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# **Designing Australia's Future Health System: Terms of Reference and Draft Principles**

## **Submission to the National Health and Hospitals Reform Commission**

**May 2008**

### ***The Australian Privacy Foundation***

The Australian Privacy Foundation is the main non-governmental organisation dedicated to protecting the privacy rights of Australians. The Foundation aims to focus public attention on emerging issues which pose a threat to the freedom and privacy of Australians. Since 1987, the Foundation has led the defence of the right of individuals to control their personal information and to be free of excessive intrusions. The Foundation uses the Australian Privacy Charter as a benchmark against which laws, regulations and privacy invasive initiatives can be assessed. For further information about the Foundation and the Charter, see [www.privacy.org.au](http://www.privacy.org.au)

### ***Introduction***

This submission centres on health information management (HIM), a vital component of effective and efficient health care, but only if done well. The *eHealth Future Directions Briefing Paper* prepared by the Australian Health Information Council (AHIC) for the AHMAC meeting held on October 4 2007 points out that a national shared electronic health record (EHR), which may be fully functional over the next five years, will transform healthcare services (1). The briefing indicates that it is important for health processes to be flexible and capable of adapting to the new and emerging nature of information management. However, both the failure of the Commonwealth Health Connect initiative, and the as yet unrealised aim of the National E-Health Transition Authority to introduce unique health identifiers (UHI), as a component of a national, shared EHR (2) demonstrate the pitfalls and obstacles. A vast amount of work has already been done in this area with HIM laying the foundation for several initiatives to be implemented by health authorities in the near future. HIM also underpins key themes incorporated into the National Health and Hospitals Reform Commission' (NHHRC) *Terms of Reference* and *Principles to shape Australia's health system* documents (3, 4). However, we submit that most of the UHI and EHR initiatives have failed to adequately address legitimate privacy concerns and health consumer expectations.

## **NHHRC Terms of reference**

2. *By June 2009, the Commission will report on a long-term health reform plan to provide sustainable improvements in the performance of the health systems addressing the need to ...*

...

*(h) provide a well qualified and sustainable health workforce into the future*

In relation to (h), new and emerging computer technologies underpin the challenges to sustainable improvement in health. Yet most clinicians are not trained to use practice computers and many consider them as irrelevant to patient care (5, 6). There is evidence to suggest that the current health workforce is not well qualified to provide patient care in an integrated and coordinated health sector. Thus, guidelines that will assist the health system to develop clinician computer training programs need to be added to the NHHRC Terms of Reference.

## **NHHRC's proposed design and governance principles**

The APF's comments about the NHHRC proposed design principles are as follows:

- *Principle 1 includes the aim that that health care should be based on reliable information.*  
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) (7-9). 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 suggests that the technological resources available to support our health system should be driven by cost effectiveness, and Principle 14 emphasises responsible spending on health care*  
There are massive dis-economies of scale and scope in the technological resources that are available to health care (10). As the AHIC Briefing Paper points out, "The ceaseless debate about benefits realisation and economic value of e-Health is a distracting and mostly futile exercise. The fact is that e-Health will not save money for Treasuries" (1). Hence, while the use of information technology may equate to responsible, effective spending on health care, it is costly to implement.
- *Principle 9 argues for the need to take the long term view and think strategically, to seek input from the community and those within the health sector to assess and develop plans to improve health and health care.*

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 (11). A 'motherhood' statement about input "from the community and those within the health sector" is no substitute for consumer representation on the Commission.

- *Principle 10 suggests that clinical governance to ensure the safety and quality of health services is*

*needed at all levels of the health system.*

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 (12, 13). Moreover, the clinical environment is complex and highly interruptive and health workers are known to be time-poor (14). Clinical governance cannot ensure patient safety and quality unless support for context of patient care is integral to the way it is organised (9, 15).

- *Principle 12 discusses the importance of public participation in health reform efforts.*

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 (16, 17).

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 suggests that we need to respect and value the health workforce.*

Health care professionals, being human, have limited cognitive capacity and so ignore the vast majority of information thrust at them (18). They ignore the information because they **have** to (19, 20). The information that they collect from patients is highly situation-specific. Only a small amount of it is relevant across multiple contexts (15). 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.

## ***Health Information Management and Privacy***

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 (21-23) 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 (16, 24-27). 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 (15, 5, 6).

By contrast, localised identifiers and federated data management are more appropriate than a central database storing national EHRs and linked by UHIs, as pointed out repeatedly by the APF and others. Localised, federated approaches scale to the problem and match the patterns of behaviour of health care organisations (28). In contrast, determining interoperability standards and protocols, demonstrators and software development kits does need to be done centrally (13). Yet the NHRRC *Terms of Reference* and *Principles to shape Australia's health system* documents continue to overlook these issues (3, 4). Unless patient priorities, such their clear preference for federated models of data management and identifiers and

record keeping, 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.

## **Conclusion**

While the APF acknowledges that performance measures need to be gathered and submitted up the line, the primary focus should be the quality and safety of patient care, as indicated in the NHHRC *Terms of Reference*. This necessarily centres on the support of health care operations for problem-recognition, problem-analysis and constructive intervention. The information needed for those purposes is mainly about non-financial matters, and can be managed so it is mainly drawn from data that is already captured as part of normal operations. Regrettably, it seems almost inevitable that the primary focus will instead be budgetary, and the primary data will be financial and financially-related, with empowerment of hospital and head office accountants instead of empowerment of health care professionals. This focus also drives a demand for ever more intrusive centralised databases of personal information with those responsible barely even recognising the serious privacy issues arising.

The APF considers 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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