

Northern Territory Health Care Decision Makers Discussion Paper

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Part 1 Background and Issues

1. Introduction

The NT Government is considering the need for legislation providing for statutory health care decision makers and for the clarification of the requirements of all substitute decision makers concerning health care decisions.

A statutory health care decision maker is a person who has automatic authority under legislation to make health care decisions for an adult with impaired decision-making capacity who cannot provide informed consent to health care.

Providing for statutory health care decision makers would complete the framework created by the *Advance Personal Planning Act 2013* and the *Guardianship of Adults Act 2016* for the making of health care decisions for an adult with impaired decision-making capacity. See Appendix 1 below.

It will give legal authority to family members and other persons who have an existing relationship to the adult to make health care decisions on their behalf and will ensure that wherever possible, health care decisions are made for the adult by a person who is familiar with the adult's views and wishes.

The NT has drawn from the work of other jurisdictions and most recently the work of the Victorian Department of Health and Human Services in the development of the *Medical Treatment Planning and Decisions Act 2016* (Vic). The Victorian legislation reflects contemporary thinking in relation to health care decision-making for adults with impaired decision-making capacity and has informed the content of this discussion paper.

Considerable work has been undertaken with the Office of the Public Guardian in the development of this discussion paper. Part 1 (paragraphs 1-7) outlines the background and issues, including legislative provisions that may unduly restrict the provision of health care action, that have identified the need for legislative reform and Part 2 (paragraph 8-15) details possible elements of the proposed health care decision makers legislation and identifies specific points for discussion.

Submissions are invited about the specific discussion points or any aspect of the proposed legislation.

2. General principles

2.1. Human right to determine own health care

As a statement of general principle every adult has a right to determine his or her own health care including to commence, continue or withdraw health care. An adult with impaired decision-making capacity may be unable to provide informed consent to his or her own health care and legislation is necessary to:

- protect the adult's right to autonomy of decision and action and to ensure that any interference with this right is least restrictive
- provide a pathway for health care decision-making for the adult to ensure that the adult receives timely health care.

The corollary to this principle, is that a health care provider who is carrying out health care action needs to ensure they have obtained full, free and informed consent for the health care.

2.2. Interference with an adult's human rights should be least restrictive

Consistent with the United Nations Convention on the Rights of Persons with Disabilities any legislation that provides for a process of obtaining consent for health care for an adult with impaired decision-making capacity should be least restrictive and in alignment with the adult's views and wishes.

2.3. Presumption of capacity

Under the *Advance Personal Planning Act 2013* and the *Guardianship of Adults Act 2016* an adult has decision-making capacity for a matter if he or she has the capacity to:

- (a) understand and retain information about the matter; and
- (b) weigh the information in order to make a decision about the matter; and
- (c) communicate that decision in some way.

An adult is presumed to have decision-making capacity until the contrary is shown.

An adult's decision-making capacity may be decision and time specific.

3. Existing NT statute law

Existing NT legislation that governs consent for health care action for Territorians includes the *Advance Personal Planning Act 2013*, *Guardianship of Adults Act 2016*, *Mental Health and Related Services Act 1998* and the *Emergency Medical Operations Act 1973*.

3.1. Advance Personal Planning Act 2013

The *Advance Personal Planning Act 2013* provides an adult with planning capacity to plan for how decisions (including health care decisions) will be made for them if their decision-making capacity becomes impaired by:

- making advance consent decisions in relation to their future health care
- making advance care directives to guide decision makers in how they make decisions for the adult
- appointing a decision maker with decision-making authority for the adult's financial matters or any or all of the adult's personal matters including health care matters.

Part 4 of the *Advance Personal Planning Act 2013* provides for health care decision-making for adults with impaired decision-making capacity by a decision maker appointed under an advance personal plan, a guardian appointed under a guardianship order and the Northern Territory Civil and Administrative Tribunal (NTCAT).

Decision makers exercising decision-making authority under the *Advance Personal Planning Act 2013* must exercise their authority in accordance with the decision-making principles set out in section 22 of the *Advance Personal Planning Act 2013*.

3.2. Guardianship of Adults Act 2016

Under the *Guardianship of Adults Act 2016* NTCAT may appoint a guardian with decision-making authority for health care for an adult with impaired decision-making capacity. The extent of a guardian's health care authority is determined by the guardianship order under which they are appointed and is subject to sections 41 (advance consent decisions) and 42 (consent decision by decision-makers or guardian) of the *Advance Personal Planning Act 2013*.

A guardian must exercise their decision-making authority in accordance with the guardianship principles set out in section 4 of the *Guardianship of Adults Act 2016*.

3.3. *Mental Health and Related Services Act 1998*

The *Mental Health and Related Services Act 1998* governs the delivery of mental health services including the compulsory treatment of an involuntary patient with a mental illness. The Mental Health Review Tribunal¹ oversees the compulsory treatment of an involuntary patient.

This Act includes provisions to regulate the administration of certain treatments to voluntary and involuntary patients, including pathways for obtaining consent or authorisation. It also includes provisions for the administration of certain treatment without the need to obtain consent or authorisation in situations where it is immediately necessary to save the patient's life or to prevent the patient suffering mental or physical deterioration or irreparable harm.

