Response to Request for Comment

on AHMAC Discussion Paper on "Health Identifiers & Privacy"

August 2009

Authored by Fellows and Members of the

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Healthcare identifiers and privacy: AHMAC Discussion paper on proposals for legislative support

Response from the Australian College of Health Informatics (ACHI)

August 2009

This document has been prepared following distribution of the AHMAC discussion paper to the ACHI membership.

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General

The Australian College of Health Informatics (ACHI) is pleased to provide input into the process of developing an appropriate environment for E-Health in Australia. Before offering comment ACHI notes that the scope of the request for response is limited to legislative change. ACHI believes a valuable response could be provided had input been sought on the wider aspects of NEHTA's present IHI initiative. ACHI is thus concerned that at present adequate details of the overall IHI proposal may not be in the public domain and as a result our response to not fully meet the consultation objectives.

In submitting this response, we are keen to suggest that that the precautionary principle is applied as the planning and implementation of the proposed Health Identification (HI) Service proceeds, that the precautionary principle is applied and that we ensure that the clinical maxim of 'primum non nocere' (i.e. First, do no harm) is top of mind. Both providers and consumers need to have their personal information properly protected while the larger community objectives are being pursued. Getting the planning, public education, governance or implementation processes wrong could have long term negative consequences for the progress of e-Health in Australia.

ACHI was formed in 2002 to be Australia's peak health informatics professional body, representing the interests of a broad range of clinical and non-clinical professionals working within the health

informatics sphere. ACHI is committed to quality, standards and ethical practice.

The ACHI membership strives to work as a change agent in the health system, encouraging the appropriate use of health informatics methods and technologies. ACHI has the expertise to advise government and the professions on eHealth matters, in particular the national direction, implementation and support for health informatics and educational and capacity building, innovation and diffusion, standards development, research, performance and quality management.

ACHI's expertise ranges from university-based health informatics R & D and education to implementation and systems analysis consultancies with health services and government. Fellows of the ACHI have been involved in a range of large scale projects such as the implementation of the Regenstrief EMR system in Africa, MediConnect, HealthConnect, National EDS Taskforce, National EHR Taskforce, Patient ID, Clinical Terminology and a range of national and international projects.

Scope of the HI Project

We find in reading the document that it perforce must deal with some of the basic underpinnings of the identifier process, and it makes some assumptions that we feel have not yet had sufficient public debate. In particular, there has not yet been adequate public debate on the health benefits provided by E-Health, in terms of reduction of errors, unnecessary tests and the overall efficiencies that can be provided. Some of the detail about how the identifiers will be used in practice is also missing.

There has also not been sufficient public discussion of just how individual personal demographic information will be protected from unwanted and unauthorised access. There are many legitimate reasons why some individuals would be concerned about disclosure of their demographic details to third parties (e.g. victims of domestic violence) and the protections provided to such individuals are not well articulated with presently available information.

Public release of a current Concept of Operations of the IHI and an associated current Privacy Impact Assessment would be very useful in this regard.

National understanding would also be enhanced if NEHTA provided an analysis of all the options for unique identification that were considered before the present proposal was settled upon.

Benefits

The framing document does not make any significant statements about the benefits to be had from the sharing of health information, which is the process that the IHI/HPI service underpins.

A survey by the Markle Foundation[1] on the use of health information the results show that from the patients' perspective, they want access to their own information:

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"It's my health information. I should have access to it anywhere, anytime."	Strongly agree 61%
"Anybody can make a mistake. I'd like to double-check what's in my medical records."	Strongly agree 54%
"It's hard to remember everything my doctor says. I'd like to get an automatic copy of my doctor's notes and records after each visit."	Strongly agree 51%
"I want to be involved in medical decisions that affect me. Having my own medical record would help me make better decisions."	Strongly agree 49%
"I'd like to have all my health information in one place and get to it with the click of mouse."	Strongly agree 38%

The document often refers to reducing inefficiencies. The presence of a UHI is considered one of the essential requirements for a national eHealth infrastructure but 'as of itself' will not reduce the inefficiencies of a complex health system. It does not provide the tools for computerised Clinical Decision Support Systems (CDSS) and Clinical Provider Order Entry (CPOE) which are considered the most powerful building blocks to improve Health system safety and efficiency. CDSS reduce clinical resource utilization and costs, medication utilization and length of stay (Tierney, 1993).[2].

We acknowledge that this paper is solely about the process of creating and maintaining health identifiers, not necessarily about the uses to which those identifiers will be put in the wider health system. Nevertheless, some of the discussion must take into account the potential uses that these identifiers will be put. In

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[1] Markle Foundaton an the Robert Wood Foundation – Am Med News May 2005

[2] Physician inpatient order writing on microcomputer workstations-effects on resource utilisation. WM Tierney and others. J[2]AMA 1993;269:379-383

particular, ACHI believes that the primary use of the IHI and UPI should be to link the electronic information available across the various repositories, in effect creating an electronic ‘ghost’ of the patient. The process by which those links are made are therefore critical to the ultimate performance of the system, and it therefore follows that the links are made shapes between the distributed services and the IHI service are also critical. We support the idea that the number is primarily linked to either a token (such as the Medicare card), or is drawn down at the time of care. The number of itself is not to be used to identify a patient nor a health care provider. The only purpose of the identifiers is to link clinical documents that belong to an individual (to form a longitudinal EHR) and to link providers to individuals for whom they have provided care.

