

## **Review of the Privacy Act 1988 – submission from The Cancer Council Australia and the Clinical Oncological Society of Australia**

**The Cancer Council Australia** is Australia's peak non-government national cancer control organisation. Its member bodies are the eight state and territory cancer councils, whose views and priorities it represents on a national level.



The **Clinical Oncological Society of Australia** is the peak multidisciplinary society for health professionals working in cancer research or the treatment, rehabilitation or palliation of cancer patients.



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# **Review of the Privacy Act 1988 – submission from The Cancer Council Australia and the Clinical Oncological Society of Australia**

## **Overview**

The Cancer Council Australia and the Clinical Oncological Society of Australia (COSA) welcome this review of Australian privacy law. The Australian Law Reform Commission should be commended for reviewing privacy in relation to inter-jurisdictional matters, technological change and perceptions of privacy in the context of health care and health research, as substantially explored throughout *Discussion paper 72*.

It is noted that the terms of reference for this review include a focus on “rapid advances in information, communication, storage, surveillance and other relevant technologies; possible changing community perceptions of privacy and the extent to which it should be protected by legislation; the expansion of State and Territory legislative activity in relevant areas; and emerging areas that may require privacy protection”. This submission provides general comment in response to the examination of these issues in *Discussion paper 72*, as well as specific comment regarding individual proposals put forward by the ALRC in the discussion paper.

## **General comment**

As health promotion and cancer control agencies, The Cancer Council Australia and COSA assert that the first priority of any legislative framework should be saving, extending and improving the quality of human life. To this end, while the objectives of privacy law are manifold, it is our view that laws designed to protect individual privacy must be subject to exceptions where necessary to save, extend or improve human life. Access to individual genetic cancer information that could save or extend a blood relative’s life, and more efficient use of personal health information more generally for epidemiological research, are salient examples of the need to provide greater clarity and efficiency in privacy law in the public interest.

## Cancer in Australia

Cancer is Australia’s largest disease burden, accounts for more deaths than any other individual cause and will continue to increase markedly in incidence as our population ages. One in two Australian men and one in three Australian women are expected to be diagnosed with cancer by the age of 85.<sup>1,2,3</sup>

Cancer survival in Australia has improved by 30% over the past two decades,<sup>4</sup> in large part due to breakthroughs in epidemiological, laboratory and clinical research. The Cancer Council Australia and COSA therefore assert that health and medical research must not be restricted by the inappropriate application of privacy laws – particularly when there are a range of mechanisms (ethics committees, de-identification protocols etc.) aimed at preventing misuse of individual health information. Our comments below, in response to relevant proposals in *Discussion paper 72*, reflect this important priority.

## Genetic cancer

More than 5000 Australians are diagnosed each year with potentially fatal cancers that could be prevented or detected early through genetic testing or surveillance.<sup>5</sup> Lack of

clarity in current privacy law could empower an individual to withhold genetic health information about themselves essential to the appropriate testing and monitoring of a blood relative for the prevention, early detection or treatment of cancer. Moreover, the complexities and inter-jurisdictional inconsistencies characteristic of current arrangements present barriers to optimal cancer-risk monitoring of individuals in Australia. The Cancer Council Australia and COSA comment in the following section on proposals in *Discussion paper 72* that could improve cancer outcomes in Australia through clearer application of privacy law.

As genetic technology in the prevention, detection and treatment of cancer improves, the need for greater clarity and consistency in privacy law and for exceptions that ensure human life is not at risk through inappropriate application of privacy law will become greater.

### Epidemiological research

Cancer registries and linking data between jurisdictional collections to give an Australia-wide picture of cancer control is ultimately the best quality assurance tool for epidemiological cancer research. This approach also provides an early indication of the value of screening programs or new treatment initiatives, benefits that must be weighed against the (usually very low) risk of being able to identify individual data. Far more considerable and detrimental to the public interest is the risk of restricting the timely collection of data by insisting on personal consent.

A recently published study shows that the vast majority of patients are not concerned about the use of their health information, provided it is in the public interest and subject to appropriate safeguards.<sup>6</sup> This suggests that the public would be even more supportive of the efficient use of their health information if they had a better understanding of how it could contribute to improvements in cancer prevention, detection and treatment, and of the mechanisms available to protect their privacy.