In a recent matter² investigated by the Health and Community Services Complaints Commission, the Commission considered relevant provisions within the *Mental Health and Related Services Act 1998* in relation to obtaining consent or authorisation for certain treatments. Opinion was also provided regarding a patient's right to have their views and preferences considered even if they lack capacity to provide informed consent.

The matter involved "a young Aboriginal woman who was admitted to hospital for involuntary mental health treatment. She was from a remote community and did not speak English as her first language. She did not have a guardian appointed who could consent to treatment if she was unable to do so. It is clear that she was highly vulnerable. It is also clear that her medical and psychiatric circumstances were extremely complex, and that clinicians endeavoured to provide appropriate treatment in a very challenging situation. This treatment included two major medical procedures (intubation and ventilation), and four episodes of electroconvulsive therapy (ECT)³".

The Recommendations of the Health and Community Services Complaints Commission in this matter reflect the importance of legislative provisions regarding the administration of treatment being unambiguous, rectifying legislative gaps with regard to the regulation of chemical restraint in the mental health context and the need for appropriate procedures and documentation in relation to obtaining consent or authorisation for treatment.

3.4. *Emergency Medical Operations Act 1973*

Under section 3 of the *Emergency Medical Operations Act 1973* a medical practitioner may perform a **surgical operation** on a patient without consent if the medical practitioner is of the opinion that:

- the patient is in danger of dying or of suffering a serious permanent disability and
- the performance of an operation on the patient is desirable in order to prevent the death of the patient or the occurrence of the disability and
- if the patient is an adult with impaired decision-making capacity it is not practicable to delay performing the operation until:
 - it can be ascertained whether the patient has made an advance consent decision about the operation or
 - a consent decision about the operation can be made, in accordance with the *Advance Personal Planning Act*.

¹ Noting that the operations of the Tribunal have been incorporated into the operations of NTCAT.

² Health and Community Services Complaints Commission, *De-identified Investigation Report* 8 August 2019

³ *Ibid* p6

4. Existing framework for health care decision-making in the NT

Currently the *Advance Personal Planning Act 2013* and the *Guardianship of Adults Act 2016* govern health care decision-making for adults with impaired decision-making capacity in the NT in the following ways:

- An adult with planning capacity⁴ can make an advance consent decision in an advance personal plan in relation to specific health care decisions. A person only has “planning capacity” if they have decision making capacity (as defined in section 6(1)) of the *Advance Personal Planning Act 2013*⁵
- An adult with planning capacity may appoint a decision maker with decision-making authority for health care matters in an advance personal plan.
- A guardian may be appointed under the *Guardianship of Adults Act 2016* with decision-making authority for health care matters by NTCAT.
- Where there is no decision maker or guardian willing or able to make a decision, NTCAT may make a health care decision under Part 4 of the *Advance Personal Planning Act 2013*.

5. Other Australian jurisdictions

5.1. Current interstate provisions

All other Australian jurisdictions have legislation for the statutory appointment of a health care decision maker (or similar title, including person responsible, health attorney and medical treatment decision makers) to make health care decisions for an adult with impaired decision-making capacity.

Similar elements of the legislation across jurisdictions include:

- a regime that determines a person’s health care decision maker according to a hierarchy that includes a decision maker appointed in an advance care document, a guardian appointed in a guardianship order and family or other persons who have a relationship to the adult
- principles to guide health care decision makers in the exercise of their decision-making authority
- provisions to authorise the administration of health care without consent in cases of emergency or for health care considered as minor or routine
- a pathway to obtain consent to significant or major health care when there is no available decision makers
- specific provisions in relation to participation in specified medical research.

A key difference across jurisdictions is the legislation in which the health care decision-making provisions are contained and what other legislative provisions sit within the same piece of legislation. In South

⁴ Section 4 of the *Advance Personal Planning Act 2013* defines a person with planning capacity as follows:

“An adult has **planning capacity** if the adult:

- (a) has decision-making capacity for making an advance personal plan; and
- (b) does not have an adult guardian.

⁵ (1) An adult has **decision-making capacity** for a matter if he or she has the capacity to:

- (a) understand and retain information about the matter; and
- (b) weigh the information in order to make a decision about the matter; and
- (c) communicate that decision in some way.

(2) An adult is presumed to have decision-making capacity for a matter until the contrary is shown.

Australia⁶ and Victoria⁷ there is separate legislation which deals with consent to medical treatment. In Victoria this legislation is coupled with advance personal planning provisions.

In New South Wales⁸, Tasmania⁹ and Western Australia¹⁰ the health care decision makers' provisions and consent to health care for an adult with impaired decision-making capacity sits within the relevant guardianship legislation. In Western Australia the guardianship legislation also contains provisions in relation to advance health planning.

In Queensland¹¹ the consent to health care provisions sit within the guardianship legislation but the statutory health attorneys are detailed in the *Powers of Attorney Act 1998* (Qld).

