



australian  
nursing federation

Submission to consultation by the Australian  
Health Ministers' Advisory Council on Healthcare  
identifiers and privacy: Discussion paper on  
proposals for legislative support

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## 1. Introduction

The Australian Nursing Federation (ANF) was established in 1924. The ANF is the largest professional and industrial organisation in Australia for nurses and midwives, with Branches in each State and Territory of Australia.

With a membership of over 170,000 nurses and midwives, members are employed in a wide range of enterprises in urban, rural and remote locations in both the public and private sectors. The core business for the ANF is the professional and industrial representation of our members and the professions of nursing and midwifery.

The ANF participates in the development of policy relating to nursing and midwifery practice and professionalism, nursing and midwifery regulation, health, community services, veterans' affairs, education, training, occupational health and safety, industrial relations, social justice, human rights, immigration, foreign affairs and law reform.

The ANF is pleased to provide comment to the Australian Health Ministers' Advisory Council (AHMAC) in the development of the legislation which will support the establishment and implementation of national healthcare identifiers and enhanced arrangements for the privacy of health information.

## 2. The nursing and midwifery professions

Nurses and midwives form the largest health profession in Australia, providing health care to people across their lifespan. Nurses and midwives are the most geographically dispersed health professionals in Australia, working in homes, schools, communities, general practice, local councils, industry, offshore territories, aged care, retrieval services, rural and remote communities, Aboriginal and Torres Strait Islander health services, hospitals, the armed forces, universities, mental health facilities, statutory authorities, general businesses, and professional organisations.

There is a combined total of 244,360 registered and enrolled nurses actually employed in nursing in Australia, with 18,297 of these being midwives.<sup>1</sup> Nurses and midwives comprise over 55% of the entire health workforce.<sup>2</sup>

Numerically then, they make up the majority proportion of the health workforce and the nature of their knowledge, skills, experience and work means they are located in most practice environments in the health and aged care sector. This breadth of their interactions with the community means that they will play a central role in the use of electronic systems developed to manage healthcare records, including the use of healthcare identifiers.

### 3. E-Health

The introduction to the Australian Health Ministers' Conference publication National E-Health Strategy: Summary 2008 quite rightly points out that

*Australia has one of the best health systems in the world based on the health outcomes of its citizens. However, maintaining or improving the health outcomes of Australians will require a fundamental change in approach to the way health care is delivered in this country.<sup>3</sup>*

Part of that 'fundamental change' is the way in which health information is managed across the health and aged care sectors. The moves to electronic systems for health information management will mean more timely access to information for nurses, midwives, other health professionals and consumers of health and aged care services. Benefits will include the ability to: retrieve, transfer and utilise information across primary, secondary and tertiary sectors within the health and aged care systems; access a person's personal health history (Individual Electronic Health Record), reducing the need to recite their full history or remember their medicines regime with every visit to a different health professional; and consult, diagnose and advise treatment across remote sites in a more interactive manner.

The National Health and Hospitals Reform Commission (NHHRC), has strongly advocated for the introduction of a person-controlled electronic health record as being essential to improving communication in the healthcare sector. In their final report, *A Healthier Future for all Australians*, the NHHRC says

*We want our future health system to be powered by the smart use of data and enabled by the electronic flow of essential information between individuals and the health professionals from whom they seek care and advice....Data should enhance decision-making, drive improvements in clinical practice, guide how resources are marshalled and employed and provide the basis for feedback loops to promote improvement in access to, and quality and efficiency of, care.<sup>4</sup>*

The ANF fully supports the introduction of e-health capabilities within all health and aged care settings across the country. In order to gain maximum potential from electronic information management systems, the ANF continues to advocate on behalf of nurses and midwives – as noted already, the largest single component of the health and aged care workforce – in terms of inclusion in consultation on all aspects of planning, implementation and evaluation of such systems.

