoms, where does that leave euthanasia?

## Conclusion

A single volume cannot do more than sample the ethical issues that arise in cancer control and the topic covers a spectrum from prevention to palliative care and from individual health to population health. A sampling shows the complexity of competing values and perspectives. However, promoting awareness and discussion moves the debate towards 'reasonable' decisions and policies.

---

## References

1. Muhlack E, Elliott J, Carter D, et al. Ethical justifications in alcohol-related health warning discourses. *Cancer Forum*. 2016;40(2):97-104.
2. Carter SM. Ethical aspects of cancer screening. *Cancer Forum*. 2016;40(2):105-109.
3. Garvey G, Percival N, Izquierdo L, et al Big data in an Indigenous health context: opportunities and obstacles. *Cancer Forum*. 2016;40(2):110-114.
4. Otlowski M. Ethical issues arising in the use of genomics in cancer. *Cancer Forum*. 2016;40(2):114-118.
5. Lipworth W, Ghinea N, Kerridge I. Negotiating limits to the funding of high cost cancer medicines. *Cancer Forum*. 2016;40(2):119-122.
6. National Statement on ethical conduct in human research of the National Health and Medical Research Council <https://www.nhmrc.gov.au/guidelines-publications/e35>. Accessed 19-02-2016.
7. Xafis V. What consent model is ethically justifiable in cancer population research? *Cancer Forum*. 2016;40(2):123-127.
8. Joffe S, Cook EF, Cleary PD, et al. Quality of informed consent in cancer trials: a cross-sectional survey. *Lancet*. 2001;358:1772-1777.

# ETHICS IN CANCER

9. Olver IN, Whitford HS, Denson LA, et al. Improving informed consent to chemotherapy: a randomized controlled trial of written information versus an interactive multimedia CD-ROM. *Patient Edu and Couns.* 2009;74:197-204.
10. Simes RJ, Tattersall MHN, Coates AS, et al. Randomised comparison of procedures for obtaining informed consent in clinical trials of treatment for cancer. *Brit Med J.* 1986;293:1065-1068.
11. Tattersall M. Ethical issues around phase I and phase III trials in cancer. *Cancer Forum.* 2016;40(2):128-130.
12. Brown RF, Butow P, Ellis P, et al. Seeking informed consent to cancer clinical trials: describing current practice. *Soc Sci Med.* 2004;58:2445-2457.
13. Gillam L. Current ethical issues in advanced cancer care. *Cancer Forum.* 2016;40(2):131-134.