The NT has drawn from the work of other jurisdiction and particularly the recent work of the Victorian Department of Health and Human Services in the development of the *Medical Treatment Planning and Decisions Act 2018* (Vic) as it reflects contemporary thinking in relation to health care decision-making for adults with impaired decision-making capacity.

5.2. Law reform proposals elsewhere in Australia

The New South Wales Law Reform Commission (the Commission) undertook a comprehensive review of guardianship laws in NSW and in August 2018 tabled its Final Report in the NSW Parliament. The Commission recommended a single piece of legislation to contain provisions relating to substitute decision making (Tribunal appointed decision makers), supported decision making, advance planning and health care decision-making for adults with impaired decision-making capacity (person responsible provisions)¹².

The Commission made thirty four recommendations in relation to health care decision-making and medical research including:

- a will and preferences approach to health care decisions by the person responsible so that health care decisions are made in accordance with the adult's will and preferences¹³
- a person responsible should have decision-making authority in relation to a medical research project approved by a human research ethics committee¹⁴.

6. Need for legislative amendment

6.1. Problems with current last resort decision making

In circumstances where there is no advance consent decision and no available consentor (either a decision maker or guardian with health care authority who is willing and able to make a decision) the pathway for health care decision-making under Part 4 of the *Advance Personal Planning Act 2013* leads to:

1. a guardianship application being made to NTCAT for the appointment of a guardian under the *Guardianship of Adults Act 2016* to make the required health care decision or

⁶ *Consent to Medical Treatment and Palliative Care Act 1995* (SA)

⁷ *Medical Treatment Planning and Decisions Act 2016* (Vic)

⁸ *Guardianship Act 1987* (NSW)

⁹ *Guardianship and Administration Act 1995* (Tas)

¹⁰ *Guardianship and Administration Act 1990* (WA)

¹¹ *Guardianship and Administration Act 2000* (Qld)

¹² New South Wales Law Reform Commission (2018) Report 145 *Review of the Guardianship Act 1987* NSW, p25-26

¹³ *Ibid* p48 and 175

¹⁴ *Ibid* p184

2. an application being made to NTCAT to make the required decision under section 44 of the *Advance Personal Planning Act 2013*.

Difficulties arise with these two pathways because:-

1. They do not optimise the principle that any interference with an adult's decision-making should be least restrictive and in accordance with the adult's views and wishes.
2. In circumstances of urgency the health care needs of the adult may not allow time to make an application to NTCAT.
3. The adult's familial or support networks are not recognised and persons with whom the adult has a close relationship and who are familiar with the adult's views and wishes have no legal authority to make health care decisions for the adult.
4. There is no authority to provide health care without obtaining consent even in circumstances where the health care is routine and therefore leads to the appointment of a guardian or an application to NTCAT for the required health care decision.

Legislative amendment to provide an alternative pathway for health care decision-making for an adult with impaired decision-making capacity that is both timely and least restrictive may address these difficulties.

6.2. Definitions of health care and restricted health care

Decision makers appointed with health care authority in an advance personal plan exercise their authority in accordance with the definition of health care in section 3 but cannot make any decisions in relation to restricted health matters in section 25 of the *Advance Personal Planning Act 2013*.

Guardians appointed with health care authority under the *Guardianship of Adults Act 2016* exercise their authority in accordance with the definition of health care in section 3 but cannot make any decisions in relation to restricted health care as defined in section 8 of the *Guardianship of Adults Act 2016*.

6.2.1. Health care

The definitions of health care in the *Advance Personal Planning Act 2013* and the *Guardianship of Adults Act 2016* are consistent and define health care as health care of any kind, including

- (a) anything that is part of a health service as defined in section 5 of the Health Practitioner Regulation National Law and
- (b) the removal of tissue from a person's body in accordance with Part 2 of the *Transplantation and Anatomy Act 1979*

Section 5 of the Health Practitioner Regulation National Law includes the following services (whether provided as public or private services):

- services provided by registered health practitioners
- hospital services
- mental health services
- pharmaceutical services
- ambulance services
- community health services
- health education services
- welfare services necessary to implement any of the services listed above
- services provided by dietitians, masseurs, naturopaths, social workers, speech pathologists, audiologists or audiometrists;
- pathology services.

This definition of health care is very wide and some stakeholders have argued that it authorises guardians under the *Guardianship of Adults Act 2016* to make decisions in relation to non-therapeutic care that is provided as part of a health service, including a restrictive practice. However, in a recent decision by the Northern Territory Civil and Administrative Tribunal¹⁵ it was determined, having regard to provisions within the *Guardianship of Adults Act 2016* and Part 4 of the *Advance Personal Planning Act 2013*, that there is no implied authority for a guardian under the *Guardianship of Adults Act 2016* to authorise restrictive practices.

For certainty, any legislative amendment for statutory health care decision makers should necessarily include clear guidance as to the extent of the health care decision maker's authority. Legislative amendment of the existing definition of health care and its intended scope may be required to achieve this clarity and guidance.