In order to gauge the preparedness of nurses for the advent of electronic health records in all health and aged care facilities in the future, the ANF undertook a study in 2007, with Australian Government funding. The synopsis of that study, *Nurses and information technology*,<sup>5</sup> is included below:

*A study of 10,000 nurses in Australia (44% response rate) on their use of information technology has clearly identified that nurses recognize benefits to adopting more information technology in the workplace. They are however frustrated by limitations of access to the technology, software that is not always fit for purpose; and lack of opportunities for training. The level of use of information technology and information management systems is generally low and confidence in use is low even among those nurses who are users. There is evidence that familiarity, use and confidence in use are slightly higher in nurses who have recent tertiary education. Nurses feel poorly informed about information technology health initiatives and poorly consulted about implementation of these initiatives. Workload, number of computers, inadequate technical support and lack of training are principal barriers to the use of information technology. Technical support is especially poor in more remote locations. Neither the full potential of information technology in the provision of health and aged care nor the recognition by all nurses that information technology is an integral part of nursing will be realized until these limitations are addressed.*

As indicated in this synopsis, there is considerable work to be done with nurses and midwives in readiness for the implementation of e-health systems. The ANF is currently managing a second project, again funded by the Australian Government, which resulted from one of the recommendations of the *Nurse and information technology* study. This latest study, in conjunction with the Queensland University of Technology aims to develop, validate and publish Informatics Competency Standards for the nursing profession in Australia.

Information on these two studies has been included to highlight the fact that the success of the unique health identifiers initiative, even as a building block for electronic health records and information systems, hinges on nurses and midwives having an understanding of information management and having access to appropriate computing equipment in their workplace. It will be imperative too that nurses and midwives are consulted throughout the planning and implementation phases, and constitute a substantial component of the communication strategy. (refer to Section 6 of this submission)

#### **4. Issues relating to Healthcare Identifiers and Privacy**

General comments are provided in this submission to assist the AHMAC in deliberations on the development of healthcare identifiers and related legislation on privacy.

#### 4.1 National healthcare identifiers

In advocating for a person-controlled electronic health record the NHHRC highlights the current difficulty in being able to “identify that a set of data is actually that of one person or another, as there are often many different identifiers for an individual in each service that they are treated.”<sup>6</sup> The NHHRC therefore recommended that

*...the Commonwealth Government legislate to ensure the privacy of a person’s electronic health data, while enabling secure access to the data by the person’s authorised health providers.*<sup>7</sup>

The NHHRC further recommended that there be unique identifiers established for each individual, for health care purposes, as well as unique identifiers for each health professional (beginning with nationally registered health professionals), and for each healthcare facility and service.<sup>8</sup>

The ANF fully supports the development of the unique healthcare identifier, acknowledging that it is the first building block needed to be established before the introduction of a national e-health system, which will incorporate an individual electronic healthcare record (IEHR).

The ANF shares the views of the Health Issues Centre that:

*The collection, use and disclosure of health information by practitioners involves issues of great sensitivity to consumers. Consumers are vulnerable to, and dependent on, the skills, expertise and goodwill of their health practitioner and, by extension, the agency in which they practice. The need for frank and open sharing of information between consumers and their practitioner is fundamental to the building of trust in these relationships. While practitioners have a range of professional, ethical and statutory obligations relating to health information, this information is increasingly handled by people with little or no specific training in responding professionally to these particular sensitivities. So, for example, while consumers may trust their practitioner, they may not have the same level of trust for the hospital or corporation that employs that practitioner or the government that monitors that service. Information given with confidence in a practitioner can move quickly beyond that practitioner’s control.*

*Consumers are also entitled to know that due attention is paid to the quality, integrity and security of their health records and what steps they can follow to obtain access to their health records.*<sup>9</sup>

The establishment of regulatory arrangements to ensure appropriate safeguards for patient health information is seen by the ANF as a critical adjunct to the implementation of a unique healthcare identifier for both health professionals and consumers of health services and the introduction of an individual electronic healthcare record (IEHR).

#### 4.1.1 Issuing of Healthcare Identifiers

The ANF recognises that there will need to be three unique identifiers issued:

- an Individual Healthcare Identifier (IHI) for all individual consumers receiving health services in Australia,
- a Healthcare Provider Identifier – Individual (HPI-I), and
- a Healthcare Provider Identifier – Organisation (HPI-O).

