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Mr. Iwan Walters MP

Chair Scrutiny of Acts and Regulations Committee

Parliament House

Spring Street

East Melbourne, Vic, 3002

By email only: iwan.walters@parliament.vic.gov.au
sarc@parliament.vic.gov.au

Dear Mr Walters,

RE: Health Legislation Amendment (Information Sharing) Bill 2023

We are writing to you in your role as Chair of the Scrutiny of Acts and Regulations Committee of the Victorian Parliament regarding the recent re-introduction of the *Health Legislation Amendment (Information Sharing) Bill* 2023 ('the Bill') and wish to express our serious concerns regarding aspects of the Bill.

The Law Institute of Victoria (**LIV**) is Victoria's peak body for lawyers and those who work with them in the legal sector, representing over 18,000 members. The LIV has a long history of contributing to, shaping, and developing effective legislation.

Executive Summary

The Bill proposes a new system of sharing health information without the knowledge or consent of the patients involved. In recent years, Victorian health legislation has progressively focused on prioritising patient autonomy (principally by giving effect to the wishes of a patient). It is very concerning that this Bill takes the other direction and abandons patient autonomy.

The LIV expressed concerns with the previous iteration of the Bill, as introduced in 2021, and we continue to have concerns with the 2023 iteration of the Bill which is largely unchanged from the earlier version.

Our main concern is the absence of an opt-out provision. The Bill dismisses the principle of patient autonomy primarily due to the absence of an ability to opt-out of the proposed information sharing system. The inclusion of an express clause that states that a participating health service (and the

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Secretary) may collect, use or disclose a patient's health information *without the need to obtain the patient's consent* is particularly concerning.

We are also concerned about the Freedom of Information (FOI) provisions of the Bill. Both the 'Electronic Patient Health Information Sharing System' and the Department are exempt from FOI requests, and so patients will be unable to determine who has accessed their record under the system, when, and for what purpose. This is a significant departure from the general right under FOI, which permits Victorians to access information about them held by government.

Urgent Amendments Needed

The LIV urgently calls for the Bill to be amended to include the ability for patients to **opt-out** of the system. The LIV is very concerned that the failure to provide an opt-out provision is not only contrary to other Victorian legislation which protects patient autonomy, but ignores a fundamental human right, the same principle that allows a patient to refuse medical treatment that they may not wish to have.

The LIV also urgently calls for the FOI exemption provisions to be deleted from the Bill.

Considerations – the absence of an opt-out provision

Lack of patient autonomy

The LIV's central concern with the Bill is the omission of an opt-out provision. The lack of an opt-out provision signifies a move away from a human-rights and patient-orientated framework to a 'best interests' model, meaning Victorians will effectively lose the right to decide how their health information is used. Over the past three decades patient-centred care has become internationally recognised as a broader concept of high-quality health care[1], and was a defining feature in the *Mental Health Act 2014* (Vic). Under section 134ZL of the Bill, 'a participating health service[2]' can use, collect and disclose patient health information without the consent of the patient to whom the information relates. This contrasts with the equivalent scheme at a Commonwealth level (My Health Record), where patients were given the right to opt-out and more than 2.5 million Australians exercised their right to opt-out[3].

The Targeting Zero report ('the Report') was a review into the safety and quality of our healthcare system. The Report recommended that Victorian hospitals have an electronic health record that enables interchange of information with other hospitals. However, it did not recommend automatically sharing every patient's information with every other health service, and it did not recommend sharing patient information with the Department of Health. This Report alone is
not sufficient to justify the lack of an opt-out provision.

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[1] Australian Commission on Safety and Quality in Health Care. (2010) *Patient-Centred Care: Improving Quality and Safety By Focusing Care on Patients and Consumers - Discussion Paper – Draft for Public Consultation.* 17

[2] Health Legislation Amendment (Information Sharing) Bill 2023, 134ZE Definitions.

[3] Commonwealth of Australia 2019, *Estimates: Community Affairs Legislation Committee: official Hansard*, 20 February 2019, pp. 64.

The Report's initial recommendation is centred on the transition from paper-based to electronic patient record (EPR) systems to support clinical decision making.[4] The Report does not consider consumer concerns regarding the absence of an opt-out system. Moreover, the Report does not consider how the EPR will comply with the UN Convention on the Rights of Persons with Disabilities (CRPD) or supported decision-making principles, which are centred on respecting the autonomy and decision-making capacity of patients receiving care.