6.2.2. Restricted health care

The definition of restricted health matters in the *Advance Personal Planning Act 2013* and restricted health care in the *Guardianship of Adults Act 2016* have the following key differences:

- the scope of medical research that may be excluded from the authority of a decision maker and a guardian, and
- Regulation 4 of the *Advance Personal Planning Regulations* includes any treatment that involves the use of an aversive stimulus, whether mechanical, chemical physical or otherwise as a restricted health matter.

The definition of special medical research or experimental health care in the *Advance Personal Planning Regulations 2014* excludes psychological research or approved clinical research from its scope. However, it does not prescribe how clinical research may be approved and therefore fall within a decision maker's authority. This is challenging because there are situations where it is appropriate for adults with impaired decision-making capacity to participate in clinical research and for this decision to be made by a health care decision maker.

Consideration is required to determine:

1. the appropriate matters which should be excluded from a health care decision maker's authority under the definition of restricted health care and
2. how the *Advance Personal Planning Regulations 2014* should be amended to prescribe in what way clinical research is approved and therefore allow adults with impaired decision-making capacity to participate in clinical trials but also safeguard their interests.

6.3. Special health matters

Some jurisdictions have recognised that certain health care require separate legislative provisions to guide health care providers and health care decisions makers and to safeguard the rights and interests of the adult with impaired decision-making capacity.

In Victoria, decision-making around palliative care is treated differently to other medical treatment decisions so that medical treatment decision makers cannot refuse the provision of palliative care to an adult with impaired decision-making capacity.

¹⁵ Re CC [2019] NTCAT 13

Legislative provisions may be required to recognise that certain health care should be treated differently to other health care as defined in the *Advance Personal Planning Act 2013* and the *Guardianship of Adults Act 2016*.

6.4. Summary of possible law reform issues

1. Enact legislation that removes the necessity for decisions to be made by NTCAT in situations where there are family or other persons who would, as general rule be expected to be able to make health care decisions for the adult with impaired decision-making capacity.

Discussion point

(1) Do you agree that there should be legislation to provide for health care decision makers?

2. Amend the *Advance Personal Planning Act 2013* and the *Advance Personal Planning Regulations 2014* to:
 - (a) clarify the scope of a health care decision maker's authority
 - (b) prescribe how clinical research may be approved and therefore fall within a health care decision maker's authority
 - (c) provide for certain health care, for example palliative care to be treated differently to other health care.

Discussion point

(2) Do you agree the *Advance Personal Planning Act 2013* and the *Advance Personal Planning Regulations 2013* should be amended to

- (a) clarify the scope of a health care decision maker's authority
- (b) prescribe how clinical research may be approved and therefore fall within a health care decision maker's authority
- (c) provide for certain health care, for example palliative care to be treated differently to other health care?

7. Purpose of reforming legislation

Any legislation for the purpose of dealing with the issues summarised above should:

- promote the least restrictive interference of an adult's right of autonomy of decision and action
- provide a timely pathway for obtaining consent to health care for an adult with impaired decision-making capacity
- provide certainty to health care providers regarding who has legal authority for health care decisions for an adult with impaired decision-making capacity
- provide comfort to Territorians that should their decision-making capacity become impaired health care decisions will be made for them by people with whom they have an ongoing relationship and who have an understanding of how they would have made the relevant health care decision and their views and wishes
- provide a timely pathway for delivering health care in circumstances where there is no health care decision maker or the urgency of the adult's health needs requires immediate health care
- provide consistency for all health care decision makers as to the scope of their decision-making authority and how this authority should be exercised
- provide appropriate safeguards for adults with impaired decision-making capacity who require health care.

Part 2 Possible elements of the proposed legislation

8. Options for legislative amendment

It is proposed that the health care decision makers legislation could be an amendment to the *Advance Personal Planning Act 2013*. The *Advance Personal Planning Act 2013* is considered an appropriate host for health care decision makers because:

- Part 4 of this Act already provides a regime for consent to health care action when an adult has impaired decision-making capacity
- the decision-making principles at section 22 of this Act align with the United Nations Convention on the Rights of Persons with Disabilities and an adult's right to autonomy of decision and action and decision-making authority being least restrictive
- the decision-making principles' primary objective is for decisions to be made as the adult would have made in the circumstances and in accordance with the adult's views and wishes
- health care decision-making for adults with impaired decision-making is not a specific issue of guardianship – it applies to many adults who may never require guardianship.

Discussion points

(3) Do you agree that health care decision makers should sit within the *Advance Personal Planning Act 2013*?

(4) If the *Advance Personal Planning Act 2013* is amended so as to provide for health care decision makers is there a need for any consequential amendments to the *Guardianship of Adults Act 2016* or to any other Act?

9. Authority of health care decision makers

A health care decision maker's authority should arise when the adult's decision-making capacity is impaired in relation to a health care decision and the adult has not made an advance consent decision in relation to the health care.

Discussion points

(5) Is it clear when a health care decision maker's authority will arise?

(6) Are there any other preconditions that should be satisfied before a health care decision maker's authority should arise?

10. Proposed health care decision makers

The proposed legislation will provide that an adult's health care decision maker is the first person in the health care decision makers' hierarchy who is willing and able to exercise decision-making authority for the adult's health care¹⁶.