Regarding the question of whether the Individual Healthcare Identifier (IHI) (that is, the one for individual consumers) should be issued on a universal or voluntary basis, it is the view of the ANF that the IHI be universally assigned. It is noted that this is the preferred approach identified in the AHMAC discussion paper. The ANF understands that this would be the simplest process and that in essence the IHI does not carry any health information – it is just an identifier of an individual.

In relation to the assigning of a Healthcare Provider Identifier – Individual, the ANF considers that the issuing of this HPI-I to an individual nurse or midwife through their regulatory body is the most appropriate mechanism. After 1 July 2010 there will be a national regulatory body for nurses and midwives, the National Nursing and Midwifery Board. The approach to assigning the IHI-I through the regulatory database provides comprehensive coverage of all registered nurses and midwives practising across the country.

The ANF notes that, in assigning a HPI-I through the regulatory process there are health professionals and health workers who are currently not regulated. The ANF suggests that, in the second tranche for assigning identifiers, AHMAC look more broadly at the health workers who will need to be identified to access healthcare records. The ANF advises caution in this allocation round as there are some health workers who may or may not need such access in their day to day practice.

The ANF commissioned an issues paper *Balancing risk and safety for our community: unlicensed health workers in the health and aged care systems*<sup>10</sup> in which the author, Amanda Adrian, points out that

*Identifying these workers in terms of who they are, where they work and what they do is a challenge for researchers as there are no data bases that capture the full extent of this large but unstructured workforce. This workforce is scattered across numerous care environments: increasingly in all units of hospitals, residential aged care facilities, community health and welfare services, home care services, primary care settings, schools and disability services, to name but a few.*

Essentially, the ANF wishes to highlight that while there are groups such as Speech Pathologists and Audiologists, for whom it is entirely appropriate that they be considered for the assigning of a HPI-I, it is not appropriate to just assign wholesale to all currently unregulated workers engaged in care across the health and aged care sectors.

#### 4.1.2 Healthcare Identifiers Service

The proposal that, initially, the Healthcare Identifiers Service (HI Service) will be undertaken by Medicare Australia is supported by the ANF. The rationale given that Medicare already has a tried and trusted database for identifying individuals, is seen by the ANF to have merit.

However, the ANF notes that this may be an 'interim arrangement' for expediency and places on record our request that there be full consultation with all stakeholders before any change is made for a longer term arrangement for the HI Service.

The issue that any changes to details of an individual with Medicare, such as a name or address change, will be automatically available to the HI Service, is another positive aspect of using Medicare Australia as the HI Service. This reduces the inconvenience to the individual of having to make such changes across multiple agencies and increases the accuracy of the data held for the unique healthcare identifier.

#### 4.1.3 Legislative support for the Healthcare Identifiers Service

The HI Service will be a fundamental starting point for secure, reliable electronic exchange of information for healthcare purposes. The ANF agrees that legislation is required to support the establishment of the HI Service, and that it must operate within a national privacy environment suited to the particular privacy needs of health information.

##### 4.1.3.1 Proposals for legislation

In response to the general questions posed in the discussion paper<sup>11</sup> (p20) the ANF offers the following brief comments:

*Are the proposals for legislation fit for purpose and support the objectives of the Healthcare Identifiers Service (HI Service)?*

It is proposed that in order for the HI Service to have sufficient protections that can ensure public confidence, there will be statutory arrangements to support its operation which will provide a similar level of accountability and scrutiny as apply to Medicare Australia. As stated previously the ANF supports the allocating of the functions of the HI Service to an existing statutory authority – Medicare Australia. This support is given because Medicare Australia has existing information and service infrastructure and so there is no need to set up duplicate services. In addition, the use of existing infrastructure means that the HI Service can be operational sooner than would be possible with a completely new service having to be established. It is the ANF's view that the Healthcare Identifiers always remain discreetly in Government ownership and this should be reflected in the privacy legislation.

*Will the proposals for legislation raise any significant issues for stakeholders if they are implemented as proposed.*

The ANF gives in principle support to the proposed legislation that it will not raise any significant issues for stakeholders if they are implemented as proposed.

