



WANADA Submission on Privacy and Responsible Information Sharing

About WANADA

The Western Australian Network of Alcohol and other Drug Agencies (WANADA) is the peak body for the alcohol and other drug education, prevention, treatment and support sector in Western Australia. WANADA is an independent, membership-driven not-for-profit association.

WANADA is driven by the passion and hard work of its member organisations, which include: community alcohol and other drug counselling; therapeutic communities; residential rehabilitation; intoxication management; harm reduction; peer based; prevention; and community development services.

Privacy and information sharing in the specialist alcohol and other drug service sector

WANADA supports efforts to clarify and improve privacy protections within the WA public sector. We are, however, concerned about the potential implications of the proposed privacy and responsible information sharing legislation for the specialist alcohol and other drug service sector. Further consultation with service users and service providers is essential to inform the proposed legislation and avoid unintended consequences.

Currently in Western Australia, many non-government organisations (NGOs) that provide state-funded alcohol and other drug treatment services enter a unique data relationship with the Mental Health Commission (MHC). NGOs provide the MHC with service user data related to treatment episodes, including the Alcohol and Other Drug Treatment Services National Minimum Data Set. Under the current policy agreement, the MHC is the custodian of this data. It is currently unclear how this custodian arrangement may be impacted by the proposed privacy and information sharing legislation, in particular potential information sharing arrangements between the MHC and other public sector agencies or associated third parties. There is a similar lack of clarity for those NGOs that deliver integrated services with government-operated services such as Next Step.

Service user data collected within the specialist alcohol and other drug service sector is highly sensitive and must be managed accordingly. There are potential benefits to the appropriate sharing of aggregated de-identified data for the purposes of research, policy, and service planning. There remains, however, the risk of potential negative consequences from the sharing of service user data between agencies, including reduced trust and help-seeking behaviour by service users. We note there have been examples at the federal level, such as within the social services portfolio and through the My Health Record initiative, where data availability and sharing have had unintended and adverse consequences for vulnerable people.

It is WANADA's position that managing data and privacy for people experiencing harms associated with alcohol and other drugs requires additional targeted consultation with service users and specialist service providers, so as to avoid unintended consequences.

Key considerations in developing privacy legislation in WA

Data sharing arrangements and stigma¹

With the information currently available, WANADA has strong reservations regarding information sharing between government agencies, or with associated third parties, for the purpose of service delivery. There may be some benefits to sharing identified data, but there are also significant risks to service users:

People with chronic conditions and people with complex needs can find themselves struggling to overcome the weight of accumulated judgements made about them by various professionals they work with. These judgements are held in records that are passed from one agency to another, from one worker to another. People need to be able to start again, to have an opportunity to be taken for who they are now, not for who they have been deemed to be by previous case workers, medical staff and others they have worked with.

– Statement from WANADA member organisation

People affected by alcohol and other drugs experience significant levels of stigma and discrimination. Illicit drug dependence is the most stigmatised social health condition in the world; alcohol dependence is rated fourth.²

Stigma impedes help seeking behaviour and results in discriminatory practices that inhibit access to health and human services.³

The need to address stigma has been widely recognised in government strategies. For example, the *WA Alcohol and Drug Interagency Strategy 2018-2022* affirms the need to:

...reduce the stigma experienced by service users and their families when they seek support for their problems associated with alcohol and other drug use to increase service engagement with appropriate programs and services.⁴

Data sharing arrangements involving sensitive information relating to alcohol and other drug use have the potential to expose people, families and communities to further stigma and discrimination. The State Government must ensure that the proposed legislation is developed with this sensitivity and risk in mind. In particular, data sharing between government agencies, or with associated third parties, should be restricted to those service users and organisations that have provided informed consent through a robust and voluntary opt-in arrangement. This must include mechanisms for the review and/or withdrawal of consent.

Consultation and co-design are needed to ensure successful implementation⁵

For the successful implementation of privacy and information sharing arrangements, service users and providers must be involved in a genuine co-design process. This includes co-design of:

- Criteria and procedures for determining whether an information sharing project meets the 'Five Safes'.
- Procedures for obtaining informed consent for information sharing between government agencies, or with associated third parties. This must address the needs of all service users, including those who are vulnerable or for whom language presents a barrier to engagement.
- Procedures for making complaints and raising breaches of privacy with the proposed Privacy Commissioner.

¹ Response to discussion paper question 1 (What issues should be considered when developing privacy and information sharing legislation for Western Australia?); questions 5 (When should government agencies be allowed to share personal information? Are there any circumstance in which it would not be appropriate to do so?) and 9 (Under what circumstances would it be considered acceptable to share confidential information within the public sector).

² Kelly, J F & Westerhoff, C M (2010) Does it matter how we refer to individuals with substance-related conditions? A randomized study of two commonly used terms, *International Journal of Drug Policy*, vol. 21, no. 3, pp. 202–207.

³ Global Commission on Drug Policy (2017) *The World Drug Perception Problem: Countering prejudices about people who use drugs*, p.28. Available at: <http://www.globalcommissionondrugs.org/reports/changing-perceptions/>. Accessed on 17/12/18.

⁴ Mental Health Commission (2018) *Western Australian Alcohol and Drug Interagency Strategy 2018-2022*. Mental Health Commission, Government of Western Australia, p37.

⁵ Response to discussion paper questions 1 (What issues should be considered when developing privacy and information sharing legislation for Western Australia?) and 10 (What should the WA Government be doing to support successful implementation of privacy and information sharing?).

- Education and capacity building initiatives to help service users and providers understand the implications of any new legislation.

The self-determination of Aboriginal peoples must also be considered in the planning, consultation, development, and implementation of privacy and information sharing legislation in Western Australia. In doing so, data sovereignty and governance must be respected, so that Aboriginal peoples, communities, and organisations are involved in decision making regarding when and to whom data can be shared.^{6,7}

Associated third parties' needs⁸

NGOs that receive state funding to deliver alcohol and other drug treatment services must currently comply with the Australian Privacy Principles under the *Privacy Act 1988*. It is possible that data sharing arrangements arising from the proposed privacy and responsible information sharing legislation will encompass these organisations. As such, any new privacy protections should be compatible with the Australian Privacy Principles and requirements under the *Privacy Act*, and not present a duplication or additional layer of requirements.

Breaches of privacy must be addressed⁹

Breaches of privacy could have significant consequences for service users, including impacts on trust, stigma and discrimination, help-seeking behaviour, and service provision. There must be appropriate responses to privacy breaches to ensure that learnings are embedded in system processes, thereby preventing future privacy breaches.

Where there are breaches in privacy, the Auditor General or proposed Privacy Commissioner may play a role in auditing agency practices and recommending changes in procedures and practice.

⁶ Maïam nayri Wingara and Australian Indigenous Governance Institute, Indigenous Data Sovereignty Communique, Indigenous Data Sovereignty Summit, 20 June 2018. Available at: <http://www.aigi.com.au/wp-content/uploads/2018/07/Communique-Indigenous-Data-Sovereignty-Summit.pdf>. Accessed on 14/10/2019.

⁷ Snipp, C M (2016), What does data sovereignty imply: what does it look like?, p52. In Kukutai, T. and Taylor, J. (eds), *Indigenous data sovereignty: Toward an agenda*, Research Monograph No. 38, ANU Press.

⁸ Response to discussion paper questions 1 (What issues should be considered when developing privacy and information sharing legislation for Western Australia?) and 10 (What should the WA Government be doing to support successful implementation of privacy and information sharing?).

⁹ Response to discussion paper question 4: How should breaches of privacy be managed, and what action should be taken in response to a breach?