Summary of the Australian Privacy Foundation's Submission on the Design of Australia's Future Health Care System.

The APF's submission centres on health information management (HIM), a vital component of effective and efficient health care. Although not expressly idenitified, it is clear that HIM underpins key themes incorporated into the National Health and Hospitals Reform Commission' (NHHRC) *Terms of Reference* and *Principles to shape Australia's health system.* However, we note the failure of the Health Connect initiative and the so far unrealised aim of National E-Health Transition Authority to introduce unique health identifiers (UHI) as a key component of a national, shared Electronic Health Record (EHR) system. We suggest that one reason why EHR systems have proved so difficult to introduce, despite massive investment of resources, is a failure to adequately address privacy concerns.

Data centralisation and UHIs may help administrators, auditors and insurers, but they do **not** generally help health care professionals or patients and do not automatically or necessarily improve the quality of health care. Instead, they store millions of EHRs on databases vulnerable to information breach, and with highly variable data quality. Global experiences with unified national EHRs indicate that patients are not comfortable about the privacy protection of their sensitive health information. They also absorb large quantities of funding and far too much of the time and effort of front-line health care staff because they subtract from the resources available for providing health care itself.

By contrast, localised identifiers and federated data management are more appropriate than a central database storing national EHRs linked by UHIs, as pointed out several times by the APF and others. They scale to the problem and match the patterns of behaviour of health care organisations. Further, determining interoperability standards and protocols, demonstrators and software development kits does need to be done centrally. Yet the NHHRC *Terms of Reference* and *Principles to shape Australia's health system* documents continue to overlook these issues.

More generally, we are particularly concerned about the lack of any direct consumer representation on the Commission, and believe that this is likely to result in important perspectives and interests being overlooked.

The APF's comments about the NHHRC proposed design and governance principles include:

Principle1: Health care professionals distrust most data, including e-data, because it is generally dated, unreliable, and 'wrong' (at least for the context in which they are operating). Any e-health initiatives must acknowledge and address the reality of poor data quality, while seeking to improve it. Data quality is a key principle in all information privacy laws, but so too is a requirement to take account of variable quality when using or disclosing personal information.

Principle 6: There are massive dis-economies of scale and scope in the technological resources that are available to health care. As the AHIC Briefing Paper points out, "The fact is that e-Health will not save money for Treasuries". While the use of information technology may equate to responsible, effective spending on health care, it is costly to implement.

Principle 9: Our experience indicates that health authorities seem to make decisions without regard to repeated input from groups such as the APF or the Consumers Health Forum. For instance, most recently these and other groups have contributed valuable insights to NEHTA roundtables and other submission processes, yet there is a disappointing lack of consumer representation on the Commission. A ‘motherhood’ statement about input “from the community and those within the health sector” is no substitute for direct consumer representation on the Commission.

Principle 10: The demand for health care is highly dispersed and so the facilities and business processes are also highly dispersed. Information activities concerning patient care are complicated and intricate too. Moreover, the clinical environment is complex and highly interruptive and health workers are known to be time-poor. Clinical governance cannot ensure patient safety and quality unless support for context of patient care is integral to the way it is organised.

Principle 12: Global evidence suggests that clinical and public participation in health reform based on national e-health records often result in concerted attempts to remove their sensitive and personal information from the system or to opt out from it due to perceived or actual privacy shortcomings. Privacy and consent are clearly major issues and the APF hopes the NHRRC will not only consult widely, but will be seen to consult widely. To reiterate the point made above, the lack of consumer representation on the Commission is disappointing.

Principle 13: Health care professionals, being human, have limited cognitive capacity and so ignore the vast majority of information thrust at them. They ignore the information because they **have** to. The information that they collect from patients is highly situation-specific. Only a small amount of it is relevant across multiple contexts. Pushing more data at them by coordinating care across all aspects of health will reduce the quality of health care, further burden time-poor clinicians and does not demonstrate respect or value for the health workforce either.

Conclusion

Unless patient priorities in relation to Health Information Management, such as their clear preference for federated models of data management and localised identifiers, are addressed it is difficult to understand how the NHHRC can meaningfully advise the Federal Government on the design of Australia’s future health system.

The APF submits that the NHHRC is unlikely to be capable of providing meaningful advice to the federal Government about the design of Australia’s future health system *unless* the assumption that central databases containing patient health records are desirable is revisited with grass-roots community groups as part of this enquiry.

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