As discussed in The Cancer Council Australia and COSA's comments against specific ALRC proposals (below), the current review of privacy law provides an important opportunity to improve potentially life-saving health research without significant risk to individual privacy.

### Young people

While *Discussion paper 72* is a comprehensive and well-documented compilation of the issues, there appears to be no proposed safeguard to ensure people under 18 cannot use privacy law to overrule medical advice based on optimal clinical practice.

For example, a situation could arise where a 15-year-old girl concerned about breast cancer demands a test to determine if she is at genetic risk of breast cancer (i.e. carries the genes BRCA1 or BRCA2). As there is no clinical benefit in knowing the girl carries the genes – even if she tested positive, it could be at least 10 years before any beneficial surveillance or treatment could begin – clinicians applying best practice would under normal circumstances deny the girl such a test. However, there is a concern that, without clarity in privacy law, the girl could insist on a test because the legislation vaguely states that she has total control over her health information.

We therefore recommend that the laws include an amendment to the effect that, in cases where health data has no short-term impact on the circumstances of an individual aged under 18, clinical decision making cannot be the sole responsibility of the patient.

## **Specific comments in response to Discussion Paper 72**

### **Access to genetic information about a deceased person – proposal 3-12**

The Cancer Council Australia and COSA strongly support proposals for “an organisation to use or disclose genetic information to a genetic relative of a deceased individual where the organisation reasonably believes that the use or disclosure is necessary to lessen or prevent a serious threat to the life, health or safety of a genetic relative”.

This is particularly relevant to cancer control, as genetic information can facilitate improved surveillance of individuals at genetic risk of developing particular cancers.

However, further clarity is required. Access should extend beyond “organisation” to private individuals gaining appropriate access to genetic information about a deceased relative. DP 72 (*An overview*) states that this “... change would only apply to private sector organisations, because freedom of information and archives laws already provide access to information about deceased people that is held by public sector agencies”.

This statement does not reflect current practical realities, particularly in the experience of clinicians involved in the surveillance of individuals at genetic cancer risk and their patients. Cross-border inconsistencies in policy and practice can impede timely access to genetic data required to reduce cancer risk in individual patients. As the ALRC contends in *Essentially yours*,<sup>7</sup> individuals should be entitled to access the medical records of deceased blood relatives within the federal Privacy Act’s current framework. However, complications arise due to jurisdictional inconsistencies, which could be addressed by uniform national rules for health services (see following).

### **‘One set of rules for health services’ – proposals 4-1, 4-3, 4-4, 4-6, 4-7; 12-1, 34-5, 56-2, 56-3, 56-4, 56-5, 58-1, 58-5**

The Cancer Council Australia and COSA strongly support the ALRC’s wide-ranging proposals that would facilitate national uniformity and consistency in the management of health information and the enabling of federal law to override state or territory laws in relation to health data, where clearly in the public interest in terms of individual or community health outcomes.

The current system of varying jurisdictional laws and arrangements and the lack of a coherent national structure impede evidence-based, epidemiological health research and create cross-border barriers to optimal monitoring of familial cancer risks.

The Cancer Council Australia and COSA believe there are adequate checks built into privacy law and in the ALRC’s proposals (e.g. proposed exceptions to the Collection and Disclosure principles) to ensure the protection of individual information is balanced against the core priority of contributing to better public and individual health outcomes.

**Collection of health information about third parties – proposals 20-2, 20-5, 22-3, 26-6, 57-3, 58-8 (b & c), 58-9; question 57-1**

The Cancer Council Australia and COSA strongly support the ALRC's proposal for an exception (2) to the "specific notification" and "use and disclosure" principles where notifying a third party could pose threats to the life and health of an individual through the withholding of health information.

We also strongly support the proposal (57-3) that "a health service provider may collect health information from a health consumer, or a person responsible for the health consumer, about third parties without consent" when such information may improve an individual's health outcomes. This is particularly relevant to cancer control, where early intervention on the basis of third-party genetic information may save or prolong life.

