To whom this may concern,

Please accept this email as a submission to the OAIC's Consultation on health and medical research guidelines. I hope you will be able to accept this despite it being submitted shortly after the deadline. This submission pertains in particular to the **s95AA Guidelines**.

I wish to make **three brief points** regarding these guidelines.

1. I am concerned that a self-repeal clause will leave those bound by the Cth Privacy Act in a legal vacuum regarding the discretion to disclose genetic information to at-risk relatives. Even with the best intent, new regulation may not be in place after five years. To this end, I urge the OAIC to keep these guidelines current unless or until a suitable replacement is identified. The s95AA guidelines were innovative globally when they were introduced, as they carefully allow the disclosure of genetic information, with significant discretion resting with the clinical team. The s95AA guidelines have also been effectively mirrored in NSW, meaning this is the only state that provides consistency of regulation (and thus certainty for stakeholders) about disclosure of genetic information to at-risk relatives.
2. It should be borne in mind that the s95AA regulations apply only to clinical practice, and not research. The summary of the Privacy Act Review on the Consultation website relating to the rationale for the proposal only focuses on research, not clinical practice. It is imperative that health care professionals handling this information have certainty in their practice and to this end the s95AA guidelines may need to be considered exceptionally.
3. When the time is right (for example when there is more certainty about amendments to the Privacy Act), the s95AA guidelines would benefit from a refresh, to allow them to better integrate and respond to developments in the field of genomics since they were first drafted. For example, there are now gaps regarding:
    a. Provision of clinically accredited testing in a clinically accredited laboratory, yet via research funding. Would such tests fall under the guidelines?
    b. Information gleaned from carrier testing, e.g. to inform reproductive benefit. Now there is Medicare funding for some such tests, they will be undertaken more frequently
    c. Polygenic scores and whether/how they may fall under these guidelines.

I am willing for this submission to be made public.

Kind regards,

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