

Submission to the Commonwealth Government on the Exposure Draft Healthcare Identifiers Bill 2010



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**Council of Social Service of NSW (NCOSS)
66 Albion Street, Surry Hills 2010**

Ph: 02 9211 2599 Fax: 9281 1968 email: solange@ncoss.org.au

**Prepared by the Council of Social Service of NSW (NCOSS) on behalf of the COSS
Network.**

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Prepared by the NSW Council of Social Service (NCOSS) on behalf of the COSS Network:

Australian Council of Social Service (ACOSS);
ACT Council of Social Service (ACTCOSS);
Council of Social Service of NSW (NCOSS);
Northern Territory Council of Social Service (NTCOSS);
South Australian Council of Social Service (SACOSS);
Queensland Council of Social Service (QCOSS);
Tasmanian Council of Social Service (TasCOSS);
Victorian Council of Social Service (VCOSS); and
Western Australia Council of Social Service (WACOSS).

For further information or to discuss this submission, please contact:

Solange Frost, Senior Policy Officer, Council of Social Service of NSW (NCOSS) on +61 2 9211 2599 or email: solange@ncoss.org.au

About the COSS Network

The Councils of Social Service (COSS) in Australia are the peak bodies representing the needs and interests of service providers and their clients in the non-profit social service sector. Our members comprise community service providers, professional associations and advocacy organisations. We provide:

- independent and informed policy development, advice, advocacy and representation about issues facing the community services sector;
- a voice for all Australians affected by poverty and inequality; and
- a key coordinating and leadership role for non-profit social services across the country.

We work with our members, clients and service users, the non-profit sector, governments, departments and other relevant agencies on current, emerging and ongoing social, systemic and operational issues.

This submission draws on feedback received from consultation with our health policy advice groups in the states, territories and federally; our experience working with members in the health, privacy, and consumer sectors; and from our ongoing policy and advocacy work towards achieving a fair and equitable health system for all Australians.

Introduction

The COSS Network welcomes the opportunity to comment on the *Exposure Draft Healthcare Identifiers Bill 2010*.

The development of an e-health system has the potential to improve the quality of healthcare services, patient experiences, and health outcomes through the more efficient management and communication of health information.

However, it is important that any system is underpinned by a rigorous governance and regulatory framework to maintain consumer privacy, transparency and public accountability.

The COSS network has identified a number of key principles to underpin the development of an e-health system, including healthcare identifiers (HIs). We have also made comments on specific sections of the draft legislation and some more general comments about HIs.

General principles to underpin the e-health system

1. Access

Individual access to health care services and entitlement to Medicare benefits should not be adversely affected in anyway by the introduction of HIs. This includes:

- Rights to access healthcare services anonymously. Being able to use a pseudonym is an important safeguard for vulnerable individuals, such as victims of domestic violence, to ensure they can receive universal health care without the risk of being exposed to further harm.
- Existing rights to obtain a Medicare benefit for healthcare services should be retained by individuals who choose to receive healthcare services anonymously¹.

Individuals should be able to access personal information held about them by the HI Service Operator. Any cost for individuals to access this information must be reasonable and flexible in order to take into account the financial situation of disadvantaged people.

The complaints system for HIs should be accessible and available to all Australians, including those people from culturally and linguistically diverse backgrounds, people with no or limited English language skills, Aboriginal and Torres Strait Islander people, people with a disability, and people in rural and remote areas.

Implementation of the health identifiers also depends upon strong links between service operators and other bodies, both those responsible for developing e-health standards and for other infrastructure. The July 2009 discussion paper raised the need for such links to ensure the e-health system is developed in a cohesive manner.² These links are also an important mechanism for ensuring that rights and access to universal access to health care are protected and promoted under the framework of e-health system.

¹ NEHTA Privacy Impact Assessment (PIA) August 2009, Mallesons Stephen Jacques, Sydney, 2009.

² 'Healthcare identifiers and privacy: Discussion paper on proposals for legislative support', Australian Health Ministers' Advisory Council July 2009.