Provided the proposed exceptions designed to ensure there are no risks to the health and wellbeing of any individual through genetic data unavailability are adopted, The Cancer Council Australia and COSA strongly support the proposals ensuring that individuals are consulted about use of their genetic information.

The Cancer Council Australia and COSA answer "yes" to question 57-1, "Should the proposed *Privacy (Health Information) Regulations* provide that health information may be collected without consent where it is necessary to provide a health service to the individual and the individual would reasonably expect the agency or organisation to collect the information for that purpose?"

Proposal 58-8 (a-e) is consistent with our views on exempting blood-relative information from privacy laws. However, there is ambiguity in the additional sentence, "Where an agency or organisation collects sensitive information about an individual in accordance with this provision, it must take reasonable steps to ensure that the information is not disclosed in a form that would identify the individual or from which the individual would be reasonably identifiable." This proposal needs to be re-written to clarify that some information must by definition identify an individual, for example when it relates to cancer risk in a blood relative.

Proposal 58-9 addresses to some extent our concerns about the ambiguity of proposal 58-8. However, should 58-8 be incorporated into law but 58-9 is overlooked, an individual's capacity to obtain potentially life-saving genetic cancer information could be compromised. There are also implications for epidemiological research (see page 8).

**Representation – proposal 43-4**

The Cancer Council Australia and COSA strongly support the proposal to "require the appointment of a person from the health sector" to the Privacy Advisory Committee. We recommend that the proposal should be extended to require that such a person should be formally affiliated with, or have formal access to, an independent, evidence-based health organisation that can advise on public health, occupational health, clinical and epidemiological research, and genetic health issues.

### **Regulatory frameworks – proposal 56-1**

The Cancer Council Australia and COSA support the proposal to consider delegating the power to handle complaints relating to interferences with health information to state and territory health complaints agencies, where such interference is a threat to the health of an individual or impeding research in the public interest.

### **Definitions (general) – proposals 57-2, 57-3, 57-4**

The Cancer Council Australia and COSA recommend that the ALRC consider adding the terms “evidence” or “evidence-based” to the definition of a health service that seeks an exception to privacy rules in order to obtain genetic information about a third-party individual to improve health outcomes for a blood relative.

The Cancer Council Australia and COSA support the proposals (57-4) to authorise individuals to represent patients deemed “incapable of giving consent” to disclose genetic health information that would benefit blood relatives and contribute to medical research.

The Cancer Council Australia and COSA support replacing “de facto spouse” with “de facto partner” provided the intent is to promote the principles of access and equity.

### **Research – proposal 58-3**

The Cancer Council Australia and COSA are concerned that defining “research” as an activity subject to review by a Human Research Ethics Committee (HREC) could unnecessarily impede important epidemiological and clinical cancer research in the public interest.

Currently, a range of epidemiological cancer research essential to public health and clinical care is undertaken without HREC review, including the analysis of cancer registry data, without any threat to personal privacy. Requiring that “research” by definition be subject to complex HREC reviews, potentially across nine jurisdictions, could detrimentally restrict and delay life-saving cancer research in Australia.

The Cancer Council Australia and COSA recommend that HREC review and approval should only apply in this context to health information that can be identified with a private individual.

### **Research – proposal 58-4**

The Cancer Council Australia and COSA strongly support the change in emphasis from “substantially outweighs” in the previous act to “outweighs”.

There is considerable anecdotal evidence that HRECs have struggled to determine what “substantially outweighs” means, consequently taking a conservative approach to reviewing research proposals in terms of privacy considerations. (These observations are supported in Discussion paper 72,<sup>8</sup> paragraphs 58.85 – “As to the test itself, the ALRC is concerned that the current test may be leading to overly conservative decision making by HRECs that is not in the overall public interest. If the public interest in a particular research proposal going forward outweighs the public interest in maintaining

the level of privacy protection provided by the privacy principles, then there is an argument that the research should be allowed to proceed.” And in paragraph 58.87 – “...The public interest in protecting this private right must be considered in the context of other rights and other public interests. The ALRC’s view is that it is not the degree to which one public interest outweighs another—whether slightly or substantially—that should be at issue. If, taking all relevant factors into account, the public interest in one course of action outweighs the public interest in another course of action, the ALRC is of the view that the appropriate course of action is clear...”).