However, the ANF cannot say definitively whether or not the existing legislative provisions relating to personal privacy are adequate or that if they may require amendment at a future stage as not all the implications are clear. The ANF would urge a watching brief be maintained during each stage of the development and roll out of the HI Service and unique healthcare identifiers.

The ANF considers that there should be mechanisms built into the implementation for independent evaluation and critical review of all processes relating to the unique healthcare identifiers.

*Is there a need for modifying or adding to in order to support implementation of the Healthcare Identifiers Service and participation by individuals, healthcare providers and healthcare provider organisations.*

#### *Definitions*

The definitions of healthcare service and healthcare provider do need to be broad and those contained in the national Privacy Act would seem to be appropriate as facilities from acute through to primary health care settings, including schools, are included. However, there doesn't appear to be mention of aged care facilities. In addition, the health service definition should be inclusive of anywhere that a health professional may be employed to provide health care - for example, a building site which employs an occupational health and safety nurse.

#### *Collection*

The ANF supports the notion that only information that is necessary for the purposes of the HI Service be collected.

Information for:

IHI: The information already collected for Medicare purposes should be sufficient for the IHI.

HPI-I: With reference to the data fields outlined on page 26 of the discussion paper for collection for the HPI-I, the ANF questions the purpose of 'provider individual specialty' and 'registration status'. In the case of nursing in particular, a nurse could provide care in a range of specialty areas.

HPI-O: The ANF notes that the information suggested for collection to support a Healthcare Provider Directory Service will be optional and suggests that it is not necessary to collect 'provider individual specialisation' and 'date of death'. Also, there are health professionals who practice out of an employment agency and are not tied to one particular place of business.

#### 4.1.4 Governance arrangements

The discussion paper, in a reference to possible future expansion of functions of the HI Service, makes mention that "...over time, some expansion of the currently proposed use of the HI Service may be required, particularly as other local and national e-health services which rely on healthcare identifiers are implemented."<sup>12</sup>

The ANF recognises the potential for 'function creep'. In agreeing with Proposal 19 "Establish a process for controlling the expansion of the future uses of the HI Service", the ANF seeks assurances from AHMAC that any broadening of the functions of the HI Service would only occur after an identified and obligatory process of rigorous impact analysis, key stakeholder and community participation in a public debate and stringent safeguards being applied to any additional functions that are introduced.

#### 4.1.5 Other issues

There needs to be specific provision in the legislation to cover the following issues:

##### *Outliers*

Currently there are people living in Australia who do not possess a Medicare Australia card for a variety of reasons. Examples include homeless people, refugees, those people who are in this country without the necessary official visas or residency requirements. It is unclear as to how these people would be dealt with in relation to the assigning of a unique healthcare identifier.

##### *Right of choice*

There are some people for whom the right of choice to their unique healthcare identifier being used is not evident either temporarily or on a longer term basis. This is an issue for people with serious mental illnesses, dementia, intellectual or physical disabilities without vigilant guardians or carers.

##### *Access to IHI*

The ANF does not support the access to a unique healthcare identifier by people where there is a commercial arrangement, such as insurance companies. This should be made clear in the legislation.

##### *Loss of disc/voucher or whatever token is used to carry the IHI*

There needs to be clear information to the community as to what implications there are, if any, should the individual lose the disc/voucher or whatever token is used to carry the IHI.

## 5. A national privacy framework

It is the view of the ANF that in the introduction and implementation of a HI Service it is critical that a national regulatory framework be developed to cover the privacy aspects of this Service in managing the information of individuals.

### 5.1 Health Information Privacy

The ANF advocates for the protection of individuals' privacy particularly in relation to health information. Health professionals have long been entrusted with delicate and personal information of those they care for and have built solid reputations around the ethical and professional boundaries of recording and communicating any such information.

Advancements in technology have had and continue to have profound effects on the health sector. The ANF acknowledges that in most instances these developments contribute to overall improvements in health outcomes and assist clinicians in the delivery of care. Ultimately the development of an electronic health record will give health professionals access to a streamlined and potentially more accurate health care history that can be carried across health sectors and jurisdictions. Whilst this could be an invaluable advancement to health care, the complex systems that allow it, will also allow for much easier, and potentially unauthorised, access to an individual's data, due to the potential for access to a larger record database than is possible with paper based records. It is in such an environment that protection of data must be stringent and of the utmost importance.