Victoria is pioneering the movement towards improving the decision-making rights of consumers in health care and guardianship settings. The LIV notes that the *Mental Health and Wellbeing Act 2022* (Vic) seeks to prioritise the views and preferences of the person receiving mental health and wellbeing services,[5] whilst the *Guardianship and Administration Act 2019* (Vic) provides that '[a] person making a decision for a represented person … should give all practicable and appropriate effect to the represented person's will and preferences, if known'.[6] Under the *Medical Treatment Planning and Decisions Act 2016* (Vic), a patient can make a binding advance care directive and can refuse medical treatment, regardless of the views of others. The LIV submits that the absence of an opt-out provision in the Bill represents a paternalistic approach that is inconsistent with Victoria's overall human rights progress.

Patient safety

The LIV acknowledges that the proposed health information sharing system has the potential to provide patient safety benefits for some Victorians. However, the system will be unsafe for other Victorian patients, many of whom do not want their private information shared and therefore do not want the potential benefits of the system. For example, the risk of harm to a victim survivor of family violence will greatly increase if their health information is widely shared against their will. Even if the Department of Health develops a framework to try to identify the risk of disclosing sensitive health information, it cannot effectively identify the safety concerns of every Victorian patient. In a patient-centred health system, patients should have the right to decide whether or not their health information is shared.

The LIV is concerned that the lack of an opt-out provision may also lead some Victorian patients to refuse to seek urgent healthcare needed, and that they may not trust how the system will collect, use and disclose their health records. The Bill does not contain sufficient safeguards to ensure that sensitive information (for example, information relating to domestic violence, termination of pregnancy, mental illness, previous drug use and sexual history) will be appropriately handled and redacted where necessary. The Bill and Explanatory Memorandum do not sufficiently detail how this sensitive health information will be monitored and filtered. Legislative clarity regarding these safeguards must also be complemented with a public educational campaign which explains in real terms how the health information of Victorians will be protected if they do not have the ability to opt-out of the system.

Without an opt-out option, the Bill does not provide an appropriate balance between clinical efficiency and safeguarding patient rights. What harm is there in respecting patient autonomy and giving patients the right to opt-out?

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[4] Newnham, H. (2016). *Targeting zero - Supporting the Victorian hospital system to eliminate avoidable harm and strengthen quality of care - Report of the Review of Hospital Safety and Quality Assurance in Victoria.* 37.

[5] *Mental Health and Wellbeing Act 2022* (Vic) s. 16, 19.

[6] *Guardianship and Administration Act 2019* (Vic) s9(1)(a).

Considerations - Freedom of information

The LIV is concerned that Victorian patients will be unable to accurately determine who has accessed their health information under the proposed information sharing system. For example, if the Department of Health were to disclose a patient's health information to a third party, the patient would have no right to make an FOI request to the Department of Health for the audit trail to determine who has accessed the information. This concern is exacerbated by a lack of an opt-out provision. The express exclusion of FOI rights in the Bill are a significant departure from the general right under FOI, which permits Victorians to access information about them held by government.

Inconsistent with other Australian jurisdictions

The LIV understands that the Bill aims to bring Victoria into line with NSW and Queensland, which have centralised health record systems. Both the NSW and Queensland health information systems differ to Victoria's proposed system, particularly in relation to the degree in which patient consent is respected.

The Queensland Health Information Sharing Guidelines provide:

"The need to share information is an ongoing part of treatment and **requires issues of consent to be considered at many points throughout a consumer's treatment and care** … **If the consumer is capable of understanding and consenting to information sharing, their consent to appropriate** and relevant information sharing should be sought, taking into account the relevant legislation and information sharing provisions applicable to the situation[7]".

Queensland patients also have a right to apply for access to their health records, by contacting the Right to Information (RTI) decision-maker at their Hospital and Health Service (HHS) or through the *Information Privacy Act 2009* (Qld)[8].

The New South Wales equivalent health information legislation limits the use of health information[9] and the disclosure of health information[10] for a secondary purpose unless consent is provided from the individual to whom the information relates.

We would welcome the opportunity to discuss these issues with you in greater detail to ensure that the rights of Victorian patients are preserved.

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[7] Queensland Health. (2021). *Information Sharing Between mental health staff, consumers, family, carers, nominated support persons and others.* https://www.health.qld.gov.au/__data/assets/pdf_file/0026/444635/info_sharing.pdf

[8] Queensland Health. (Updated 30 June 2018)."*Health Records and Personal Information" https://www.health.qld.gov.au/system-governance/records-privacy/health-personal.*

[9] *Health Records and Information Privacy Act 2002* (NSW) s. 10.

[10] *Health Records and Information Privacy Act 2002* (NSW) s. 11.

If you wish to discuss any of the matters raised above, please contact Christa Cocco, Manager Office of the President and CEO on (03) 9607 9367 or by email to ccocco@liv.asn.au

Yours faithfully,

Adam Awty

Chief Executive

Tania Wolff

President