The Cancer Council Australia and COSA believe that the revised terminology will facilitate necessary balance in the interpretation of privacy law, in favour of improved health outcomes.

#### **Research – proposal 58-5**

The Cancer Council Australia and COSA support this proposal, which would contribute to streamlined procedures for data acquisition by aligning privacy law with national ethics in human research and facilitating a uniform national approach to health information relating to privacy provisions. We recommend that “relevant stakeholders” include “bona fide health researchers and clinicians” with particular interest in epidemiology, public health, clinical trials and familial cancer, and healthcare consumers.

#### **Research – proposal 58-6**

The Cancer Council Australia and COSA note that the proposed amendment to the National statement on ethical conduct in human research (2007) would be unlikely to affect cancer research. However, our recommendations regarding proposal 58-3 should be noted; epidemiological research that does affect an individual’s privacy should not be considered in this context.

It should also be noted that the potential complications of inter-jurisdictional HREC approval further highlight the need for national uniformity in privacy law relating to health information (proposals 4-1, 4-3, 4-4, 4-6, 4-7; 12-1, 34-5, 56-2, 56-3, 56-4, 56-5, 58-1, 58-5).

#### **Research – proposal 58-7**

The Cancer Council Australia and COSA support the proposal to review the reporting requirements imposed on the Australian Health Ethics Committees and HRECs, particularly the goal of minimising administrative burden. We recommend that “relevant stakeholders” include “bona fide health researchers and clinicians” with particular interest in epidemiology, public health, clinical trials and familial cancer, and healthcare consumers.

#### **Research – proposal 58-8**

The Cancer Council Australia and COSA support points a-e, which are consistent with our views on exempting some research and blood-relative information from privacy laws. However, there is ambiguity in the additional sentence, “Where an agency or organisation collects sensitive information about an individual in accordance with this provision, it must take reasonable steps to ensure that the information is not disclosed in

a form that would identify the individual or from which the individual would be reasonably identifiable.”

This proposal needs to be re-written to clarify that some information must by definition identify an individual, for example when it relates to cancer risk in a blood relative.

### **Research – proposal 58–9**

The Cancer Council Australia and COSA strongly support 58-9 (a-e), which appear to provide necessary exemptions to privacy law for health research that is clearly in the public interest. Proposal 58-9 should also be supported to add clarity to proposal 58-8 (see ‘Third parties’, page 5).

Disclosure of identifiable health data can be integral to the quality and usefulness of epidemiological research. In our view, existing measures and the additional requirements proposed in 58-9 would ensure that researchers protect the identity of individuals whose health data may be used in research clearly in the public interest. Ethical protocols should ensure that private health information can be used for important health research in the public interest, without being made publicly available or circulated in a form that can be identified with private individuals.

### **Research – proposals 58-11, 58-12**

The Cancer Council Australia and COSA support these proposals, which have the potential to improve access to private health information for health research in the public interest.

It is recommended that, where possible:

- a uniform approach be taken to reviewing proposals to establish health databases and registries. This can be particularly important when linking datasets nationally; and
- HRECs specifically consider the requirements of genetic cancer research, occupational cancer risk research and public health research more generally when balancing potentially competing requirements of individual privacy.

### **Research – proposal 58-13**

The Cancer Council Australia and COSA support the proposal that organisations developing systems or infrastructure to allow the linkage of personal information for research purposes consult the Office of the Privacy Commissioner to encourage compliance with the Act. As well as helping to protect identifiable patient information, such an approach would also facilitate greater consistency in the management of health data, for both epidemiological and familial research.

### **Telecommunications – proposal 63-3**

The Cancer Council Australia and COSA support the proposal to amend the Telecommunications Act 1997 to enable the use of disclosure of information that may



prevent a “serious threat” to a person’s life, health or safety; or public health or public safety. It is recommended that consideration be given to a definition of “serious”.

