



Australian College of Nursing

ACN RESPONSE TO VICTORIAN LEGISLATION REFORM TO ENABLE HEALTH INFORMATION SHARING CONSULTATION

The Australian College of Nursing response to the Victorian
Government Department of Health and Human Services - Health
Information Sharing Legislation Reform Consultation Paper
(November 2020)

General comments

The Australian College of Nursing (ACN) would like to thank the Victorian Government Department of Health and Human Services (DHHS) for the opportunity to provide feedback on the *Health Information Sharing Legislation Reform* consultation paper. ACN supports the proposed legislation amendments to authorise the department to share health information between public hospitals for the care and treatment of patients. ACN acknowledges the benefits, particularly around “improved patient safety and decreased avoidable patient harm, improved continuity of care, person-centred and place-based care, and better care planning”. For the nursing profession this will ensure timely access to patient information and prevent duplication of work already conducted by other health care providers. This will ensure patient care under the supervision of a nurse is not only more efficient, but also safer for patients and potentially reducing nurses’ workload. In time critical life-saving situations, nurses will be afforded more time in attending to patient care needs rather than following up on patient histories and records.

This consultation paper aligns with ACN’s strategic vision and values. ACN is a strong proponent of the Australian Government’s National Digital Health Strategy.^{1 2 3} The role of nurses in health information sharing has the potential to not only deliver improvements in efficiency and patient outcomes, but also to facilitate improved consumer and clinician experience.⁴ As further demonstration of ACN’s commitment and advocacy around clinical information sharing (CIS), the Position Statements titled ‘[Nursing Informatics](#)’ (2017) and ‘[Leading digital health transformation: The value of Chief Nursing Information Officer \(CNIO\) roles](#)’ (2019) have been developed. In these Position Statements, ACN advocates for the role of nurses to optimise the adoption and ongoing use of information and technology to improve patient care and patient outcomes.

With reference to this consultation, ACN supports the intention of the proposed reforms provided that the patient’s rights to privacy and confidentiality is respected, ensured and maintained. ACN has long advocated for patient-centred care and equity of access for vulnerable populations and supports this inclusion in the consultation paper (see Table 2 page 13). ACN however does not support non-clinicians having access to patients’ health information. In addition, ACN does not support the sharing of patients’ health information without their consent. CIS should be available in all Australian jurisdictions, provided the patient gives consent and the information is only accessible to registered health professionals. New South Wales⁵ and Queensland⁶ have such systems in place and ACN welcomes other states and territories working towards implementing similar legislation for national consistency and as part of a national health strategy.

While this consultation is primarily focused on CIS between public hospitals, ACN believes there is opportunity for expansion amongst registered health care providers across the primary (community) and tertiary care (hospital) sectors as described in a February 2018 - [ACN submission to the Pharmaceutical Society of Australia consultation for My Health Record –Guidelines for pharmacists](#).

¹ Australian College of Nursing 2019. Position statement: Leading digital health transformation: The value of Chief Nursing Information Officer roles. Australian College of Nursing. Retrieved from: <https://www.acn.edu.au/wp-content/uploads/position-statement-leading-digital-health-transformation-value-cnio-roles.pdf>

² ACN 2017. Feedback to the Australian Digital Health Agency on the National Digital Health Strategy. Australian College of Nursing. Retrieved from: https://www.acn.edu.au/wp-content/uploads/2018/03/20170203_final_digital_health_strategy_with_kw_signature.pdf

³ Australian College of Nursing 2018. Submission to the Pharmaceutical Society of Australia (PSA) on the consultation for My Health Record – Guidelines for pharmacists. Australian College of Nursing. Retrieved from: https://www.acn.edu.au/wp-content/uploads/2018/02/20180216_PSA-Submission_My-Health-Record.pdf

⁴ Australian College of Nursing, Health Informatics Society of Australia & Nursing Informatics Australia 2017. Joint Position Statement: Nursing Informatics. <https://www.acn.edu.au/wp-content/uploads/joint-position-statement-nursing-informatics-hisa-nia.pdf>

⁵ NSW Government NSW Health, eHealth Strategy for NSW Health, accessed at <https://www.health.nsw.gov.au/eHealth/Documents/eHealth-Strategy-for-NSW-Health-2016-2026.pdf>

⁶ Queensland Government Clinical Excellence Queensland, *Office of the Chief Clinical Information Officer*, accessed at <https://clinicalexcellence.qld.gov.au/priority-areas/service-improvement/office-chief-clinical-information-officer-occio>



In our response to this submission, ACN encouraged patients to share their health information with providers through 'My Health Record' and consistently advocated for privacy and protecting individual information.

ACN's responses to the consultation questions are below.

To what extent do you support the intention of the proposed reform - to facilitate health information sharing between public hospitals and health services when it is required in connection with the treatment of a patient?