2. Privacy

A clear policy commitment and effective mechanism to safeguard personal information and data is essential to gain public confidence in the new e-health system. The COSS Network welcomes NETHAs public commitment to protecting individual privacy and embedding privacy safeguards in the platform for the e-health system.

However, we are disappointed that the HI legislation is preceding the introduction of a consistent national privacy framework. The COSS Network refers the Government to the submission of the Public Interest and Advocacy Centre³ on the HI Discussion Paper in August 2009 that recommends the introduction of the e-health system be deferred until a new comprehensive national privacy framework is in place to ensure consumer confidence in the system.

3. Consumer choice and control

A public information and awareness campaign should support the introduction of HIs and the commencement of operation of the HI service to support consumer control over personal information and their HI records. A well-informed consumer base will also support the effective monitoring and compliance of the system. Key components of the campaign should include:

- What HIs are and why they are being introduced;
- Difference between HIs and individual e-health records;
- About the HI Service and how the HI system will work; and
- Individual's rights to access information relating to their HI and how they can access it.

While it is preferable that consumers are offered the choice to 'opt-in' rather than 'opt-out', the COSS network recognises the need for a universal system of HIs to maximise the benefits of a national e-health system. However, we would not support the introduction of a compulsory system and strongly recommend that this be clearly expressed in the legislation (this issue is explored further below).

We also believe that consumer control and choice over their personal health information is a fundamental right. Any system of individual e-health records must reflect this right. This includes consumer involvement both federally, in the systems and implementation processes under the Commonwealth Government, and nationally, in those implemented as part of state and territory governance arrangements. Consistent and appropriate consumer involvement will be vital to ensuring the success and effective of e-health across the country.

³ Public Interest Advocacy Centre (PIAC), PIAC submission to Department of Health and Ageing - Healthcare identifiers and privacy discussion paper, Sydney, 13 August 2009.

4. Consultation and engagement

The COSS Network strongly believes that community and consumer participation in health planning, policy development and service delivery supports a more effective, appropriate and responsive healthcare system leading to positive health outcomes.

We welcome the public consultation on HIs undertaken by DoHA and NEHTA, including the release of the discussion paper in August and the stakeholder consultation workshop in November 2009. However, some of our members have reported that the limited nature of explanation and consultation with consumers and the wider public, particularly in South Australia, has meant there is a general lack of awareness about the implications and benefits of HIs. This in turn reduces the capacity of consumers to respond.

We also note the particularly short timeframe for the provision of comments on the exposure draft legislation. The timing of the consultation period over Christmas when many organisations are closed minimises the capacity of stakeholders to provide considered feedback and ensure a robust and equitable consultation process.

The COSS Network strongly advocates for ongoing public consultations, with a particular focus on the regulations to support the draft legislation on HIs; the implementation of HIs; and the development of the e-health system in order to build consumer support, ensure a transparent and accountable process, and develop a robust and responsive e-health system for all Australians.

5. Transparency and accountability

Effective monitoring and enforcement of the legislation and regulations supporting the e-health system are essential to ensure a robust, transparent system that engenders public confidence⁴.

We welcome the establishment of the Privacy Commissioner as the regulator of the HI service and strongly support public reporting on the operation of the HI service and of any breaches under the HI legislation.

⁴ NEHTA Privacy Impact Assessment (PIA) August 2009, Mallesons Stephen Jacques, Sydney, 2009. Joint COSS submission to the Commonwealth Government on the *Exposure Draft Healthcare Identifiers Bill 2010*

Comments on draft legislation

Part Two

Section 6, line 3

The legislation currently provides that the service operator 'may' assign an HI. While this implies that HIs are not mandatory, this could be clarified by an upfront statement that HIs are not compulsory.

Section 6 (3)

The process for assigning HIs is a crucial component of how the system will operate. This includes considerations of the type and level of identifying information required; whether it will be an opt-in or opt-out system; and on what basis people or providers will be exempt from requiring an HI.

Further consultation must be undertaken on the regulations that outline the requirements for assigning HIs.

