

Department of the Prime Minister and Cabinet
datalegislation@pmc.gov.au

Re: Submission to the New Australian Government Data Sharing and Release Legislation Issues Paper for Consultation

To the Department of the Prime Minister and Cabinet,

Thank you for the opportunity to provide feedback on the New Australian Government Data Sharing and Release Legislation Issues Paper for Consultation (Issues Paper). We are:

The **National Association for People with HIV Australia (NAPWHA)** is Australia's peak non-government organisation representing community-based groups of people living with HIV (PLHIV). We provide advocacy, policy, health promotion, effective representation, and outreach on a national level, and work includes a range of health and education initiatives that promote the highest quality standard of care for HIV-positive people.

Positive Life NSW is the state-wide peer based non-profit organisation that speaks for and on behalf of people living with and affected by HIV (PLHIV) in NSW. We provide leadership and advocacy in advancing the human rights and quality of life of all PLHIV, and to change systems and practices that discriminate against PLHIV, our friends, family and carers in NSW.

We agree that public data has the capability to strategically benefit the Australian public, contribute to economic prosperity, and improve a range of policy outcomes. The 'data' discussed within the Issues Paper for the purposes of developing new legislation, the Data Sharing and Release Bill (DS&R Bill), primarily focuses on private (individual), rather than public, data. We advocate for and support legislation to create more streamlined and efficient processes for sharing and releasing public data within the scope relating to government agencies, the environment, and non-government businesses, held by government agencies. This will contribute to greater transparency, accountability, service efficiency and value, and public trust in government and wider business processes.

We do not support broader scope, open access to individual data, identifiable or de-identified, for purposes other than that which data was originally collected and having received specific informed consent from the individual on a case by case basis. This is particularly the case given the limitations to existing privacy legislation within Australia and the current state of (lack of) respect for the fundamental right to privacy and control of personal information for Australian individuals (data sovereignty). We disagree with the recommendation by the Privacy Commission in 2016 of *"the creation of a data sharing and release structure that indicates to all data custodians a strong and clear cultural shift towards better data use that can be dialled up for the sharing or release of higher-risk datasets"*. Higher-risk datasets, by definition, pose an unacceptably high risk to individual Australian's right to privacy and control over our own personal information and data. Data linkage and use of de-identified data needs to be ethically and transparently managed. Recent evidence of the simple process of patient re-identification risk in public health records, along with privacy breaches confirms the high-risk nature of data sharing and release, even in secure systems and when data is de-identified.

Key Principles - Issues Paper have been proposed *“to realise the immense value of public sector data to improve government services and policies”*. This purpose should be routinely referred to during the development of the proposed legislation processes. Any discussion of release and sharing of data must be underpinned by the principle aim of benefit to the Australian public, not commercial or other private gain.

We assert that the primary aim of the DS&R Bill should be to *“enhance and support the right to individual privacy of data within the context of the Australian data sharing landscape”*. This aim is in addition and supplementary to the five aims currently proposed by the Issues Paper.

Though we agree with the stated aim to *“safeguard data consistently and appropriately”*, we would recommend amending so that the data to be considered by this legislation is public only, and does not include personal, individual data, whether identifiable or de-identified. No release or sharing of individual Australian data, particularly health data, outside of the original purpose and intent of collecting such data, can be consistently and appropriately safeguarded within the landscape of Australia’s current privacy laws. This is particularly the case given a significant amount of data collected about Australian individuals is not reasonably required or relevant to the purpose for which that data is collected, and consent for the gathering of this information is regularly uninformed, misinformed, bundled and/or coerced.

If personal, individual data is to be captured within the DS&R Bill, we recommend strengthening privacy provisions in the Privacy Act, as well as requirements for gaining fully informed, easily-understood, freely-given consent during any data gathering processes. This includes re-attaining consent from individuals any time an amendment in purpose for use of data or data sharing is requested or processed. This is particularly important for individuals who may not speak English as their primary language, have cognition-based impairments, have limited access to information, support or IT literacy to access or amend information gathered about them.

We affirm the stated aim to *“build trust in use of public sector data”* and recommend that this may be achieved through several transparency-based initiatives. Some initiatives could include: 1. automatic notifications sent to individuals when their data is used, shared or released if their information forms part of a dataset (whether identification is possible or not); 2. a public register of all datasets that have been requested, shared or released (with or without the actual data present in the public register depending on sensitivity); 3. a public register of all data custodians, accredited data authorities and trusted users; 4. trusted users must not include individuals, organisations or entities that will be utilising the data released or shared for commercial gain if there is to be trust in the process by the Australian public.