While the unique healthcare identifiers do not themselves hold any healthcare information, it is their proposed link to an individual's electronic healthcare record which poses a real or perceived risk and thus the need for a carefully considered legislative framework for their implementation and use.

#### 5.1.1 Potential Impact

*The potential impact on people who deliver and receive healthcare of the changes proposed in the areas of coverage, definitions and amendments to the Unified Privacy Principles.*

The ANF considers that the benefit to the public of having a system of healthcare identifiers and individual electronic healthcare records outweighs the privacy risks. However, this must not mean that privacy safeguards are foregone. It is important that privacy principles be applied to each layer of development and operation for the unique healthcare identifiers.

A regulatory framework needs to be in place to protect the public from misuse and abuse of the HI Service and unique healthcare identifiers, as well as there being the Government's responsibilities for appropriate stewardship of community resources.

### 5.1.2 Consultation

There must be consultation and cooperation with the professional and industrial organisations representing health professionals and other workers who have a key role in the development of codes and policy, in ensuring that there is agreement and consistency in approach to matters relating to health information and privacy.

### 5.1.3 Research

A plan for qualitative research to describe and evaluate the effect of the legislation on the protection of consumer privacy should be undertaken within 3 years of the introduction of the HI Service.

## 6. Communication strategy

It is imperative that the introduction of Healthcare Identifiers be accompanied by the development of a comprehensive communication strategy for both consumers and health professionals and workers in all health and aged care systems nationally. To improve the chances of success of this communication strategy, health professional and consumer input must be sought on both the development and implementation phases, including the development of information products, to educate consumers and health professionals about the scheme and legislative frameworks.

The following strategies are suggested:

- The use of various media (print, TV, and web based technology) to promulgate accessible consumer focused information about the HI. This should be in 'plain English' as well as community languages, and include scenarios and examples to ensure that consumers understand the way in which the HI is applied to their health information. These products need to be widely advertised and distributed through consumer networks and in the popular media.
- The use of various media (print, TV, web based technology) being used to promulgate accessible information for health professionals, health workers and health researchers that can be widely advertised and distributed through the conduits of professional and industrial networks. This includes articles in the plethora of health professional/worker newsletters, journals and bulletins – both print and electronic.
- Free workshops and presentations being conducted for consumers and health service providers and researchers, targeting specific groups such as:
  - o people in regional and rural areas
  - o people from migrant and refugee communities
  - o people from Indigenous communities

- o people from marginalised and vulnerable populations, people in custody
  - o people with chronic illness, young people and people affected by substance misuse
  - o different groupings of health workers - by professions, venues of work, type of work (for example, clinical practice, management, research, hotel services, administration).
- To enhance the effectiveness of these educational sessions they should be developed through consultation with consumers and health service providers that include representatives from the target community and group.
  - That the language, content and tone of the information communicated be positive in outlining the use of the healthcare identifiers, and the privacy arrangements.

## Conclusion

The ANF strongly supports the introduction of electronic systems within all health and aged care facilities across the country. Access to healthcare information through electronic systems will vastly improve the timeliness and quality of communication flows leading to enhanced outcomes of care for individuals. The assigning of unique healthcare identifiers is an essential first step in the implementation of individual healthcare records systems. The assurance of privacy for individuals is paramount and is best enshrined in legislation.

The ANF has welcomed the opportunity to participate in consultation to provide advice to the Australian Health Ministers' Advisory Council (AHMAC) on the development of the legislation which will support the establishment and implementation of national healthcare identifiers and enhanced arrangements for the privacy of health information.

The nursing and midwifery professions are a key component of the health and aged care workforce. As such it is imperative that they be engaged in the planning and implementation phases for this initiative. Inclusion of nurses and midwives in the communication strategy will be vital as their gaining an understanding of the identifier system will aid in the success of the implementation phase. The ANF would be pleased to provide further advice during this time.

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