ACN supports the intention of the proposed reform provided only health professionals have access to a patient's health data and patients give consent to the data being shared amongst health professionals. Accessible data can reduce patient frustration and nurse workload by saving time when not needing to ask patients the same questions which other health care providers may have already asked. It will also ensure critical health information is accessible in life-saving or critical situations.

To what extent do you support the intended changes to legislation as outlined in the Consultation Paper?

ACN does not support the sharing of patients' health information without their consent. (unless it is an opt out system like My health record system). ACN supports the inclusion of a lever for patients to opt in or out of enabling CIS. ACN supports the plan to develop a 'patient portal' but emphasises the need to allow patients to determine which clinical information is in the portal, rather than merely being able to view their health care records. *Noting that My health Record is an opt out system.*

Questions

Consent: How will confidentiality of health information be maintained without the requirement for patient consent?

1. To what extent do you agree with the purpose and high-level design features for the proposed legislative reform? Please provide relevant statements in support of your view.

ACN reiterates it supports patients giving consent to the sharing of their health information to registered health providers. While access to 'critical health information' may be life-saving, an agreed definition for 'critical health information' should be provided in the legislation. Ethical considerations and legal implications must also be addressed.

ACN distributed this consultation to its membership and the following scenario where included to highlight the range of privacy and ethical considerations that could arise:

- Example 1: A woman who has had a termination for an unwanted pregnancy unbeknownst to her partner. The critical point to consider is whether this is deemed 'critical health information' in an obstetrics setting. This raises additional questions, such as: i) who would have access to such information; ii) could the DHHS guarantee that users of the system do not disclose this information to a significant other; iii) what if the person allowed access discloses this to an unregulated staff member iv) what safeguards would be in place to prevent inappropriate disclosures of the information; v) what are the processes for remediation if such disclosures occur; vi) how would passwords be provided and what scrutinies would exist to prevent reputation damage/mental health harms.

ACN is concerned about the potential for other government agencies and departments to access private health records. ACN would like to stress that nurses are patient advocates and must adhere to the Nursing and Midwifery Board of Australia Code of Conduct for Nurses⁷. The Code of Conduct stipulates that nurses abide by patient-centred care and adhere to patient privacy and confidentiality. For some nurses, knowing that their patients' private health information could be obtained by other parties could cause moral distress.

ACN would like to mention the current review being undertaken of the *Privacy Act 1988* by the Australian Government Attorney-General's Department.⁸ The review, which includes a public consultation process, is considering whether the scope of the *Privacy Act 1988* and its enforcement mechanisms remain fit for purpose. In relation to this review, a recent Australian Financial Review article pointed out the experience of the Office of the Australian Information Commissioner in relation to data protection⁹. It quotes the Australian Information Commissioner and Privacy Commissioner, Ms Angelene Falk, stating there are four key elements to support effective privacy regulation over the next decade: "**global interoperability** — making sure our laws continue to connect around the world, so our data is protected wherever it flows; **enabling privacy self-management** — so individuals can exercise meaningful choice and control; **organisational accountability** — ensuring there are sufficient obligations built into the system; and **a contemporary approach to regulation** — having the right tools to regulate in line with community expectations." The review of the *Privacy Act 1988* will bring up issues such as consent requirements, additional privacy rights and accountability measures. Digital health records are part of the privacy challenges of the future and how widely and effectively the *Privacy Act 1988* applies will potentially have far-reaching implications.

2. What are your perspectives on the proposed entities (the department and public hospitals and health services) and uses (purpose of use) that are to be included in the legislation amendment?

ACN supports private health information only being shared by registered healthcare professionals with patient consent provided. ACN believes in strongly protecting patient confidentiality. Patients have the right to know how their health information will be protected confidentially and what the consequences are for any breaches of confidentiality. An evaluation of processes needs to take place at pre-identified times to determine whether privacy, confidentiality, security and data integrity are being adequately maintained by the proposed entities.

3. What may be some of the critical success factors to maintain public trust in the legislative changes in the absence of patient consent?

ACN believes the following points are important:

- transparent communication
- patient-centred communication
- clear information about benefits and potential harms to patients
- clear information about hospital responsibilities and accountabilities in this matter
- clear information on how information will be stored safely and who will have oversight over this.

⁷ Nursing and Midwifery Board of Australia 2018, *Code of conduct for nurses*, accessed at <http://www.nursingmidwiferyboard.gov.au/documents/default.aspx?record=WD17%2F23850&dbid=AP&checksum=L8j874hp3DTIC1Sj4kHag%3D%3D>

⁸ Australian Government Attorney General's Department 2020, *Review of the Privacy Act 1988 (Cth) – Issues paper*, accessed at <https://www.ag.gov.au/integrity/publications/review-privacy-act-1988-cth-issues-paper>

⁹ Burton, T 2020, 'Government to consider new privacy rights for citizens', *Australian Financial Review*, accessed at <https://www.afr.com/politics/federal/government-to-consider-new-privacy-rights-for-citizens-20201030-p56a91>.