What follows is the ACHI feedback in response to the specific questions raised. We would be happy to provide additional information and consultation on request.

Responses to Questions

Q1. Do you agree that the functions to be conferred on the Medicare CEO are sufficient?

Q1 No, not in its current format. We do not believe that the Medicare CDMS is sufficiently accurate to support both the IHI because audits conducted of Medicare card issuance have regularly shown error rates of more than 0.1% and that this level of error may potentially compromise the utility and reliability of the IHI. We do however support the principle of Medicare being the agency to perform this function, as long as it is adequately resourced to strengthen its data functions. We believe that the Australian public may be reassured if the legislative responsibility rested with the minister rather than the Medicare CEO – perhaps as part of a unified, overarching set of health information protections. However, we do support the use of the Medicare CDMS to form the basis of these functions. An early activity should be a scoping activity and risk assessment that forms the basis of changing the activities (and funding) of Medicare Australia to perform these functions.

Q2. Are there significant issues raised by regulating the handling of healthcare identifiers by public and private health sector organisations through existing privacy and health information laws with some additional regulatory support through specific enabling legislation for healthcare identifiers?

Q2 No, as exceptions are handled by such things as the Mental Health Act.

Q3. Are there circumstances where penalties for misuse of a healthcare identifier and associated information that is held by a healthcare provider will be inadequate?

Q3 No.

Q4. Is it appropriate that definitions contained in privacy law are adopted?

Q4 The definition as proposed for health care provider is adequate. We assume that the availability will be wide, and also assumes that other mechanisms will determine scope of practice and individual accreditation.

The definition of a health service provider seems unnecessarily vague. The adoption of an E-health environment should not be treated differently to other aspects of the health system. The problem is where does Healthcare stop & “other” care begin? For example take Aged Care. Is not some aspects of Aged Care Healthcare? Similarly for Community Care or Disability Services etc. The fact also is that Healthcare does not operate in isolation and therefore should not be defined as such.

Q5. Are there other specific terms that should be defined?

Q5 No. As above.

Q6. Do the limits on disclosure set out in Proposal 4 provide adequate protection for an individual's personal information?

Q6 Given our position that the identifiers are primarily about the linking of information, we believe that the identifiers should have the minimum amount of information necessary to achieve the purpose of linking the owner of the identifier to that number. For the IHI, where the number cannot be linked to an existing database, the minimum data set should include gender in addition to what is proposed.

For the Health care providers, we believe the same principles apply – in particular they should not include specialisation nor status of registration. These are not necessary for the primary purpose of the number, which is to link information. .

In addition we do not believe that Proposal 4 is necessary – i.e. the IHI service does not need to disclose to providers the demographic detail held. Such information is there for health providers to use to extract an IHI, not the other way around. This also protects those individuals for whom the revealing of demographic details could be significant (i.e., domestic violence)

Q7. Is the authorisation for healthcare providers set out in Proposal 5 required to provide certainty to healthcare providers, noting that the use or disclosure could occur under existing privacy arrangements as a directly related and reasonably expected secondary use or disclosure of health information?

Q7 Yes as these are details that are already in common use today. People are comfortable with what they understand and are used to.

Q8. Does the limit on disclosure set out in Proposal 6 provide adequate protection for a healthcare provider's personal information?

Q8 There is an expressed inconsistency in this proposal. The proposal only specifies "authorised users". Elsewhere in the document it implies that such users will be only owners of an HPI-I, and staff of the HI service. Yet practically most requests for the IHI will come from administrative staff in either practices or hospitals. One solution is for the legislation to specify access to the level of HPI-O, another is to widen the definition of eligibility for HPI-I. Both options need to be considered, as both have significant implications fro workflow.

Q9. **Does the proposal to apply secrecy provisions similar to those set out in the Health Insurance Act or the National Health Act provide sufficient protection for personal information held by the HI Service Operator?**

Q9 Once again this has worked satisfactorily to date, so there would seem to be little point in changing it.

Q10. Is there a need to apply a specific penalty to unauthorised use or disclosure of healthcare identifiers by health sector or other participants who hold the healthcare identifier in association with health information?

Q10 The existing penalties should suffice.

Q11. Do you agree that existing health information regulation and administrative arrangements will provide sufficient secondary use requirements for organisations handling healthcare identifiers?

Q11 Yes.

Q12. Do you agree that existing health information regulation and administrative arrangements will provide sufficient data quality requirements for organisations handling healthcare identifiers?

Q12 Yes, once again stay with what people know & understand.

Q13. Do you agree that existing health information regulation and administrative arrangements will provide sufficient data security requirements handling healthcare identifiers?