A suggested health care decision makers' hierarchy is:

1. a decision maker with health care authority appointed in the adult's advance personal plan
2. a guardian with health care authority appointed under the *Guardianship of Adults Act 2016*
3. a relative who is considered the appropriate health care decision maker in accordance with customary law or tradition (including Aboriginal customary law or tradition)
4. a spouse or domestic partner
5. the primary carer (excluding a paid carer)
6. an adult child
7. a parent
8. an adult sibling

Except for a decision maker appointed in an advance personal plan or a guardian appointed under the *Guardianship of Adults Act 2016* a health care decision maker should have a close and continuing relationship with the adult.

A health care provider will be required to make reasonable attempts to identify and contact the adult's health care decision makers in order of the hierarchy having consideration to the significance of the health care and any time constraints for a decision.

It is proposed that NTCAT will have the ability to recognise a person as an adult's health care decision maker, even if they do not have one of the listed relationships, if they can show that they have a close and continuing relationship with the adult and have an understanding of the adult's views and wishes and how they made health care decisions.

Discussion point

(7) Is the proposed hierarchy of health care decision makers clear and appropriate? If not what changes would you suggest?

(8) Do you agree that a health care provider should make reasonable attempts to identify and contact the adult's health care decision maker in order of the proposed hierarchy and having regard to the significance of the health care and any time constraints for a decision?

11. Health care decision-making

11.1. Scope of authority

The proposed legislation should provide certainty to health care decision makers about the scope of their decision-making authority and this scope should be the same for all health care decision makers regardless of whether they are appointed under the *Advance Personal Planning Act 2013* or the *Guardianship of Adults Act 2016*.

¹⁶ See sections 50 and 55 of the *Medical Treatment and Panning Decisions Act 2016* as an example of a regulatory regime that provides for this kind of option.

It is proposed that consistent with existing provisions in the *Advance Personal Planning Act 2013* and the *Guardianship of Adults Act 2016* a health care decision maker should have authority to commence, continue, withhold or withdraw health care for the adult.

There may be some areas of health care that should be excluded from the scope of any proposed legislation. For example, the Victorian provisions do not apply to medical treatment that is treatment for a mental illness at any time that the person is being treated as a mental health patient or for neurosurgery for mental illness¹⁷.

Discussion point

(9) Are there any restrictions that should be imposed on a health care decision maker's authority?

11.2. Definition of health care

Paragraph 6.2.1 contains a definition of "health care".

The issue is whether the decision-making authority of health care decision makers will include all health care matters contained in the current definition of health care as defined in the *Advance Personal Planning Act 2013* or have a much more narrow focus.

11.3. Proposed amendment to the definition of health care

As detailed in paragraph 6.2.1 the existing definition of health care is very wide and some stakeholders have argued that its scope authorises guardians to make decisions in relation to non-therapeutic care that is provided as part of a health service, including restrictive practices¹⁸. Similarly it could also be argued that cosmetic surgery provided by a health service but for non-therapeutic care falls within the existing definition of health care.

The *Medical Treatment Planning and Decisions Act 2016* (Vic) provides greater certainty as to what falls within the scope of the Victorian definition of medical treatment. In this Act medical treatment is defined as:

"Medical treatment 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—

- (a) treatment with physical or surgical therapy;
- (b) treatment for mental illness;
- (c) treatment with—
 - i. prescription pharmaceuticals; or
 - ii. an approved medicinal cannabis product within the meaning of the *Access to Medicinal Cannabis Act 2016*;
- (d) dental treatment;
- (e) palliative care—

but does not include a medical research procedure"¹⁹.

¹⁷ See section 48 of the *Medical Treatment Planning and Decisions Act 2016* (Vic)

¹⁸ A restrictive practice is defined as any practice or intervention that has the effect of restricting the rights or freedom of movement of a person with a disability including seclusion, chemical, mechanical, physical and environmental restraint. National Disability Insurance Scheme (Authorisations) Bill 2019 (NT)

¹⁹ See section 3 of the *Medical Treatment Planning and Decisions Act 2016* (Vic)

The NT could draw on this wording and in particular the use of phrases such as 'therapeutic purpose' and 'diagnosing a physical or mental condition' to clarify the existing definition of health care in the *Advance Personal Planning Act 2013* for the purpose of the scope of a health care decision maker's authority.

Legislative amendment to the definition will provide greater certainty to health care providers and health care decision makers about the scope of a health care decision maker's authority.

For consistency the *Guardianship of Adults Act 2016* would be amended to refer to the definition of health care in the *Advance Personal Planning Act 2013* (with proposed amendments).

Discussion points

(10) Do you think the definition of 'health care' should be amended for the purpose of clarifying a health care decision maker's scope of authority?

(11) If yes should the definition provide that 'health care' must be for one or more of the following purposes; a therapeutic purpose, for the purpose 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?

(12) If the definition is amended, is it necessary to specifically exclude other matters that are not intended to be encompassed by the definition of health care, including cosmetic surgery and restrictive practices?

