



29 November 2020

## SUBMISSION TO THE PRIVACY ACT REVIEW

### About the Rights in Records by Design project

The Monash University led, [Rights in Records By Design](#) project brings together archival and recordkeeping, history, social work and early childhood education researchers at Monash University and Federation University Australia . Our research project focuses on identifying and articulating the role of records as a fundamental pre-requisite to enabling the assertion of human rights for individuals, particularly children, thereby highlighting the obligations of organisations of all kinds (government, private, not-for profit) to attend to recordkeeping obligation and responsibilities for those they affect. Our project involves working with consultation those affected by poor or non-existent recordkeeping practices in child welfare and protection systems. This Australian Research Council funded research seeks to fundamentally redesign and reimagine recordkeeping and archival systems to support responsive and accountable child-centred out-of-home care and as an enabler of historical justice and reconciliation. One project stream is the development of a [Charter of Lifelong Rights in Childhood Recordkeeping in Out-of-Home Care](#).

### General rights-based approach

A robust review of the Australian Privacy Act is overdue. We fully endorse such a review, and suggest that a rights based approach to privacy be introduced. This means establishing an overarching right to privacy within which a variety of other rights can be articulated. Such an approach would bring Australia into conformance with other privacy frameworks, particularly those articulated in Chapter 3 of the European Union's General Data Protection Regulation. A rights based focus aligns to broader human rights frameworks. It should be applicable to all private and public entities, regardless of size, collecting information about, relating to, or affecting an individual or communities representing groups of individuals. Recognising community rights and different cultural concepts of privacy should not be neglected as the individual is privileged.

### Recordkeeping Rights

There is a significant overlap between the research findings of the Rights in Records By Design project and the articulation of a rights based framework for privacy. Our research into rights-based recordkeeping for out-of-home Care has identified and analysed authoritative sources that provide testimonial and instrumental warrant of human rights and child rights linked to Care recordkeeping. These include the many formal inquiries into systemic issues relating to individuals in a range of circumstances such as removal from family, alternative care situations and youth justice regimes. In these reports, the absence of documented decision making in the form of sustainable records has been demonstrated to have a life long impact on individuals and their safety, wellbeing, autonomy

and to their capacity to hold individuals and organisations to account. Recordkeeping could be articulated as a systematic mechanism to create and maintain data and information over time. As such, our articulation of recordkeeping rights overlaps with concepts which can be expressed within a privacy framework. We argue that recordkeeping is one of the fundamental systemic mechanisms for instantiating any such rights.

## Apply concepts widely

We note that discussion on information rights generally can easily fragment into dispute about the form/format of the data. We advocate an approach that positions all forms of information on a continuum of aggregation, with every level of aggregation being able to be considered from multiple perspectives simultaneously. This approach renders pointless and unproductive any discussions which create competing frameworks for data, information, records, geared towards boundary protection, carving out territory and increasing complexity for implementation. We urge that the framing of any new legislation establishes clear expectations that the rules apply to all forms, formats of data, information and records at any level of aggregation.

However, it is a reality that, at present, data practices often seek to evade incorporation into frameworks that seek to limit their operational remit. Innovation in service delivery should not come at the expense of personal privacy protections. The language and orientation of digital technology creates an emphasis on automatic data collection, continuous digital monitoring and surveillance through technologies collecting data from a myriad of devices, and datafication of individuals. The proliferation and exploitation of this ancillary data that creates the digital shadow for all individuals as we proceed through our lives is one of consequences of technologies which are creating unseen dangers and vulnerabilities to individuals and communities causing significant, and rising, social concern.

No data controls, privacy rights, complaints mechanisms or reporting requirements are sufficient unto themselves to hold wrongs to account. All these components should be brought together into a coherent framework. Any approach established should acknowledge that the creation, maintenance and continued preservation of evidence of actions (records) are required to facilitate the operationalisation of rights in the digital environment.

We acknowledge that the current state of organisational information systems containing personal information are generally poor, often disconnected, fragmented and may operate across jurisdictional boundaries. These systems, designed without adequate privacy protections, encourage discounting of basic protections as an inhibitor of innovation. While acknowledging the problems of the current operating environment, and the often parlous state of legacy data, these should not be able to be used as an excuse for enabling or ignoring behaviours that put personal information and privacy at risk.

## Specific rights

We recommend a rights based approach to privacy include the following rights:

- The right to opt out of some or all data collection about oneself, without penalty or consequence, in situations where sufficient justification for collection is not made explicit or

where collection practices exceeds principles of data minimization (only collecting what is specifically needed to provide the nominated service).

- The right to disclosure: knowing what data is collected about an individual, who has it and where it is held, when and what it is used for.
- The right of access: the right to unredacted access to records created about oneself, including records of decision making that affects oneself. This right should acknowledge intergenerational access, but prioritise any expressed wishes of the individual.
- The right to obtain copies, at no cost, of data collected about oneself. Such data/information/records should be interpretable by humans, presented in context of its collection and use, and be identified in ways that preserve the links to the original organizational system of creation/collection.
- The right to annotate or correct data and records held about oneself. This right should extend existing frameworks for personal data correction and enables alternative interpretations to be incorporated into the record and be treated as having equal authority, at the discretion of the individual, not the organization.
- The right to meaningful consent: Consent to collection, access, sharing, destruction of data about oneself should be meaningful, informed, timebound and subject to explicit periodic and use-case renewal. The mechanisms for consent need significant re-thinking in order for them to be effective, with the well known problems of click through consent agreements and common linkage to refusal of services significantly undermining the concepts of consent which should be rethought and strengthened.
- The right to know, and consent to, the sharing of data with bodies (included automated decision making tools) other than the original organization purpose for collecting the data/information, including details of what, when and under what conditions such sharing is proposed to/or has taken place.
- The right to hold organisations or individuals to account for misuse of personal information.
- The right to be forgotten: the right to require organisations to permanently delete data about oneself on request.

## Definition of personal information

The definition of personal information must be broadened to include identifiers, metadata maintained in systems, and information able to be inferred about an individual.

Barbara Reed, Research Fellow  
Professor Sue McKemmish and  
Associate Professor Joanne Evans  
Digital Equity and Digital Transformation Group  
Faculty of Information Technology  
Monash University  
Telephone +61 413217513  
Email [Barbara.reed@monash.edu](mailto:Barbara.reed@monash.edu)