## **Matters in the public interest not directly addressed in DP72**

While *Discussion paper 72* covers a very wide range of issues, there appear to be no specific proposals that address a number of additional concerns about cancer research in the context of privacy law. Important additional considerations for the review are:

- a) The need to access multiple databases (such as multiple state cancer registries) to aggregate sufficient numbers (incidence, morbidity, mortality etc.) for meaningful national data analyses;
- b) The need to link databases of different character/format to address research issues beyond the scope of data held on a single base (e.g. integrating cancer registry, Medicare and PBS data determine patterns in clinical cancer care);
- c) In the case of either (a) or (b), appropriate use (with adequate protections, as discussed in this submission) of individual subject names as a device for relevant record linkage;
- d) De-identification of data (where appropriate) at some point in the investigation but not to the extent as would preclude (c); and
- e) The principle that some information, such as full address, is essential to privacy but has no immediate relevance to most investigations.

Key measures to resolve these issues would be:

- the establishment of a single national ethics committee to consider research proposals that cover multiple jurisdictions and/or multiple databases; and
- uniform procedures to allow the release of identifiable information for the purposes of record linkage for bone-fide purposes.

The Cancer Council Australia and COSA strongly recommend these measures as follows. While consistent with a number of proposals in Discussion paper 72, the following recommendations are apparently not specifically proposed by the ALRC.

### **Single national ethics committee**

Discussion paper 72 canvasses the need for a single national ethics committee to consider research proposals that cover multiple jurisdictions and databases, without promoting a specific proposal to achieve such an outcome. The Cancer Council Australia and COSA recommend the establishment of such a committee, with associated recognition by HRECs.

The *National ethics application form* has been an important development in this area. The adoption of this form by all HRECs would also make an important contribution to the

ethics review process – but only on the condition that all HRECs accept the pro forma for ethics review application purposes.

### **Uniform procedures to allow record linkage**

A uniform national approach to data linkages would reduce the risks of individual privacy concerns unnecessarily compromising research clearly in the public interest.

The Cancer Council Australia and COSA recommend a mechanism to facilitate the release of identifiable information where it would contribute to health research that have the potentially to save, prolong or improve the quality of human life. Such situations often arise in individual studies, particularly where data sets need to be linked in order to obtain all the relevant information on a particular individual.

Concerned that use of private information in health research (particularly in light of the broader definition of research proposed) may compromise privacy principles could be addressed through tighter and more specific definitions of “research”. It is recommended that “epidemiology research” be specifically identified in the context of exceptions to privacy legislation in this context, “multiple database epidemiology” as an additional criterion as appropriate.

These measures would identify the need for population-based study, commonly involving one or more pre-existing databases, drawing on National Health and Medical Research Council guidelines and HRECs.

Privacy guidelines for “epidemiology research” could enable potentially sensitive information (such as individual names) to be available for interrogating a database, then de-identified before analysis is presented to chief investigators. Further exceptions could apply where it is important to the validity and usefulness of the study for names (or other identifying information) to be provided to the investigators (but not being made available to the public). Those having access to the identifying data could be subject to an oath of professional conduct (a breach of which would be an offence), thereby removing the need for privacy considerations to be addressed in the course of individual project-based applications for HREC approval.

Specification of “multiple database epidemiology” could be calculated to address privacy concerns in studies that involve multiple databases or multiple contributors to a single database. The current situation can require applications to multiple (sometimes more than 10) HRECs for a single project. The establishment of a single national ethics committee (see above) would also be of assistance in this regard. The goal would be for the legislation to recognise either a national HREC or one of a group of otherwise defined “senior HRECs” to approve, on a once-for-all basis, the project in question. Such approval would then permit participation of each of the databases with copy to, rather than approval of, the relevant institutional HREC.

## References

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- <sup>1</sup> Australian Institute of Health and Welfare, Cancer in Australia: an overview 2006, 2007.
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- <sup>3</sup> Australian Institute of Health and Welfare, Cancer incidence projections 2001-011, 2005.
- <sup>4</sup> Australian Institute of Health and Welfare, Cancer in Australia 2001, 2004.
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- <sup>6</sup> Beeke, Olver, McLaughlin, A survey of patients' attitudes towards the use of their health data, Journal of Registry Management, 2007.
- <sup>7</sup> ALRC, Essentially yours: the protection of human genetic information in Australia (ALRC 96), 2003.
- <sup>8</sup> ALRC, Discussion paper 72, *Review of Australian Privacy Law*, 2007.