

Aboriginal Medical Services Alliance of the Northern Territory

and

Aboriginal Health Council of South Australia

**Response to Electronic Health Records and Healthcare Identifiers: Legislation
Discussion Paper**

June 2015

Contact – Greg Henschke, AMSANT eHealth Manager,

greg.henschke@amsant.org.au 0889446651



Introduction

AMSANT is the peak body representing Aboriginal community controlled health services (ACCHS) in the Northern Territory - AMSANT represents 26 ACCHS. AHCSA is the peak body representing ACCHS in South Australia - AHCSA represents 12 ACCHS.

Both organisations have fully endorsed the national eHealth record system. Our members have been at the forefront of electronic health recording and sharing. Many ACCHS have been using an electronic clinical information system (CIS) for over 12 years. This meant that they were early adopters of the NT shared electronic health record system (SEHR).

AMSANT and AHCSA have been key members of the NT led consortium wave 2 PCEHR site in partnership with the NT Department of Health, NT Medicare Local, and WA Country Health Services. As such we are committed to the National eHealth agenda.

As a general comment we support the proposed legislation changes. Our role in supporting our membership on the ground we are in a sense more interested in the rules that will accompany the legislation as that is the framework within which they operate. We commend the DoH for proposing legislative change

We have reviewed the Electronic Health Records and Healthcare Identifiers: Legislation Discussion Paper and have provided feedback below. The document is set out to make direct reference to the Electronic Health Records and Healthcare Identifiers: Legislation Discussion Paper under the numberings and headings prescribed in that document.

3.1 Preliminary

3.1.1 Name of the PCEHR system

AMSANT and AHCSA would support the change of name from PCEHR to My Health Record

3.1.2 Definitions

Alignment between HI and PCEHR Acts

AMSANT and AHCSA would support the alignment of both acts.

Clarification of “healthcare”

AMSANT and AHCSA would support the alignment of the three acts

Distinguishing between healthcare providers and organisations

AMSANT and AHCSA would support the easing of privacy considerations for healthcare provider organisations.

Expanding “identifying information”

AMSANT and AHCSA would support this with the proviso that use of such data is part of the data log that is audited for improper use

3.2 Governance

AMSANT and AHCSA would support the creation of the Australian Commission for Electronic Health (ACeH). We are pleased to see the use of a skills-based board but would like to see detail on the selection/election process.

3.2.1 Establishment of ACeH

AMSANT and AHCSA would support the creation of the ACeH by July 2016.

Disbanding current arrangements

AMSANT and AHCSA would support the measures to disband the current arrangements

Transition to new arrangements

AMSANT and AHCSA would support the outlined transition arrangements

ACeH functions

AMSANT and AHCSA would support the outlined functions of the ACeH.

We do however believe that it is critical for the ACeH to retain:

1. An ongoing research and development role in health technology. Technology does not stand still and ACeH must lead this in the Australian context.
2. Mechanisms like the CUP whereby key players in the primary health care sector can discuss issues at the highest level.

ACeH Board

AMSANT and AHCSA would support the proposed construct of the Board. We would like to see a well-defined selection/election process. We believe it is also important for a Board member to be drawn from outside of the Eastern seaboard urban environment as eHealth is an essential component of a functioning health system in rural and remote locations. These locations also frequently suffer from slow or low bandwidth internet connectivity.

ACeH staff

AMSANT and AHCSA would support the staffing arrangements outlined

3.2.2 HI Service Operator

AMSANT and AHCSA would support providing the flexibility to determine the HI Service Operator

3.3 Participation

3.3.1 An opt-out PCEHR system?

AMSANT and AHCSA would support the trial of an opt-out system. Recognising that there will be challenges in the same way that there are challenges with an opt-in system. We acknowledge that the equity of an opt-out system will be dependent on the rules governing the procedures of opting out. Many parts of Australia do not have access to Medicare branches and can have limited access to telephone or internet connections. Likewise many Australians have English as a second language.

Opting out in trial regions

AMSANT and AHCSA recognise that the opt-out process could be difficult for some Aboriginal and Torres Strait Islander people. In the current opt-in process the role played by healthcare providers in verifying identity through assisted registration has proved to be critical. This needs to be allowed for and mirrored in the opt-out process – assisted opt-out.