Section 9(1)

As currently drafted, this section allows for healthcare providers to be assigned an HI. However, the supporting Release Note suggests that the intention of this section is to enable individuals to be assigned temporary HIs for emergency care etc...(see page 2). If the intention of this section is to authorise healthcare providers to provide the HI Service Operator with patient demographic information for the assignment of interim HIs, then it needs to be re-drafted to this effect. If not, other provisions need to be made in the legislation to give effect to the intentions outlined in the Release Note.

Part Three

The COSS Network welcomes the commitment made in the Release Note to the rights of an individual to be able to access information held about them by the Service Operator. However this is not expressly stated in the legislation. We recommend the inclusion of a note in the legislation confirming an individual's right to access information in relation to their HIs and held by the Service Operator.

Section 11(2)(b)

The authorisation of a healthcare provider to use HIs for the provision of health care is narrower than the definition at s15(1) which also allows for other purposes, including:

“(b) the management, funding, monitoring and evaluation of health care, or

(c) the conduct of health or medical research...”

We recommend that Section 11(2)(b) and s15(1) be made consistent to avoid confusion regarding the authorised use of HIs.

Part Four

Section 15(1)

We recommend that consistent with the stated purpose of the legislation in Part One Section 3, line 23 should be amended as follows (addition in italics):

“...communication or management of *health* information....”

Part Six

In order to safeguard an individual's right to access universal healthcare services, we suggest the inclusion of an additional section on Access, stating that an individual will not be precluded from receiving healthcare services if they do not have an HI and existing entitlements to Medicare benefits will not be adversely affected.

Section 18

The COSS Network strongly advocates for additional resources to be allocated to the Privacy Commissioner to ensure the Commissioner is able to fulfil the additional responsibilities under the legislation effectively.

Section 21 & 22

The legislation currently provides for reports on the operation of the HI Service and compliance and enforcement activities of the Privacy Commissioner be made to the Ministerial Council. However, we believe that it is in the public interest for these reports to be made publicly available.

Section 23

The COSS Network notes that the review report on the operation of the Act will be prepared within 3 years after the legislation has been in effect. We would recommend that ongoing review of the impact of HIs on individual privacy be embedded in the Act's design and implementation, with particular consideration to be given to consumer comments and concerns. Damage to public confidence in the security of sensitive health information could have serious ramifications for effective health care provision and the future developments of an e-health system.

Additional comments on HIs

Allocation of HIs to non-traditional healthcare providers

In order to maximise the advantages of an e-health system for all consumers it is essential that HIs are allocated to all providers of healthcare services, including non-traditional healthcare providers, such as drug and alcohol services or women's community health centres.

Non-government organisations are key providers of health prevention and promotion services, and play an essential role in minimising the burden on the acute care system. However, many people employed by these organisations are not covered by registration boards. A process must be put in place to ensure that all healthcare providers, in both clinical and non clinical services, can be allocated an HI.

Cost of health care services

It is anticipated that HIs and an e-health system will increase the administrative burden for some health care practices, particularly in the introductory stage. It is important that these costs do not result in rising health care costs for individuals and families. The Australian Government should consider strategies to minimise the cost of implementing an e-health system for providers and to mitigate the risk of rising health care costs for consumer. This should be subject to a guarantee and adequate protections from the Australian Government that out of pocket costs will not rise as a direct result of the introduction of the new system.

Framework for the e-health system

The COSS Network welcomes the implementation of HIs as the foundations of an e-health system. However, it is ultimately the design of the e-health system itself that will have the greatest impact on consumers, in particular individual health care records. We therefore strongly support ongoing consultation and engagement with health consumers, healthcare providers, peak bodies and the general community to develop a robust and effective system for the communication and management of health information.

Conclusion

The COSS network would like to thank the Commonwealth Government for the opportunity to provide this submission.

For inquiries or further information in relation to this submission, please contact Solange Frost, Senior Policy Officer (Health) NCOS on 02 9211 2599 ext. 130 or solange@ncoss.org.au.