11.4. Restricted health care

A statutory health care decision maker will not have authority to make consent decisions in relation to restricted health matters as defined in section 25 of the *Advance Personal Planning Act 2013*. This includes sterilisation, termination of pregnancy, removal of non-generative tissue (eg a kidney), special medical research or experimental health care, new health care of a kind that is not yet accepted as evidenced-based, best practice health care, electroconvulsive therapy and any treatment that involves the use of an aversive stimulus. These types of health care are considered so serious and sensitive that consent for them will continue to be obtained from NTCAT under Part 4 of the *Advance Personal Planning Act 2013*.

11.4.1. Medical research

It is proposed that the definition of restricted health care in the *Advance Personal Planning Act 2013* and the *Advance Personal Planning Regulations 2014* could be amended to:

- clarify the medical research that is currently encompassed within the definition of restricted health care and therefore excluded from a health care decision maker's decision-making authority
- prescribe how clinical research may be approved and therefore fall within a health care decision-maker's authority.

The effect of the second amendment would be that in certain circumstance health care decision makers will have authority to consent to an adult with impaired decision-making capacity receiving health care that is part of an approved clinical trial. For example, the *Advance Personal Planning Regulations* could prescribe that 'approved clinical research' means a clinical trial approved by the Chief Health Officer of the Department of Health, upon recommendation of the Ethics Committee.

Discussion point

(13) Do you agree that the definition of medical research should be amended to clarify what is encompassed by the definition?

(14) Is it appropriate for clinical research that is approved by the Chief Health Officer of the Department of Health, upon recommendation of the Ethics Committee to fall within a health care decision maker's authority? If no, how may clinical research be approved?

11.5. Palliative care

Palliative care is defined as the provision of reasonable medical treatment for the relief of pain, suffering and discomfort and the reasonable provision of food and water. No treatment is being offered that requires consent of the adult or their health care decision makers. It is believed that the nature of palliative care, to reduce a person's suffering, necessitates that it should not be subject to refusal by a health care decision maker.

In Victoria a health practitioner who intends to administer palliative care to an adult is required to consider the views and wishes of the adult as expressed in any way including by way of an advance care statement and must consult with the adult's health care decision maker about the proposed palliative care²⁰.

The proposed legislation is not intended to create any obligation on a health care provider to provide futile or burdensome health care.

Discussion point

(15) Do you agree that palliative care should be treated differently to other health care under the proposed amendments to the *Advance Personal Planning Act 2013* so that health care decision makers cannot refuse palliative care?

(16) Are there any other types of health care that requires separate legislative provisions to guide health care providers and health care decision makers and protect the rights of the adult with impaired decision-making capacity?

12. How will health care decision makers exercise their authority?

Currently a decision-maker appointed with health care authority in an advance personal plan and a guardian appointed with health care authority under a guardianship order exercise their decision-making authority in different ways.

A decision-maker with health care authority appointed in an advance personal plan must exercise their authority in accordance with the decision-making principles at section 22 of the *Advance Personal Planning Act 2013*. These principles require decision makers to exercise their authority so as to give effect to any advance care directive made by the adult and as they reasonably believe the adult would have done in the circumstances. If the decision maker cannot reasonably ascertain what the adult would have done in the circumstances they must then exercise their authority in the best interests of the adult. The decision-making principles ensure wherever possible that decisions are made as the adult would have and gives effect to the adult's views and wishes.

²⁰ See section 54 of the of the *Medical Treatment Planning and Decisions Act 2016* (Vic)

A guardian with health care authority appointed in a guardianship order under the *Guardianship of Adults Act 2016* must exercise their authority in accordance with the guardianship principles at section 4 of the *Guardianship of Adults Act 2016*. These principles require a guardian to exercise their authority in a way that they reasonably believe is in the best interests of the adult. The guardian must have regard to the adult's views and wishes and relevant considerations detailed at section 4(5) of the Act to ensure their authority is least restrictive of the adult's freedom of decision and action and provides the adult with as much support as is practicable to make their own decisions. The guardianship principles require a guardian to consider all relevant considerations and not only the views and wishes of the adult in the exercise of their decision-making authority.

For consistency and certainty all health care decision makers (including guardians appointed under the *Guardianship of Adults Act 2016*) should exercise their decision-making authority in accordance with the same principles. It is proposed that these principles are the decision-making principles in section 22 of the *Advance Personal Planning Act 2013*. This will ensure consistency in the exercise of decision-making authority across all health care decision makers.

The decision-making principles could remain unchanged and guide health care decision makers as follows:

- The health care decision makers must exercise their decision-making authority to give effect to any advance care statement made by the adult and in a way that they believe the adult would have done in the circumstances.
- If the adult has not made an advance care statement about the matter the health care decision makers must exercise their authority in a way that they reasonably believe the adult would have done in the circumstances.
- In determining what the adult would have done in the circumstances the health care decision makers must seek and take into account the adult's current and previously stated views and wishes about the matter, the health care decision maker's personal knowledge of the adult and his or her views and wishes about the matter and other matters generally and may consult with other persons who have relevant information.
- If the health care decision maker is unable to form a reasonable belief about what the adult would have done in the circumstances he or she must exercise their authority in the way that they reasonably believe is in the adult's best interests.
- In determining what is in the adult's best interests the health care decision makers must take into account a number of relevant considerations detailed in the *Advance Personal Planning Act 2013* and weigh up the considerations giving them the weight that the health care decision maker believes is appropriate in the circumstances.

