

## **Submission from the Centre for Law and Genetics**

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These guidelines each play an important role and we support their extension for a five year period. We endorse the logic of not reviewing these at this time in the light of the *Privacy Act* Review, which is anticipated to have implications for the operation of the guidelines, at least for the two research related guidelines (s95, s 95A).

The only concern that we have about what is proposed is the ‘self-repeal’ of the guidelines. This isn’t elaborated on in the information provided but we take this to mean that after the end of the five year extension, the guidelines will automatically be repealed.

We are troubled about creating this ‘cliff’ effect as this may leave a void and create uncertainty for stakeholders should the broader review of the guidelines be delayed or incomplete at this time. We recommend that the preferred approach would be to review the guidelines toward the conclusion of the five-year period to assess the implications of the *Privacy Act* Review on the guidelines. This should include the standards for authorising a waiver of consent as well as the appropriate body to provide such an authorisation. (For your information, a number of us have recently had a paper published on this topic: L Eckstein, M Otlowski, M Taylor and R McWhirter, ‘Reversing the ‘Quasi-Tribunal’ Role of Human Research Ethics Committees: A Waiver of Consent Case Study’ (2023) 46(2) *University of New South Wales Law Review* 498-534.)

This concern relates to each of the guidelines, but we particularly note this in relation to the s95AA guidelines (use and disclosure of genetic information of an individual to that individual’s genetic relatives by health practitioner) as these are clinical, not research related, guidelines and are unlikely to be affected by the review process. We believe it is imperative that we avoid creating uncertainty for health practitioners navigating this complex domain which this proposed self-repeal clause would create. Uncertainty in this context would most likely lead to health practitioners choosing not to disclose clinically-actionable genetic information to at-risk relatives, potentially leading to delayed preventive or therapeutic interventions with negative consequences for the health outcomes experienced by affected individuals. Ensuring that health practitioners feel confident in their legal position when disclosing genetic information of this nature is the purpose underpinning the s95AA guidelines.

In summary, we support the five-year extension of these guidelines but recommend that reference to ‘self-repeal’ of the guidelines be removed and that instead a process is put in place for the review of the guidelines as would normally be done, allowing for consideration of the *Privacy Act* Review outcomes and ensuring that there is continuity of the guidelines where required.