National Healthcare Identifier Inquiry

Primary and Ambulatory Care Division (MDP 1)
Department of Health and Ageing
GPO Box 9848
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"A CONSUMER PERSPECTIVE ON HEALTHCARE IDENTIFIERS"

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"A System for Secure Distribution of Electronic Content and Collection of Fees"

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EXECUTIVE SUMMARY

To avoid a repeat of the *Australia Card*, the Department of Health and Aging needs to ensure that e-health legislation provides:

(a) Rights for healthcare consumers to control their National Healthcare Idetifiers (NHIs), alias-NHIs or when in doubt use anonymous NHIs;

(b) Anti-discrimination laws protecting people who use an alias-NHI or anonymous NHI;

(c) Legislated NHI neutrality to ensure the accuracy of NHI-based reporting;

(d) A ban the acquisition or use of an NHI for any non-health promoting purpose; and

(e) Any decision made concerning NHIs is reviewable by the AAT.

If all these safeguards are enacted, NHIs would not be perceived as the linchpin of the surveillance society, but rather *digital paper clips* to hold e-health records together.

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NEED FOR LEGISLATIVE GUARANTEES OF RIGHTS AND LIBERTIES

1.1 Building regulations specify standards for fireplaces because fire is a dangerous technology. Standards of electrical wiring have legislative force because electricity is a dangerous technology. The wheel is a dangerous technology, requiring legislation controlling motor vehicles. Microwave radiation is a very dangerous technology, which is why we have a legislative framework of approvals for microwave ovens. There is no doubt legislative schemes can make almost any technology safe, if properly enacted and enforced.

1.2 Just like any other technology, depending on how they are used, National Healthcare Identifiers (NHIs) can do both good and evil; *only more so,* because NHIs are about people, not things. This means the statutes enacted by the States, Territories and Commonwealth governments must be both failsafe and foolproof. It is still within living memory, that in the name of public health, the tattooing of numbers, issue of identity papers and wearing of badges was enacted in Germany, the most technologically advanced nation of that time. **This was the underlying reason for the spectacular failure fifty years later of the Australia Card, half a world away.**

1.3 Although less acute than in 1987, acceptance of a public identity system today still goes beyond the issues of privacy to that of liberty. Therefore, if the proposed NHIs are to win wide public acceptance, as they should, they must first clear this historical bar. The two key questions are:

1) Will discrimination against anonymous healthcare consumers (because they choose to remain anonymous) be effectively outlawed?

and

2) How much real control will individual consumers have over their NHIs?

EXTENDING THE DISCUSSION PAPER'S PRIVACY CONCEPT

2.1 The proposed health consumer NHIs are based on a person's name and address. However, at common law, Australians are free to use an alias and a private post office box if they wish, or to change their name and address. Even with official government business, it is often possible to get information concerning one's options without providing any identification.

2.2 To its credit, the discussion paper contemplates *"robust regulatory arrangements to ensure appropriate safeguards"*. These are viewed as *"central to the successful implementation of a national e-health system"*. So the issue is not so much the principles of liberty and privacy, as the degree to which they must be observed.

2.3 Unfortunately, the discussion falls short of canvassing what is required to gain public acceptance regarding anti-discrimination measures for anonymous consumers, and individual control over one's own identification. Without such guarantees in place, the proposed system to a considerable extent represents the abolition of privacy. This is because **NHIs can facilitate wholesale data matching**, a factor which the ALRC may not fully appreciate (the author has data-matching experience), particularly if the healthcare market consolidates along U.S. lines.

2.4 Moreover, the discussion so far only identifies the need for initial consumer consent, not ongoing consumer consent. But health consumers should be entitled to block their main NHIs and assume alias-NHIs instead at will, as is their common law right in the non-digital world today. For

example, a person may not wish their employer's doctor to easily match health records with her own doctor, since finding out she has a disease (such as diabetes) might decrease her chances of promotion. **The fact NHIs are made to enable such data matching sends a very negative message to consumers. Without sufficient safeguards, after a few horror stories, people will become more cautious in sharing their confidences with health professionals.**

2.5 Therefore the ready availability and use of alias-NHIs will be necessary to maintain consumer confidence in the health professions. Such an arrangement should not at all affect the health system's viability from a systemic reporting standpoint. Of course the alternative to offering such consumer control is decreased participation, or outright conscientious objection.

INCREASING CONFIDENCE WITH CONSUMER RIGHTS

3.1 For the above reasons, the privacy concept in the discussion paper should be extended to incorporate guarantees of liberty also. At the very least, there should be:

i. A legislated right for healthcare consumers to maintain their own alias-NHIs for semi-anonymous consultations without prejudice of any kind; and

ii. A legislated right for healthcare consumers to suspend their own NHIs to conduct anonymous consultations without prejudice of any kind.