It is important to note that the decision-making principles include provisions whereby in certain circumstances a decision-maker is excused from exercising their decision-making authority in accordance with the decision-making principles when:

- the adult having decision-making capacity states that he or she does not want effect to be given to an advance care statement or
- the decision maker is excused from giving effect to the advance care statement or making a decision as they believe the adult would have if one or more of the following reasons (detailed in section 23 of the *Advance Personal Planning Act 2013*) apply:
 - it is impracticable
 - it would be unlawful
 - it would impose a burden on another person that is unreasonably onerous
 - there is no reasonable possibility that the adult would have intended an advance care statement to apply in the circumstances
 - it would be so unreasonable that it is justifiable to override the adult's wishes.

Discussion points

(17) Do you agree that all health care decision makers should be required to exercise their decision-making authority in accordance with the same principles?

(18) Do you agree that these principles should be the decision making principles in section 22 of the *Advance Personal Planning Act 2013*?

(19) Is any amendment required to the decision-making principles to guide health care decision-makers in their decision-making?

(20) Is any amendment required to section 23 of the *Advance Personal Planning Act 2013* to ensure that the decision to not give effect to an advance care statement or to not make a decision as the health care decision maker believes the adult would have done is justified and appropriate?

(21) Should the legislation create an obligation on a health care provider to make a report if a health care decision makers makes a decision that does not give effect to an advance care statement and without an excuse detailed in section 23 of the *Advance Personal Planning Act 2013*? If yes, who should this report be made to?

13. Health care action where there is no advance consent decision and no health care decision makers

Health care action for an adult with impaired decision-making capacity should only occur when informed consent has been obtained from the adult by way of an advance consent decision or from another person with legal authority to make the decision on behalf of the adult.

An existing exception is emergency medical operations under the *Emergency Medical Operations Act 1973*.

It is proposed that the health care decision makers legislation introduce the concept of routine and significant health care so that in the event there is no advance consent decision and no health care decision maker there will be a clear and time conscious pathway to obtain consent and/or administer the necessary health care.

The pathways could be:-

- For routine health care – the health care provider will be authorised to proceed with the health care without obtaining consent.
- For significant health care – the health care provider will be required to obtain consent from the Public Guardian or NTCAT for the health care.

Significant health care could be defined as any health care that involves any of the following:

- a significant degree of bodily intrusion
- a significant risk to the adult
- significant side effects
- significant distress to the person²¹.

²¹ Sourced from the *Medical Treatment Planning and Decisions Act 2016 (Vic)*

Routine health care could be defined as any health care other than significant health care²².

It is also proposed that the legislation could authorise the administration of emergency health care in circumstances where there is no advance consent decision, no available health care decision makers and the need to administer health care (to save the adult's life, to prevent serious damage to the adult's health or to prevent the adult suffering or continuing to suffer significant pain or distress) means there is insufficient time to seek authority from the Public Guardian or NTCAT.

Discussion point

(22) When there is no advance consent decision and no health care decision maker who is willing and able to give consent to significant health care – who is the appropriate body to give consent – the Public Guardian or NTCAT?

(23) Should the concept of routine and significant health care be introduced to provide different pathways for the provision of health care when there is no advance consent decision and no health care decision maker?

(24) Should there be any safeguards built into the administration of routine health care? For example should the health care provider be required to make reasonable attempts to locate and contact a health care decision maker?

(25) Should the legislation authorise the administration of emergency health care in circumstances where there is no advance consent decision, no available health care decision makers and the need to administer health care means there is insufficient time to seek authority from the Public Guardian or NTCAT?

14. Time requirements for health care decision makers

The introduction of health care decision makers' legislation will remove the need to apply for guardianship for an adult with impaired decision-making capacity in circumstances where the adult's impaired decision-making capacity is temporary and/or where the only decisions that are required for the adult are in relation to their health care.

It is proposed that the authority of a health care decision maker's authority will not be time limited and may continue continuously or intermittently depending on the decision-making capacity of the adult and the health care decisions that are required.

Discussion point

(26) In what circumstances, if any should an application for guardianship be required? Should this requirement be encompassed in the legislation?

15. Safeguards

It will be necessary to include safeguards in the legislation to protect the rights of the adult with impaired decision-making capacity should these legislative amendments be applied.

²² ibid

15.1. An adult objects to the health care

In its Final Report the NSW Law Reform Commission recommended that the new NSW legislation (refer paragraph 5.2) provide that the authority of a person responsible (health care decision makers) is ineffective if the adult with impaired decision-making capacity objects to the medical treatment unless one of the following circumstances exist:

1. the person responsible is a guardian and has approval from the NSW Civil and Administrative Tribunal to override the adult's objections or
2. the adult has minimal or no understanding about what the treatment entails and the treatment will cause no distress or the distress is likely to be reasonably tolerable and only transitory.

