

26 September 2024

Consultation team
ARTD Consultants and Sax Institute

By email only: submissions@artd.com.au

Dear consultation team,

Proposed use of data by the Australian Centre for Disease Control

Thank you for the opportunity to provide a submission on the planned use of data by the Australian Centre for Disease Control (CDC).

The Office of the Victorian Information Commissioner (OVIC) has combined oversight of freedom of information, privacy and information security, administering both the *Freedom of Information Act 1982* (Vic) and the *Privacy and Data Protection Act 2014* (Vic).

OVIC understands a federal CDC would enable Australia to respond to nationwide health emergencies and threats in an effective and proactive manner. This submission provides comments on privacy and security considerations in relation to the CDC's planned use of personal and health data.

As the CDC is a federal agency, any collection, use and disclosure of personal and health information will need to comply with the privacy obligations in the *Privacy Act 1988*. OVIC would encourage the CDC to engage closely with the Office of Australian Information Commissioner for guidance on the application of the Australian Privacy Principles (APPs).

OVIC also encourages the CDC to engage with the Victorian Health Complaints Commissioner as the relevant regulator of health information for both public and private Victorian healthcare providers.

Collection, use and disclosure of personal and health information

OVIC understands the CDC plans to collect, use and disclose information from individuals and organisations based in Australia and overseas.¹ OVIC suggests the CDC collects the minimum amount of personal and health information necessary to undertake its activities and functions. Collecting only

¹ https://consultations.health.gov.au/health-emergency-mangement/cdcdata/user_uploads/why-is-the-new-cdc-important-to-protecting-our-health-2.png; https://consultations.health.gov.au/health-emergency-mangement/cdcdata/user_uploads/what-is-health-data-2.png; https://consultations.health.gov.au/health-emergency-mangement/cdcdata/user_uploads/what-kinds-of-data-will-the-cdc-use-3.png.

the minimum amount of information necessary reduces the attractiveness of the data set to threat actors and reduces the consequences of a large-scale data breach.

Transparency

Building an effective CDC requires building and maintaining trust with the Australian public. Australians are increasingly concerned about how organisations are using their data following recent large-scale data breaches.²

The CDC must ensure that individuals are provided with timely, accessible and clear communications about how their personal and health information will be used by the CDC. Individuals should be notified about how their information will be handled at the time it is collected, and those organisations who are sharing personal and health information with the CDC, should also inform individuals about the potential disclosure to the CDC. OVIC encourages the CDC to build notification pathways into its processes. It is also important for the CDC to have information on its website about how it handles personal and health information.

Culturally and linguistically diverse (CALD) communities may also struggle to share personal and health information due to language barriers, mistrust in government agencies and other difficulties. The CDC may wish to consider consulting with the Australian Institute of Health and Welfare³ and the Culturally and Linguistically Diverse Communities Health Advisory Group⁴ to develop appropriate communication pathways with people from CALD backgrounds. This will help the CDC improve the health outcomes of diverse Australians.

Data de-identification and destruction

OVIC notes the CDC's plan to use de-identified data and linked data sourced locally and globally to enhance health decision making.⁵ It is unclear if the CDC will de-identify data in-house, through external parties, or will receive data already in de-identified form from the organisations that will share data with the CDC. Combining de-identified data with disparate or linked datasets will increase the risk of re-identifying previously de-identified information. CDC may wish to consider ingesting de-identified information directly from its partners, where possible, to minimise the risk of re-identification and protect the privacy of individuals.

² <https://www.theguardian.com/australia-news/2023/aug/08/australia-cybersecurity-laws-hacks-optus-medibank-privacy-data-breach>; <https://www.oaic.gov.au/engage-with-us/research-and-training-resources/research/australian-community-attitudes-to-privacy-survey/australian-community-attitudes-to-privacy-survey-2023>.

³ <https://www.aihw.gov.au/reports-data/population-groups/cald-australians/overview>.

⁴ <https://www.health.gov.au/committees-and-groups/culturally-and-linguistically-diverse-communities-health-advisory-group>.

⁵ https://consultations.health.gov.au/health-emergency-mangement/cdcdata/user_uploads/why-does-the-proposed-cdc-need-to-use-health-data.png; https://consultations.health.gov.au/health-emergency-mangement/cdcdata/user_uploads/will-the-cdc-know-information-about-individual-people-s-health-3.png; https://consultations.health.gov.au/health-emergency-mangement/cdcdata/user_uploads/why-is-the-new-cdc-important-to-protecting-our-health-2.png; https://consultations.health.gov.au/health-emergency-mangement/cdcdata/user_uploads/what-is-linked-data-1.png.

The CDC has defined *de-identified data* as “data that does not include people’s names or contact details”.⁶ However, it is still possible to identify individuals without using names and contact details. OVIC recommends revisiting this definition and internal de-identification processes to ensure other information that may identify an individual is also removed as part of the de-identification process. It is important for the CDC to be aware of the limits of de-identification. OVIC has produced guidance on de-identification that may be helpful in exploring this issue further.⁷

To further mitigate the risk of re-identification, OVIC recommends data destruction over de-identification once personal and health information is no longer required.

Data security

OVIC notes the CDC proposes to rely on the Five Safes Framework to protect and secure information held by the CDC.⁸ The CDC may wish to consider how it will put the Five Safes Framework into practice, including establishing policies, processes and procedures for adhering to the APPs and setting up strong privacy and security governance arrangements. Note that the Five Safes framework only works where the controller controls and manages the data effectively. If the data controller shares the data without particular care concerning re-identification risks, then a crucial component of the Five Safes is removed.

Cross border data sharing

OVIC understands the CDC will use global health data sources to support its work.⁹ However, it is unclear if the CDC will share any personal, health or de-identified information outside of Australia. The CDC may wish to ensure information that is shared outside of Australia remains subject to the same or equivalent privacy protections, including data retention and destruction requirements.

I have no objection to this submission being published by ARTD Consultants, the Sax Institute, or the CDC subject to my signature being removed. I also propose to publish a copy of this submission on the OVIC website.

⁶ https://consultations.health.gov.au/health-emergency-mangement/cdcdata/user_uploads/will-the-cdc-know-information-about-individual-people-s-health-3.png.

⁷ <https://ovic.vic.gov.au/privacy/resources-for-organisations/an-introduction-to-de-identification/>;
<https://ovic.vic.gov.au/privacy/resources-for-organisations/the-limitations-of-de-identification-protecting-unit-record-level-personal-information/>.

⁸ https://consultations.health.gov.au/health-emergency-mangement/cdcdata/user_uploads/the-5-safes-2.png.

⁹ https://consultations.health.gov.au/health-emergency-mangement/cdcdata/user_uploads/why-is-the-new-cdc-important-to-protecting-our-health-2.png.

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If you would like to discuss this submission, please do not hesitate to contact me or my colleague Fathia Tayib, Senior Policy Officer, at fathia.tayib@ovic.vic.gov.au.

Yours Sincerely



Sean Morrison

Information Commissioner