SUBMISSION

Review of the Privacy Act 1988

Australian Government

Attorney-General's Department

sent via PrivacyActReview@ag.gov.au

23 December 2021

Lived Experience AUSTRALIA

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Introduction

Lived Experience Australia (hereafter LEA) is a national representative organisation for Australian mental health consumers and carers, formed in 2002 with a focus on the private sector. Our core business is to advocate for systemic change, empowerment of consumers in their own care, promoting engagement and inclusion of consumers and carers within system design, planning and evaluation and most importantly, advocating for consumer choice and family and carer inclusion.

LEA is pleased to provide this Submission into the Australian Government's Attorney General's Department review of the Privacy Act 1988 – Discussion Paper and note reference to the Privacy Legislation Amendment (Enhancing Online Privacy and Other Measures) Bill 2021 (OP Bill).

LEA has focussed on the main areas we consider most critical to the people we represent.

Given mental ill-health and mental illness, personal information is particularly sensitive and could be perceived by many in a discriminatory manner, i.e., employment applications, university admission, insurability both life and income protection etc LEA is keen to provide this Submission as the people we represent, could be disadvantaged if privacy issues were either not maintained or breached.

As with any information, data etc LEA is concerned about hacking or illegal use, but we are also cognisant that full protection these days is impossible, so our approach to this Discussion Paper is one of what is in the best interests of an individual, and what protections should the Act provide.

1 Objects of the Act

LEA is of the view that clear text is required so that ambiguity in relation to defining content is removed. As such LEA supports objects that unequivocally protect the rights to privacy of the individual.

2 Questions

In practice, what types of information would the proposed definition of personal information capture which are not presently covered? (Page 28)

LEA is of the view that the review covers the types of information that is needed. The key to the information must be in a 'non identifiable' manner, and any identifying markers must be such, that persons cannot be linked in any way. LEA therefore supports the term to be changed to 'anonymous' which then removes the need for concern as this is quite clear.

We also believe that the definition of 'personal information' must be clear, to ensure obligations of entities are clear.

LEA notes researchers' comments during previous consultations regarding the use of data collection, however in all cases LEA considers this is only available in a manner which does not identify a person.

Furthermore, in terms of data sets, collection, retention and distribution of data, clear protocols for the protection of individuals must be enforced that record access to identified data, by whom, when and what data has been accessed. Additionally, clear protocols must be enforced by data custodians including administrators of data sets.

We note the term 'whether true or not' and are concerned about the possibility of maliciously provided information. This should be clearer, and reference deleted in this case. For example, once something is in electronic case-notes, whether true or not, it has a habit of sticking and then being misinterpreted as 'evidence' or 'facts'. LEA is aware of mental health consumers who have accumulated mental illness related diagnoses over many years, some which have later been found to

be incorrect, but then find it impossible to have reference to an incorrect diagnosis removed. This can have later adverse implications for employment, study, insurance, etc.

What would be the benefits and risks of amending the definition of sensitive information, or expanding it to include other types of personal information?

LEA notes the concerns regarding definitions, i.e., 'sensitive' vs 'personal' which were not generally supported by previous consultations. However, LEA has a different view; we believe there is a difference, and as such, should be reflected in the Act.

For example: Disclosures of sexual abuse would be classed as more than merely 'personal' information; they should be understood as 'sensitive' because they are likely to be more strongly linked to trauma and require a trauma-informed approach to management of this information. Their management within systems is always tricky within systems where the benefits of coordinated care are important across various health care providers, but the person's ability to have a say about which health professionals know about this can then compromised.

LEA asks the question: Is the system nuanced enough to take the person's concerns into account?

Protection of individuals is paramount and at the core for the reasons for the Act.

LEA supports the term 'anonymous information' inserted rather than 'de-identification' to ensure a clear signal and requirement to all APP and other entities to meet the higher, irreversible standard reflected in this term.

Sensitive information

Within the definition of personal information, there is reference to 'sensitive information' which specifies types of personal information, including 'health information' that are subject to additional protections, LEA supports this view.

LEA is of the view that health information is certainly sensitive information and should be updated within the Act. We note the exemptions but also note the lack of reference to broader public interest exceptions and the impact on medical professionals. What concerns LEA is under legal proceedings especially those of family law or sexual assault cases, health professionals are required to provide information by the courts or opposing counsel, for example, for matters under investigations i.e., subpoenas. For patients of mental health professionals, fear of disclosing certain information or experiences during therapy, could affect their outcomes negatively, for fear this information being used against them in court proceedings.

Consent

LEA notes the Online Privacy Bill (OP Code) and the clear requirements for consent. We believe these should also be included and introduced within the definition of consent within the Act.

LEA also supports the need for periodic renewal i.e., when 'one off' consent for long term use is taken. People's circumstances change, and what is relevant now, may not be relevant or indeed the person may change their mind in terms of consent, later.

Those in mental health care at times can lose the capacity to make informed consent because of an episode, crisis, or deterioration in their mental health status. The Act recognises certain people as 'responsible people' but this too can change over time. LEA is of the view that continual reviewing and renewal of consent process should be enshrined within the Act.

We also note concerns that under Mental Health legislation, people can have a guardian, or third party make decisions on their behalf. With the increased use of Advance Directives, LEA supports specific reference to these documents within the Act which clearly recognise a person's preferred party to make decisions on their behalf.

Consumer comprehension testing

We think this is an interesting idea. We know from the literature on 'Voting' that having a tool to assess this can be fraught. i.e. *I might be detained in a closed ward and my capacity to give consent may be compromised…but I still know that I prefer dark chocolate to milk chocolate, or I can still and should be still asked which clothes I want to wear that day, etc*. So, capacity to provide consent is not 'total' or completely inclusive as a concept.

3 Jurisdictional differences – treatment of 'health information'

Clearly, improvements in this area are important, particularly for people who may have need to seek mental health care across jurisdictions and families who may live in other jurisdictions to the person they care about.

Cross-border communications that clarify access processes, rights, responsibilities, etc would be critical. We know from practice, each jurisdiction has a separate Mental Health Act with only some having reciprocal rights for people under detention or community treatment orders, to transfer across state/territory boundaries for the purpose of being closer to family, kinship, community and supports.

Given the critical nature of the Act to people with mental ill-health, mental illness etc and the implications of discriminatory practices should information be leaked, LEA requests a representative on any working group which could be established to oversee the harmonisation.

4 Contact

We would welcome the opportunity to have further discussions with you on this critical issue. We have been represented on a mental health working group in the past, which reviewed the previous Act and its applicability specifically to mental health professionals and mental health consumers, families, and carers.

We believe as a national organisation we are well placed to be able to provide further clarification and input into this area.

Please feel free to contact me, my details are below.

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