ACN believes it is also important to monitor who accesses the health information and enforce tight control of what level of staff have this access.

4. Are there additional opportunities created by the legislation reform to support better patient and health system outcomes?

ACN believes opportunities may arise including innovations in digital information systems with strengthened information protection and IT systems. There may also be opportunities in primary health care and aged care for better patient and health system outcomes through these digital innovations.

Safeguards: What safeguards will be put in place to ensure data integrity, security and record keeping requirements are met?

1. Are there additional safeguards necessary to protect patient privacy through the legislative changes?

ACN argues that only the required data should be kept that is determined as being 'critical health information'. Feedback by an ACN member suggests implementing a system which deletes acute health information that is considered unlikely to have a relevant health impact in the long term. This could be achieved by enabling the practitioner to set the use-by date for certain information at the time of documentation. It is important to evaluate the quality, accuracy and integrity of the data going into the CIS system.

2. Will the proposed legislative reform create any risks, and what (if any) mitigations may be put in place in response?

ACN considers that there are risks to data security if the proposed legislated reform is approved. Mitigation measures include fostering and maintaining ongoing collaboration with IT departments, frequently updating protection schemes and ensuring an appropriate de-identification scheme.

3. How might the department communicate the legislative changes to patients in a way that maintains trust between health providers, patients and the department?

ACN reiterates its belief that patient consent and confidentiality is paramount. The Department of Health and Human Services should communicate this via letter and through advertising material in multiple languages in an appropriate level to address the community level of health literacy, (e.g. brochures, posters) displayed across a variety of clinical settings. The benefits of the CIS system should be reiterated in these communications: "improved patient safety and decreased avoidable patient harm, improved continuity of care, person-centred and place-based care, and better care planning". This should also be re-iterated in person by the patients' regular health care providers (including GP, nurse and pharmacists) to ensure confidence in the system and the well-meaning intentions of the system. Any myths or potential concerns should be dispelled in advertising material.

4. Are the sanctions and financial penalties sufficiently prohibitive for breaches that relate to the proposed amendment to the legislation?

While it may not always be possible to impose consequences, ACN believes sanctions and financial penalties should be in force to deter criminal activity around breaching/undermining patient privacy and safety. Consider, for example, the 'WannaCry' cyberattack on the NHS in the UK in 2017¹⁰. This attack alone caused the cancellation of 19,000 appointments and is believed to have been carried out by a nation state actor. The damage it inflicted cost more than 92

¹⁰ Williams, O 2018, The WannaCry ransomware attack left the NHS with a £73m IT bill, NS Tech, accessed at <https://tech.newstatesman.com/security/cost-wannacry-ransomware-attack-nhs>



million British pounds but the true cost cannot be known because human lives may have been impacted by delayed ambulance services and incorrect treatment.

5. How might the department reduce any risk that patients may withhold information from their public hospitals and health services because of fears their privacy will be breached?

ACN believes transparent communication and informed consent to information is crucial to addressing this risk. Nurses as the largest health professional group and trusted health care provide, can play a key role in educating patients and minimising these fears.

6. The CIS technical specifications emphasise data security, data integrity and record keeping. What additional operational considerations could be put in place to ensure only high-quality health information is available within the CIS solution? (Selected audience only.)

A nurse informatician informed ACN that not all data is coded in the manner mentioned in the consultation paper. The management of free text needs to be considered. Consideration also needs to be given to who is doing the mapping and whether the CIS system is relying on a vendor to do the mapping. Furthermore, the vendor's skills are important in terms of how they are measured in relation to SNOMED CT. This refers to the 'Systematized Nomenclature of Medicine Clinical Terms' and is a common clinical language consisting of sets of clinical phrases or terms, that can be grouped together with relationships between terms.

Medico-legal: Are there any potential medical legal issues presented by the new legislation?

1. Are there potential medico-legal implications (in clinical practice, and for the department) related to the introduction of the health information sharing legislative changes? Are there additional legislative amendments required to overcome these issues? And what should be communicated to clinicians about these? (Selected audience only.)

Yes, breaches in patient consent and confidentiality could result in reputational damage and psychological harm to the health provider as well as the health care consumer and DHHS. ACN supports training for clinicians to equip them with the knowledge of the changes, which includes technical and legal assistance for clinicians. This should also be easily accessible on the AHPRA website.

In addition to the impact on mental health following a privacy breach, consideration must be given to the impact of unintended disclosures on the family unit and occurrences of family/domestic violence. In addition, consideration needs to be given to whether social workers will require details or use in the CIS system, as this is not currently explicitly mentioned in the consultation paper.