The Issues Paper says that without such Legislation *“improved service delivery and research outcomes will be missed”*. We agree with this in principle, however, the point has been missed that community and consumer partners in research, such as PLHIV and HIV organisations, require investment, support and resourcing. Otherwise, improved public services and service delivery outcomes, especially in health and social service related contexts will not be able to ensure consumers are actively engaged and participate in the design, planning and evaluation of services. When considering health services, social and clinical research and associated legislation at a community level, people need to be resourced, empowered and enabled to assist in making sense of data, so they can actively contribute to efficient and effective outcomes for government and the public. Community resourcing is required during the aggregation of data, as well as, when the questions are asked, for example, what data needs to be aggregated and why? Is the request and data being requested fit for purpose? What are the expected and unintended outcomes, if the data is going to be released and used in this way? The Issues Paper only address the benefits to external

parties of having aggregated data sets made available to them and fails to address the benefits (or potential risks) for individuals or communities.

Purpose - the Issues Paper specifies that the DS&R Bill will have purpose tests inbuilt that will ensure all data shared and released is for the right purposes. Two of these purposes are “*informing government policy making*” and “*supporting the efficient delivery of government services or government operations*”. These purposes must not be overlooked or undermined if and when data accessed by government entities provides proof of a service requirement or adjustment that may be unpalatable to the government entity, particularly when the data is calling for a service or adjustment that would be of significant benefit to Australian citizens. An example of such data providing dissonance can be found with the National HIV Strategy target to end HIV transmission and immigration policy. Currently, services aim to prevent HIV transmission and provide treatment and care to PLHIV yet doesn’t fund programs for people at high risk of HIV acquisition, namely men who have sex with men, or those diagnosed with HIV who are Medicare ineligible. The Australian government continues to avoid funding services for people who are Medicare ineligible while encouraging international student and temporary resident visas holders to come to study and work in Australia. Therefore, the government expects people to pay tax and university fee’s and doesn’t provide access the HIV prevention and treatment services via Medicare.

Additionally, we believe that to achieve the purpose of efficient delivery of services, that government-based public data should be made widely, publicly available for greater transparency and accountability, to facilitate swifter adjustments to services as necessitated by the data made available.

Rights and Responsibilities - Privacy of all individual’s personal information and data is not only an expectation but a fundamental human right. Privacy is not a privilege or a burden to the governmental or economic system, nor a constriction to the efficient functioning of governmental processes and policy outcomes. The right to privacy is one that must be enthusiastically embraced by government in developing this legislation and the processes it aims to outline as an opportunity to foster a stronger data sharing system in relationship with the Australian public. A continual conflation of privacy and confidentiality with undue secrecy will undermine the purpose, aims and processes of the proposed DS&R Bill and contribute to ongoing mistrust by the Australian public in another government privacy-based initiative. We recommend that the framing and processes of the DS&R Bill be focused on and centred around the fundamental right for all individuals to maintain sovereignty over our personal information and data, and control over how our data is accessed and utilised. This extends to building processes into the Bill that provide for tangible mechanisms for individual’s right to opt-in, access, amend and control the storage and use of our personal information and data.

The Issues Paper states that “*the starting point for the data sharing and release framework is a focus on creating incentives for self-management of risks and voluntary improvement of data management practices within public sector agencies*”. The DS&R bill and framework should consider incentivising or legislating for increased responsibilities on public and private sector agencies to strengthen the quality of fit for purpose data acquisition in their data management practices. Only collecting data strictly relevant to the intended purpose of such data collection, and gaining informed, explicit, user-friendly consent at each stage of data collection and use from all individuals involved will better facilitate public trust and efficient processes. There must be significant disincentives and/or penalties for data misuse and non-compliance built into the DS&R Bill if such data management protections are insufficient. We recommend free access to justice and compensation provided to individuals who have had damage caused due to a privacy breaches be built into the Bill.

A further responsibility we recommend be inbuilt into the development of the DS&R Bill is an evaluation framework. This should be in the form of an evaluation of the outcomes from development and implementation of the proposed legislation, the data which is publicly available with a mechanism to allow for amendment of the Bill when evaluated, showing the net costs of the new sharing and release legislation outweigh the benefits received by the Australian public.

Further Ethical and Data Protection Considerations - the proposed aims and purpose the DS&R Bill, if developed and implemented appropriately and ethically, will no doubt contribute to numerous benefits to government processes, economic performance and service delivery. Balancing the benefits to the Australian public, economy and governmental processes with the risk of breach of privacy and harm to individuals, particularly our most isolated, discriminated against, and oppressed populations must not be overlooked. At all times the Australian government is charged with protecting its citizens, and particularly its most vulnerable citizens. NAPWHA and Positive Life respectfully advocate for the principles underpinning the proposed DS&R Bill be the ethical consideration and upholding of all Australian individual's fundamental human right to privacy and sovereignty over our own personal information.

We note Australia is observing the European Union General Data Protection Regulation, rather than actively exploring the development and implementation of like legislation. With respect, it may have been prudent if the Australian Government had concurrently introduced a Data Protection Bill along with DS&R Bill and amendments to the Privacy Act, so the public, community organisations and researchers could comprehend the relationship and intersectionality across differing pieces of legislation and what this means for us.

If additional information or citations in relation to this submission are required, please feel free to contact Craig on craigc@positivelife.org.au or Aaron on aaron@napwha.org.au.

Yours sincerely,

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