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AMSANT Submission in response to the Northern Territory Health Care Decision Maker Discussion Paper

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Introduction

Thank you for the opportunity to provide a submission in response to the Northern Territory Health Care Decision Maker Discussion Paper.

The Aboriginal Medical Services Alliance NT (AMSANT) is the peak body for Aboriginal Community Controlled Health Services (ACCHSs) in the Northern Territory (NT). AMSANT has been established for over 25 years and has a major policy and advocacy role at the NT and national levels. Our 26 members are located right across the NT from Darwin to the most remote areas. The ACCHSs sector in the NT is comparatively more significant than in other jurisdictions, being the largest provider of Aboriginal primary health care services to Aboriginal people in the NT. Around two thirds of all Aboriginal PHC services in the NT are provided by ACCHSs.

ACCHSs deliver comprehensive primary health care in an integrated, holistic, culturally secure framework which combines a population health approach with primary health care service delivery. ACCHSs are also involved in diverse health research activities as well as being strong advocates for their communities. AMSANT provides guidance and advocacy on a wide range of research, public health issues, education, workforce, continual quality improvement programs, social and emotional wellbeing, housing and other determinants of health that affect NT Aboriginal people. AMSANT has high level collaborations with the NT and Commonwealth Governments on these issues.

AMSANT embraces a social and cultural determinants of health perspective which recognises that health and wellbeing are profoundly affected by a range of interacting economic, social and cultural factors.

General comments

AMSANT broadly supports the proposed legislative changes that will provide a paradigm shift away from a paternalistic 'best interests' approach, to one that recognises a person's rights to autonomy and self-determination in respect of peoples' wishes and values. This is consistent with a human rights approach to health care whereby people are empowered to claim and exercise their rights and freedoms, and participate in decisions that affect their human rights. This is particularly important in the context of Aboriginal health where there is a history of paternalistic policy measures imposed on our people.

We also support changes that provide clarity and consistency in the way that health care decisions are made on behalf of people who are deemed to have impaired decision-making capacity. We recognise that the current legislative vehicles for consent and decision-making are convoluted, protracted, inconsistent and complicated, and that amendments are necessary for the benefit of people with impaired decision-making capacity, their decision makers, and health care providers.

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Addressing gaps in current NT legislation

AMSANT acknowledges that there are gaps in the current NT legislation relating to last resort decision making, particularly in circumstances where there is no advance consent decision (e.g. an advance personal plan), and no available consenter where a person is deemed to not have decision making capacity. We recognise that there may be times where a person is not (and never will be) under a guardianship order but – at a particular point in time – may not have decision making capacity or the ability to provide consent.

AMSANT supports amendments to the *Advance Personal Planning Act 2013* (and relevant regulations) that clarify the scope of a health care decision maker's authority, including how this authority relates to clinical research, and provides for certain health care to be treated differently to other health care.

It seems most fitting that the *Advance Personal Planning Act 2013* contain the proposed amendments and additions relating to health care decision makers, and not the *Guardianship of Adults Act 2016*. There is greater synergy between the proposed role, scope and authority of a substitute decision maker and a decision maker as appointed under an advance personal plan, than there is between the former and an appointed guardian. It is noted that in other jurisdictions, provisions relating to health care decision makers do not sit within legislation relating to guardianship. In Victoria, legislation for health care decision makers sits within the *Medical Treatment Planning and Decisions Act 2016*, and in South Australia it falls under the *Consent to Medical Treatment and Palliative Care Act 1995*.

To this end, AMSANT would recommend that amendments are made firstly to the to the *Advance Personal Planning Act 2013*, and then the *Guardianship of Adults Act 2016* to ensure consistency between all NT legislation relating to health care decision makers, including the principles upon which health care decisions are made.

AMSANT supports the decision-making principles as contained within section 22 of the *Advance Personal Planning Act 2013*, and recommend that these principles be adopted by the *Guardianship of Adults Act 2016*.

Scope and role of health care decision makers

Current wording set out by section 20 (2) of the *Advance Personal Planning Act 2013* provides that a health care decision maker's authority arises 'only when the represented adult has impaired decision-making capacity for the matter'. The Act also provides for the presumption of decision-making capacity (section 6) which should be retained.

AMSANT believes there would be benefit in the NT context for section 6 – *Decision making capacity and impaired decision making capacity* to be amended to include additional wording as appears in section 4 of the Victorian *Medical Treatment Planning and Decisions Act 2016*:

> *(4)(d) a person has decision-making capacity to make a decision if it is possible for the person to make a decision with practicable and appropriate support.*

(5) A person who is assessing whether a person has decision-making capacity must take reasonable steps to conduct the assessment at a time and in an environment in which the person's decision-making capacity can be most accurately assessed.

This would strengthen the current NT legislation by providing further measures to ensure all efforts are made in respect of the diversity of cultures, languages and customs of people across the Northern Territory, particularly in respect of Aboriginal people, in assessing a person's decision-making capacity.