The Queensland²³ legislation contains a provision similar to the second circumstance in the event that an adult objects to the proposed health care.

Discussion Point

(27) Should a health care decision maker's authority be effective if the adult with impaired decision making capacity objects to the health care? If yes, in what circumstances?

15.2. Health care decision makers refuses significant health care

The refusal of significant health care by a health care decision maker may raise concerns for a health care provider in circumstances where the health care provider believes the health care decision maker cannot know or cannot infer the views and wishes of the adult. This may arise in a situation where an adult has never been able to express their views and wishes in relation to the health care or who has never had decision-making capacity in relation to the health care.

To safeguard the interests of the adult with impaired decision-making capacity the health care provider could be required to notify the Public Guardian for the purpose of the Public Guardian reviewing the decision. If the Public Guardian agrees that the refusal of treatment was unreasonable the Public Guardian could refer the matter to NTCAT for a decision.

Discussion point

(28) Should a health care provider be required to make a notification to the Public Guardian if a health care decision makers refuses significant treatment for an adult and the health care provider is of the belief that the health care decision makers does not know and cannot infer the views and wishes of the adult?

15.3. Conflict between possible health care decision makers

If there is conflict between possible health care decision makers in relation to who is the adult's health care decision maker or the appropriate health care decision for the adult, an application may be made to NTCAT for orders in relation to who is the adult's health care decision maker. Once an order is made by NTCAT as to the adult's health care decision maker the health care provider must act in accordance with the decisions of this person, despite any conflict that may continue with other parties.

Discussion point

(29) Do you agree that NTCAT should have authority to determine an adult's health care decision makers?

²³ s67 *Guardianship and Administration Act 2000* (Qld)

15.4. When the adult is likely to regain decision-making capacity

Health care decisions may be required for an adult whose decision-making capacity is temporary and for whom there is a belief that they will regain their decision-making capacity within a reasonable period of time.

Discussion point

(30) Should there be legislated constraints around what health care decisions may be made by a health care decision maker for an adult who is expected to regain decision-making capacity within a reasonable time?

15.5. Authority of NTCAT

NTCAT would have authority under the *Advance Personal Planning Act 2013* to make orders in relation to a health care decision maker's authority and any other orders in relation to health care decision-making as necessary.

Discussion point

(31) Are there other safeguards that should be included in the health care decision makers' legislation?

16. Submissions invited

Submissions are invited in relation to the all aspects of the proposed health care decision makers' legislation and in particular the specific discussion points identified in this paper. Submissions will inform the content of the proposed legislation.

Please forward any submissions to: AGD.ExecCorrespondence@nt.gov.au

Comments and submissions close 31 January 2020.

Any feedback or comment received by the Department of the Attorney-General and Justice will be treated as a public document unless clearly marked as 'confidential'.

In the absence of such clear indication, the Department of the Attorney-General and Justice will treat the feedback or comment as non-confidential.

Non-confidential feedback or comments may be made publicly available and published on the Department of the Attorney-General and Justice website. The Department of the Attorney-General and Justice may draw upon the contents of such and quote from them or refer to them in reports, which may be made publicly available.

Any requests made to the Department of the Attorney-General and Justice for access to a confidential submission, feedback or comment will be determined in accordance with the *Information Act 2002*.

Note: Although every care has been taken in the preparation of this Discussion Paper to ensure accuracy, it has been produced for the general guidance only of persons wishing to provide comments on the issues. The contents of the paper do not constitute legal advice or legal information and they do not constitute Government policy documents.

Appendix 1

Health care decision-making framework for adults with impaired decision-making capacity

Advance Personal Planning Act 2013

Adults with planning capacity may plan for when their decision-making capacity becomes impaired by:

- Making advance consent decisions for healthcare
- Appointing a decision maker with decision-making authority for healthcare
- Making advance care statements which set out the adult's views, wishes and beliefs as the basis on which any decision maker should make decisions.

Decision makers appointed under the *Advance Personal Planning Act 2013* must exercise their decision-making authority in accordance with the decision-making principles.

Guardianship of Adults Act 2016

Where there is no relevant advance consent decision and no decision maker appointed by the adult with authority for health care, NTCAT may appoint a guardian with authority for health care.

Guardians appointed under the *Guardianship of Adults Act 2016* must exercise their decision-making authority in accordance with the guardianship principles.

No advance personal plan and no guardian

Where there is no relevant advance consent decision, no decision maker appointed by the adult with authority for health care and no guardian, NTCAT may make a health care decision for the adult under Part 4 of the *Advance Personal Planning Act 2013*.

Health care decision maker legislation

Under the proposed legislation where there is no advance consent decision, no decision maker appointed by the adult with authority for health care and no guardian with authority for health care, a statutory health care decision maker could automatically be appointed to make decisions for the adult with impaired decision-making capacity.

Health care decision makers could exercise their decision-making authority in accordance with the decision-making principles in the *Advance Personal Planning Act 2013*.

 Current framework

 Proposed legislative amendment