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**SUBMISSION TO THE AUSTRALIAN GOVERNMENT ATTORNEY-GENERAL'S DEPARTMENT  
ON THE REVIEW OF THE PRIVACY ACT 1988 (CWTH)**

**Introduction**

Thank you for the opportunity to contribute to this review. The following brief comments are made at a personal professional level in my capacity as a qualified, experienced Health Information Manager, consultant and academic in the discipline of Health Information Management. The comments apply to privacy only within the contexts of health-related data and information including genetic data.

The maintenance of privacy of patients' and health service clients' individual and aggregated health information, supported by a rigorous regulatory infrastructure, is a critically important element in our society. The concept of the right of an individual to the privacy of his or her health data and information, including personal information and genetic information, is firmly grounded in long-standing bioethical principles and codes. In professional health information management practice, the collection, applications and dissemination of health and genetic data and information are, necessarily, directly informed by an overarching, protective legal framework. This framework should provide a degree of standardisation, and enable stability and consistency in health information management practice across temporal, technological and jurisdictional boundaries.

**Re certain of the matters under consideration by the Review**

*1. Definition of 'personal information'*

Synergy and consistency in the legislative definitions of 'personal information' (and 'sensitive information' and 'health information') across different jurisdictions are necessary in order to facilitate practical 'on-the-ground' protection of patients' and clients' health and genetic information. Australia currently has a plethora of legislation concerning different categories of health and genetic information, including personal information, within different health sectors across the states, territories and Commonwealth. There are some extant, useful definitional consistencies between the Privacy Act 1988 (Cwth) and state laws relevant to health information (e.g. Health Records Act 2001 [Vic], Information Privacy Act 2009 [Qld]). The expanding reach and capabilities of electronic health records in acute and non-acute primary, secondary and tertiary care environments, the use of purposive stand-alone and relational databases and, in particular, the rapidly increasing mobility of health and genetic data, all present privacy-governance challenges for Health Information Managers, who are the professional data custodians. Any change to the definition of 'personal information' within the Privacy Act 1988 (Cwth) needs to be made in consideration of these important practical requirements for standardisation and consistency.

*2. The problematic of privacy in the management of health data and information*

There are several rapidly emerging challenges in the management of privacy of health data and information that have been – and continue to be – propelled by the shift to digital platforms and electronic media in the healthcare sector. They present significant problems for both health service providers and custodians of Australia's medical records and health data. They relate potentially to overseas and trans-border data flows, and to patient/client notification and consent requirements. Some examples follow.

- The mobility of health data which enables overseas data flows for medical transcription and other health data and information transformation services, and the associated lack of custodial control once these data are sent off-shore.
  - It is not unreasonable to ask, given this lack of control, whether it should be illegal to send confidential, identifiable health information off-shore in the absence of specific patient consent.

- The collection of patient and client data by legitimate commercial entities, e.g. some ‘telehealth, appointment booking and pre-screening services’ (Henderson 2020).
  - As Henderson has flagged, this raises potential ‘questions unanswered in terms of governance and privacy protections’ for some of these data.
- The mobility of health data that facilitates potential pressures for access by legitimate entities for other non-clinical treatment and non-medical research purposes.
  - For example, for commercial and related purposes such as insurance, and by employers and others seeking individuals’ genetic profiles or information.
- The mobility of health data enabling overseas data flows for research purposes.
  - This problem does not concern ethically-approved, genuine medical research, for which Australian hospitals have sound protocols in place. In contrast, however, there have been noteworthy examples during the COVID-19 pandemic where the owners of an off-shore, proprietary research database have falsely claimed to have secured confidential medical record data directly from Australian hospitals. These claims raise the issue of unrealistic and unreasonable expectations which are almost certainly contrary to public expectations about the transfer and use of private health information; they also raise serious concerns around its potential commercialisation and commodification (Robinson 2020).
- The exponential increase in health information cyber-breaches.
  - Thus far, this has affected Australian hospitals and health services to a lesser extent than in other countries such as the USA; however, it presents a clear and present risk to patients’ and clients’ health information privacy.

### Suggestion

Health Information Managers are the professionals responsible for health information analysis, governance and privacy. It is respectfully suggested that in the next stage, the Review may consider consulting with the peak professional body, the Health Information Management Association of Australia.

### References

Henderson J (2020) Patient privacy in the Covid-19 era: Data access, transparency, rights, regulation and the case for retaining the status quo. *Health Information Management Journal* [Online First, 12 November]

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