Opt-out transition in trial regions

AMSANT and AHCSA support the process outlined

The proposed timing for the opt-out trials is as follows:

AMSANT and AHCSA would support the timing process outlined

Individual consent

AMSANT and AHCSA can see that there could be a need for health care providers to assist with this process. This is based on our experience with assisted registration.

Secondary use of information

Privacy and security on information are significant concerns for our member services and this sector generally. The legislative framework and technical safeguards built into the PCEHR system will be critical to the adoption of the national eHealth Record system by ACCHS and Aboriginal and Torres Strait peoples.

Of significant concern is the way in which Aboriginal and Torres Strait Islander peoples' health data is used and the history of mis-use and mis-interpretation of data in this sector. AMSANT recognises the future potential of data extracted from the national eHealth record system to improve public health outcomes, and furthermore, sees how this information will be useful to policy makers and researchers.

We believe that:

1. There is not unanimous support across AMSANT and AHCSA members for secondary use of data from the PCEHR system.
2. We accept the use of identified data on an individual consent basis, however, requests a statement from the System Operator on how de-identified data will be dealt with.
3. We support a process where data is treated in an ethical way. The Aboriginal Health and Medical Research Council (AH&MRC) ethics committee principles should be adhered for collection of data on Aboriginal health to ensure these activities will be conducted ethically.
4. We recommend the establishment of an Ethics Committee with a core function to monitor data quality and the use of data for secondary purpose. It is critical that the membership of the committee have the authority to speak on behalf of Aboriginal and Torres Strait Islander peoples for this purpose.

Registering individuals in opt-out trials

AMSANT and AHCSA would support the process outlined

3.4 Obligations of parties

3.4.1 Obligation to enter into participation agreement

AMSANT and AHCSA would support the removal of the Obligation to enter into participation agreement

Intellectual property

AMSANT and AHCSA would support this change

Liability

We are unsure what this means in practice. The term common law suggests that liability is decided through a court process. This in turn suggests a dollar cost to an organisation were they to be the target of litigation based on something that was previously deemed to be the bailiwick of the service operator.

Data breach notifications

AMSANT and AHCSA would support this change recognising that would impact on the role of the RO within an organisation. This would need to be communicated clearly.

3.4.2 Centralising and simplifying participant obligations

AMSANT and AHCSA would support this change

3.4.3 Obligation for organisations to have PCEHR policy

AMSANT and AHCSA would support this aspiration. Our sector has a strong commitment to data quality. It should be recognised however that some issues related to quality security and data handling practices are economic rather than by intent.

3.4.4 Obligations on authorised and nominated representatives

AMSANT and AHCSA would support this change

3.4.5 Application of obligations on different types of entities

AMSANT and AHCSA would support this change

3.4.6 Obligations to use PCEHR system

AMSANT and AHCSA would support this aspiration. What happens if the PCEHR is not accessible? This could easily occur in remote and regional settings

3.4.7 Obligation for System Operator to notify decisions

AMSANT and AHCSA would support this change.

3.4.8 Obligation for System Operator to retain records

AMSANT and AHCSA would support this change.

3.4.9 Obligation for System Operator to provide system testing

AMSANT and AHCSA would support this change.

3.5 Privacy

3.5.1 Notification of PCEHR use

AMSANT and AHCSA would support this change.

3.5.2 Temporary suspension of access to a PCEHR

AMSANT and AHCSA would support this change.

3.5.3 Collection, use and disclosure of information

AMSANT and AHCSA would support this change.

Third party information

AMSANT and AHCSA would support this change.

Healthcare Provider Directory (HPD)

AMSANT and AHCSA would support this change.

Handling of healthcare identifiers by prescribed entities

AMSANT and AHCSA would support this change.

Information Commissioner's use of healthcare identifiers

AMSANT and AHCSA would support this change.

Healthcare provider organisations' use of healthcare identifiers

AMSANT and AHCSA would support this change.

Healthcare identifier searching capabilities

AMSANT and AHCSA would support this change.

Retaining information for security purposes

AMSANT and AHCSA would support retention of information

Handling by Australian Health Practitioner Regulation Agency (AHPRA)

AMSANT and AHCSA would support this change.

3.5.4 Penalties for misuse of information

AMSANT and AHCSA would support this change.

3.6 Reviews

3.6.1 Review of the legislative changes

AMSANT and AHCSA support the conducting of a review on the legislative changes

3.6.2 Privacy Assessments of AHPRA

AMSANT and AHCSA would support this change.