Q13 Agreed. The laws, along with professional principles have worked so far. The only trouble is that to date people have erred on the side of caution, just in case. While more sensible approaches are now coming to being, any changes will set the emerging practical approaches back to the risk adverse views.

Q14. Do you agree that existing health information regulation and administrative arrangements will provide sufficient openness requirements for organisations handling healthcare identifiers?

Q14 As for Q13.

Q15. Do you agree that existing health information regulation and administrative arrangements will provide sufficient access and correction capability for individuals?

Q15 Agreed.

Q16. Will the proposals to overcome current identifier restrictions on private healthcare providers effectively enable participation in the HI Service?

Q16 We believe so.

Q17**. Do these proposals raise any significant issues in relation to the handling of identifiers?**

Q17 The same principles of handling the Medicare number can basically be applied with the IHI & those of a provider number to the HPI-I, with the possible exception that they can be transported with other confidential information between providers. Not much new here so should sit quite comfortably.

Q18. Do you agree that existing health information regulation and administrative arrangements will provide sufficient anonymity requirements?

We believe the final legislation will be sufficient but still would prefer a consistent, agreed national approach. We express our concerns

that the indication is that the 'design work is underway' to fix an issue. However, we are not told what is proposed. This therefore makes it very hard (impossible?) to comment without the full facts!

Q19. Do you agree that existing health information regulation and administrative arrangements will provide sufficient requirements for transborder data flows?

Q19 Agreed for reasons stated above.

Q20. Does this proposal raise any significant issues in relation to the handling of identifiers?

Q20 Not that we are aware of.

Q21. Do you think participation agreements are an appropriate mechanism for setting out the responsibilities of the parties involved (i.e. healthcare provider organisations and the HI Service Operator)?

Q21 Whatever the form of the relationship between, HCO's and the HI service operator, it should specify clearly the obligation in terms of data protection and service provision. They should be legally binding and enforceable.

Q22. If so, do you consider that legislation is necessary to underpin the participation agreements?

Q22 As above.

Q23. Are there any other requirements that should be specified in legislation?

Q23 Not that we are aware of.

Q24. Is it necessary that arrangements for and enforceability of directions or guidelines that are jointly agreed by privacy regulators to be supported by legislation?

Q24 Yes as there is a need to develop as much uniformity & consistency as possible.

Q25. Are there any reasons for the privacy of health information about deceased persons to be treated differently to other personal information about them?

Q25 We do not believe so.

Q26. Is the proposed definition of health service provider appropriate?

Q26 This is one of the core components of the problem we perceive with the current document.. What is a Health Service and what is not? For example is wellbeing health? If yes then many things classified as Community Services are Health. We believe that there should be a clearer definition of health services provider.

Q27. Are there any other terms that need to be defined to support a health information privacy protection as part of a national framework?

Q27 We must first arrive at an answer for Q26 before we can do this.

Q28. Do you agree that the amendments proposed above are appropriate?

Q28 We agree.

Generally, we are in support of the ALRC recommendations and for the UPP's. We do not believe a sufficient case has been made to change these.

Q29. Are there any other circumstances where the collection principle might require amendment in relation to health information?

Q29 We do not believe so as there is already legislation in place covering the overall Public Health Surveillance issues.

Q30. Do you agree that the amendments proposed above are appropriate?

Q30 No, we believe the existing UPP's are adequate.

Q31. **Are there any other circumstances where additional guidance about the use or disclosure of information would be helpful?**

Q31 Not that we are aware of.

Q32. In relation to Proposal 32, should an agency or organisation be required to have a reasonable expectation that the person responsible for the individual will act in the best interests of the individual in receiving that information? Would guidelines provide sufficient certainty?

Q32 We think it is reasonable to expect the divulgence of the information will be in the best interests of the individual and guidelines in these circumstances would be useful.

Q33. **Do you agree that the consent of the individual should be obtained for the use or disclosure of health information for direct marketing purposes?**

Q33 Agree absolutely.

Q34. **Are guidelines sufficient to ensure that health information is retained for a suitable period of time?**

Q34 We believe guidelines would be sufficient.

Q35. **Do you agree with these proposals?**

Q35 No, we believe the existing UPP's are adequate.

Q36. Are guidelines sufficient to ensure processes for access to health information are understood by agencies and organisations?

Q36 Guidelines are essential.

Q37. Are any other amendments to the access principle required?

Q37 Not that we are aware of.

Q38. **Do you agree with this proposal?**

Q38 Agreed

Q39. **Are any other situations where the identifier principle might have an inappropriate effect on the use or disclosure of health information?**

Q39 Not that we are aware of.

Q40. **Do you agree with this proposal?**

Q40 A fundamental principle of Privacy is to **allow** information to flow as appropriate. Therefore we agree with the proposal.

Q41. **Are there any other exceptions for health information transferred outside Australia?**

Q41 Not that we are aware of.

1. **Submission to the National E-Health Transition Authority March 2007. The Office of the Privacy Commissioner.** http://www.privacy.gov.au/publications/subnehtauhi200703.html
2. **ACHI website** http://www.achi.org.au/hniresources/index.php?Itemid=89&id=53&option=com_content&task=view