AMSANT supports the current restrictions on health care decision makers that limits their scope to provide consent on restricted health care actions (*Advance Personal Planning Act 2013* (NT), s25). AMSANT also supports amendments that provide consistency between Acts as to what decision makers are able and unable to provide consent for.

There may be situations where senior clinicians, family members or close friends have concerns that the decision maker is not applying the principles of decision making outlined in the paper, either because they do not have capacity or because that person's decision making is influenced by other concerns rather than (or as well as) the wellbeing of the family member who is impaired. There would need to be a process whereby the decision maker's capacity and/or appropriateness of decision making is reviewed which allows all concerned parties to discuss the situation and any concerns that clinicians or family members have.

Types of health care

AMSANT recommends that the definition of 'medical treatment' as contained in the Victorian legislation be adopted and adjusted to define 'health care' within the NT legislation, with suggested wording below:

> *Health care* means any of the following treatments of a person by a health practitioner for the purposes of diagnosing a physical or mental condition, preventing disease, restoring or replacing bodily function in the face of disease or injury or improving comfort and quality of life, including: treatment with physical or surgical therapy; treatment for mental illness; treatment with prescription pharmaceuticals; dental treatment; or an approved clinical research procedure.

We agree that health care decision makers should <u>not</u> have scope or authority to approve decisions in relation to restricted health matters or non-therapeutic procedures. AMSANT also supports the proposal that palliative care may <u>not</u> be refused by a health care decision maker.

AMSANT agrees that there should be clarification contained with the legislation that defines clinical research and what it encompasses. On the face of it, it seems reasonable that health care decision makers could consent to clinical research procedures that have been approved by the Chief Health Officer of the NT Department of Health, that have also been approved by the relevant Ethics Committee (Top End or Central Australia). Part 5 of the *Medical Treatment Planning and Decisions Act 2016* (Vic) provides detailed provisions relating to medical research that should be considered as part of the NT's legislative amendments.

AMSANT supports the proposal to introduce concepts of routine and significant health care to allow for timely provision of health care balanced with a clear pathway to obtaining consent. This would mean that routine health care could be provided to a person without their consent or the consent of an appointed health care decision maker, but significant health care could only be provided with

consent obtained through an application to NTCAT. It would be expected that parallel to the process of providing routine and/or significant health care, the process of identifying and appointing a health care decision maker would continue. However, it would be critical that the NTCAT application process is streamlined and responds with appropriate urgency when required. For instance, a decision about a termination needs to be made quickly otherwise the woman will face a later termination which is likely to increase distress and risk of adverse outcomes or – if it is excessively delayed – it may be too late to have the procedure.

Hierarchy of health care decision makers

As the peak body for Aboriginal community controlled health services (ACCHS) in the Northern Territory, AMSANT has particular interest in advocating for the rights of Aboriginal people to have self-determination over all matters, including (and especially) health and wellbeing. Across the Northern Territory there is a diversity of Aboriginal cultures, customs and traditions which must be recognised as being unique, particularly in the context of the NT with a significant proportion of Aboriginal people within our population.

The recognition of Aboriginal customary law and tradition within the proposed legislative amendments is welcomed by AMSANT as it relates to the suggested hierarchy of health care decision makers. AMSANT supports the proposed hierarchy as it stands, whereby priority is first provided to decision makers that have been appointed through legislative instruments (either through an advance personal plan or through guardianship), and once these have been ruled out, the next most appropriate person is determined through considering customary law or tradition (including Aboriginal customary law or tradition).

AMSANT notes that the priority placed on customary law and tradition in determining an appropriate decision maker is significantly stronger in the proposed NT legislative changes than in other jurisdictions (*Medical Treatment Planning and Decisions Act 2016* (Vic) s55(3), and *Consent to Medical Treatment and Palliative Care Act 1995* (SA) s14).

AMSANT supports the comments made by Central Australian Aboriginal Congress in their submission that provides insight into the difficulties that may arise from the practical application of the proposed legislative amendments. That is not to say that these changes should not go ahead because of such difficulties. AMSANT supports Congress' recommendation that the legislation is supported by guidelines developed at a regional level to provide assistance to health care providers and empower Aboriginal people in making health care decisions in accordance to Aboriginal culture and kinship.

Safeguards and role of NTCAT

AMSANT notes that in the current *Advance Personal Planning Act 2013* (NT), the NT Civil and Administrative Tribunal (NTCAT) has jurisdiction to deal with matters under this Act. We support the proposal that NTCAT, and not the Public Guardian, is the appropriate body that provides authority on any matters that are unable to be resolved under the amended legislation, such as:

- Instances where there is no advance consent decision and no health care decision maker who is willing and able to give consent to significant health care
- Determining and appointing a health care decision maker
- Providing approval for any non-immediate but permanent and irreversible health care decisions where a person is likely to regain decision-making capacity.