3.2 As previously discussed, these "as of right" digital equivalents to established common law principles, must be accompanied by legislative anti-discrimination guarantees. At the very least, it should be:

A) An offense to refuse to accept alias-NHIs or discriminate against a person for using an alias-NHI;

B) An offense to refuse to accept an anonymous NHI or discriminate against a person for using an anonymous NHI; and

C) An offense to obtain or use a person's NHI for a non-health promoting purpose.

3.3 These offenses should be punishable by the usual breach of privacy penalties. The stronger these provisions, the more safeguarded people will feel, the less likely they are to choose anonymity. Any decision made concerning an NHI should also be reviewable by the AAT, for easy access to justice should a problem arise.

3.4 For example, homebirth mothers are presently being alienated by the health system, after being stigmatized by the AMA in a "three times more likely to die" scare campaign. In fact, infant mortality rates are lower than in hospitals among properly qualified homebirth midwives, because they refer their difficult cases to the hospitals. NHIs would quickly prove this. So with adequate consumer safeguards in place, what are today considered fringe consumers would be incented to participate in the system, if health policies became driven by actual facts rather than seemingly vested interests. On the other hand, if the AMA's unqualified claims apply to independent midwives, NHIs could be used to negate any suspicion of self-interest in the resulting policy recommendations.

3.5 There is some talk in the discussion paper about putting NHIs to work for other purposes. Only the purposes authorized by the enabling Acts of parliament should be allowed. The NHI exception to the general privacy rule can only be justified in the best interests of the people as health consumers, not Australia's interests at large. If these goal posts are destined to be moved, the public ought to be informed upfront about what we are signing up for. Therefore unless the purposes of NHIs are clearly enacted with easy to enforce prohibitions with appropriate penalties, consumer confidence will be undermined by loopholes. It was after all, a loophole in the 1987 legislation discovered by a former public servant, that was the final nail in the Australia Card coffin.

INCREASING CONFIDENCE WITH ACCURATE REPORTING

4.1 In the interests of consumer choice it is also important that NHIs for health practitioners and health organizations are made available in a non-discriminatory fashion. This is because the exclusion of any class of health practitioner will distort the figures, leading to inappropriate policies and uninformed individual choices.

4.2 For example, many people use alternative medicine, however if these practitioners are blocked from participating, there will be no way to tell if their services are efficacious or not. Certainly there must be no manipulation of NHIs to restrict free trade or to create a scheme of civil conscription. There must be no suggestion that NHIs have been denied as a means of skewing the perception of health outcomes, such denying access to independent midwives while providing access to clinicalized midwives.

4.2 **NHI neutrality is therefore of paramount importance to ensure the overall integrity of the system. Without this, consumers will have no confidence that the invasion of their privacy is justified by the improvement of their healthcare.** For this reason, NHI neutrality must be fully expressed in legislation, including the enacting of procedures for fair and timely issuance and maintenance of NHIs. Moreover, any administrative decision made concerning NHIs should also be reviewable by the AAT, for easy access to justice if there is a problem.

CONCLUSION

5.1 The following legislative provisions must be included in NHI-related e-health statutes; not as delegated legislation but in Acts of parliament:

- **Rights for healthcare consumers to control their NHIs, alias-NHIs or use anonymous NHIs;**
- **Anti-discrimination laws protecting people who use an alias-NHI or anonymous NHI;**
- **Legislated NHI neutrality to ensure the accuracy of NHI-based reporting;**
- **Banning the acquisition or use of an NHI for any non-health promoting purpose; and**
- **Any decision made concerning an NHI should be made reviewable by the AAT.**

5.2 In as much as the NHI system has been built before such legislative safeguards have been fully considered, the system may need to be modified before it is launched. This is because the information technology must follow the community standards laid out in the legislation, not the other way round. That said, nothing mentioned in this submission would be particularly difficult to implement - indeed, the discussion paper already foreshadows “interim numbers”. This means the

existing system contains at least some of the required flexibility to implement the necessary safeguards.

5.3 If the above safeguards are enacted and enforced, NHIs could be accurately characterized as *digital paper clips* for keeping health records together. If not, it is my considered opinion NHIs could become the linchpin of a surveillance society. It is therefore incumbent on the Department of Health and Aging to make the above safeguards very plain in legislation, and that the *digital paper clip* represents only a small sacrifice of privacy, not liberty.

5.4 In this case NHIs might be better called *digital paper clips* in my opinion, if that is their intended use and none other.

Eric Wilson
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Confirmed by post