

26 August 2021

Mr Robert Long
Director, Health Section
Social Statistics Division
Australian Bureau of Statistics

Via email robert.long@abs.gov.au

Dear Mr Long,

Re: Request for comments into draft Privacy Impact Assessment for the National Health Measure Study"

Thank you for contacting the Consumers Health Forum (CHF) as a member of the ABS Health Statistics Advisory Group requesting additional comment to the draft Privacy Impact Assessment (PIA) for the National Health Measure Study (NHMS). Ensuring that Australia has detailed, accurate and precise granular data about the health of its population is a key interest and priority for CHF as such data underpins much public policy in this area.

As an initial point, we note that the draft PIA was provided to CHF on Friday August 6th with feedback requested by Wednesday August 18th. Given the length of the draft PIA and attachments, eight business days is far too short to be a reasonable a consultation period for stakeholders. This is particularly true given the other pressing demands in the health space at this time. We hope that this was a one-off error and would urge you to build more time for consultation into your projects in future.

In our view, all the recommendations proposed in the PIA are sensible and should be adopted. We strongly support the use of both tiered consent and dynamic consent in the NHMS, based on research we have done we recommend people be prompted on an annual cycle to review and reconfirm their consent arrangements.

We also support the unbundling of NHMS participation and inclusion of data in the ABS MADIP project, letting people do the former without the latter if that is their preference. Not giving Australians full choice in where the data does and does not

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go will bias the data collected as some inevitably refuse to participate in the NHMS, reducing the value of the NHMS.

In addition to the above, we believe it should be explicitly established that the participants/consumers retain full ownership over their samples that are held in the biobank. Following that a clear liability system, including civil/criminal penalties for breaches of privacy or data security and participant compensation, should be established to ensure full efforts are made by all participating bodies to protect people's data and privacy and ensure full buy-in from the Australian public.

We would also recommend that given the large number of parties, contracts and subcontracts a clear grievance/complaint procedure be set up that encompasses the whole project and all participating parties, allowing for participants with issues have them adequately addresses. Finally, the Data Custodian should be given Ombudsman-like powers to take complaints and check the probity of researchers and their institutions, as well as the robustness of their data and/or sample handling processes. It should have the same investigative power over the pathology provider and other contractors/sub-contractors involved in the project, with no in-confidence or other confidentiality clauses should impede its functions

Thank you once again for the opportunity to provide further input into the NHMS. Should you require any additional comments or feedback, please don't hesitate to contact us.

Yours sincerely,



Leanne Wells
Chief Executive Officer

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