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AMSANT Submission

to the

Senate Inquiry into the

Personally Controlled Electronic Health Records Bill 2011 and one related bill

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Introduction

The Aboriginal Medical Service Alliance of the Northern Territory (AMSANT) is the peak body for Aboriginal community-controlled health services (ACCHS) in the NT. NT Aboriginal community controlled health services have used electronic clinical information systems for over 15 years. This has resulted in the development of extensive experience among health care providers on the use of health data and eHealth systems generally. There is no doubt that NT ACCHS are leaders in use of eHealth in Australia. The Health Connect program introduced the Shared Electronic Health Record (SEHR) five years ago beginning in the Katherine region. This program's success has been driven by participation of ACCHSs.

AMSANT is part of a wave 2 PCEHR consortium. The partners are:

- AMSANT - on behalf of NT ACCHSs
- NT Department of Health (DoH),
- Aboriginal Health Council of South Australia (AHCSA) - on behalf of SA ACCHSs
- General Practice Network of the Northern Territory (GPNNT)
- Western Australian Country Health Service (WACHS) Kimberley hospitals.

The intention of the Consortium project is to increase the registration footprint of the current NT SEHR to all populations in the Northern Territory, people accessing WA Kimberley public hospitals and South Australian ACCHSs. The project will oversee developments to current clinical information system (CIS) software and to the NT SEHR data repository to ensure they are compliant to the proposed PCEHR. The project will also implement the national identifier system into health services CISs and SEHR and improve the quality and depth of information in the NT SEHR.

General Comment Regarding PCEHR

AMSANT is supportive of any eHealth initiative that enhances the patient journey through the Australian healthcare system. Our experiences in the NT lead us to believe that the PCEHR can deliver tangible benefits to both clinicians and patients alike.

We are concerned that there is no indication of government financial support for the PCEHR post June 2012, despite the fact that it is clear that PCEHR activities undertaken by NT ACCHSs to date will need to be supported into the future. There are currently skilled people in place and a momentum amongst health care providers gains made to date will be at risk if continued resourcing is not guaranteed post June 2012.

The tangible outcomes and benefits from funded eHealth projects involving ACCHSs have been demonstrated through the NTSEHR initiative. AMSANT believes this is evidence that there can be real health outcomes from further investment into funding the ACCHS sector to implement e-Health projects. Mere "sign up" to the PCEHR is not adequate, systems and practices engendered through the PCEHR must be embedded into every clinical site in the NT – and Australia

Unless there is investment in this area, there is a risk of increasing the digital divide between ACCHSs and the private health and hospital sector, with a consequent undermining of the aims of the PCHER initiative. There should also be some future consideration to how ACCHSs keep the benefits flowing from e-health when costs increase disproportionate to funding levels.

AMSANT applauds the removal of the proposed use of data within the PCEHR for research. It must be recognised that the PCEHR is a tool to better health outcome for all Australians, and not a method to determine resource allocation and research. These activities are better conducted through analysis of data within primary clinical information systems in partnership with health providers.

Specific Responses to PCEHR Bill

Part 2 Division 1 - System Operator
Section 15 (b) (ii)

AMSANT questions what those default access controls are, and what methods of consultation with the Aboriginal community will be used to shape these access controls. Aboriginal people can lack both access to technology and adequate skills to access electronic systems. This must mean that enough consideration must go into the defaults as to allow adequate access so as to derive benefits, but not enough to endanger privacy in our complex community social structures, in which age, gender and clan and linguistic allegiances can radically determine what is "private" information.

Part 2 Division 1 - System Operator
Section 15 (d)

AMSANT supports reporting and analysis of any information as long as it is solely for the purpose of system maintenance and not for the purposes of statistical modeling. The reason is that the PCEHR contains a dataset that is not considered complete, and therefore is not a true representation of either services delivered or issues faced in the operations undertaken by AMSANT member services.

Part 2 Division 1 - System Operator
Section 16

While AMSANT is aware that the System Operator is an independent body, it would make note that it sees the unlimited power of the System Operator to be a potential threat to the integrity of the PCEHR. By allowing the System Operator to "have regard to" advice from the jurisdictional advisory committee and independent advisory council, but not be required to act on said advice, it allows for the System Operator to be negligent and dismissive of potential issues arising.

AMSANT recommends that the System Operator be *required* to have a unilateral agreement between itself and the two independent advisory groups before initiating any significant actions that may affect health outcomes.

Division 2 - Jurisdictional advisory committee
Section 19 (3)

AMSANT finds that a representative as appointed by the head of a state or territory department is an inadequate action. Our members believe that all to often the needs of Aboriginal people are not adequately served by health department representation alone. As many ACCHSs have continued issues with their respective state and territory health departments, to have representation exclusively by them would serve only to repress their needs.

As stated previously in the exposure draft, Aboriginal and Torres Strait Islander people are most likely to benefit from the benefits of the PCEHR. Added to this many Aboriginal and Torres Strait Islander people also fall into the area of chronic and complex conditions. To allow their advocacy in e-health to originate from the very source that has failed them is a potential inadequacy of the Bill.

AMSANT recommends that as Aboriginal people constitute 30% of the NT population and represent more than 50% of the burden of disease within that population that the CEO of the NT Department of Health should have their choice of representative to be ratified by the NT Aboriginal community controlled health sector.

Division 3 - Independent advisory council

Subdivision B – membership

Section 27(2) (b) (vi)

AMSANT applauds the recognition of the need for specific expertise in Aboriginal and Torres Strait Islander health on the Independent advisory council.

AMSANT recommends that the nominated representative with specific expertise in Aboriginal and Torres Strait Islander health be ratified by NACCHO

Part 3 - Registration

AMSANT has concerns around the ease of understanding for Aboriginal people when registering. Adequate translation services must be made available for Aboriginal people when signing up to ensure their privacy is not compromised and that they are able to provide informed consent.

Furthermore AMSANT believes that adequate resourcing must be given to communities to assist their community members to understand their rights and obligations when signing up for the PCEHR.

Part 3 Division 2 - Registering healthcare provider organisations

Section 45

AMSANT seeks clarification on the level of requirement placed on the attending clinician. These levels of granular information will be important to avoid any arising legal and resource issues.

Part 7 - Voluntary enforceable undertakings and injunctions

AMSANT appreciates efforts to allow unintentional breaches to be dealt with in an informed and proactive manner. Timeframes to amend any breaches must be realistic as occasionally the breaches may require re-engineering of work practices. Such change to an organisation's culture can be taxing on resources and time, and as such must be considered on a case by case basis, and resourced accordingly.

Part 8 Division 7- PCEHR Rules, regulations and other instruments

AMSANT notes that the PCEHR is a government initiative, and despite its potential for health benefits, to enforce rules that participating health providers must follow and not assist in resources and/or funding to achieve compliance would impact adversely on ACCHSs and their participation in the PCEHR