Medical Treatment Planning and Decisions Act 2016

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Medical Treatment Planning and Decisions Act 2016

1. This paper was originally prepared for presentation to the Human Research Ethics Committee of the Royal Children's Hospital. The paper deals with the regulation of clinical treatment and medical research by the Act and also addresses the position of children. There is also reference in the final section to ethical as distinct from legal considerations which arise from the Act.

THE LAW

2. The Medical Treatment Planning and Decisions Act 2016 came into operation on 12 March 2018.

Decision-Making Capacity

3. The Act regulates consent to both clinical treatment and medical research in relation to persons without decision-making capacity of their own.

4. "Decision-making capacity" under the Act is the capacity to:
   (a) understand the information relevant to the decision and the effect of the decision;
   (b) retain the information to the extent necessary to make the decision;
   (c) use or weigh the information as part of the process of making the decision; and
   (d) communicate the decision.[1]

   The full text of the definition is set out in the Appendix on page 20 below.

5. A person may have decision-making capacity in relation to some decisions but not others, temporarily but not permanently, or if he or she has appropriate support or is able to receive information by appropriate means.[2]

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[1] See section 3(1) and section 4(1) of the Act. The full text of section 4 is set out in the Appendix on page 20 below.

[2] See section 4(2).

6. If a person lacks decision-making capacity but is likely to recover it within a reasonable time:

   (a) medical treatment may not be administered unless the relevant health practitioner reasonably believes that a further delay would result in a deterioration of person's condition and the treatment is in accordance with an instructional directive or has been consented to by the medical treatment decision maker;[3]

   (b) a medical research procedure must not be administered.[4]

Clinical Treatment

7. The main provisions of the Act concerning medical treatment are contained in Part 4. The essential scheme of the legislation in relation to medical treatment (as distinct from medical research) including the medical treatment of a child[5] is that medical treatment may not be administered unless:

   (a) the patient (whether an adult or a child) has decision-making capacity in relation to the treatment and consents to it;[6] or

   (b) a health practitioner believes on reasonable grounds that the medical treatment is necessary as a matter of urgency to:

      (i) save the person's life; or

      (ii) prevent serious damage to the person's health; or

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[3] See section 59.

[4] See section 72(2). Note that section 53 (as to which see paragraph 11) applies in certain cases of urgency. In such cases, ex hypothesi, the patient would not be likely to recover decision-making capacity within a reasonable time and so there would be no prohibition of medical research procedures under section 72(2).

[5] A "child" is defined in section 3(1) of the Act as a person under the age of 18.

[6] This proposition is not found in but is assumed by the Act. It is derived from the common law coupled with section 58(1) of the Act, which provides that a medical treatment decision under Division 2 of Part 4 of the Act must be obtained or ascertained if the patient does not have decision making capacity in relation to the relevant treatment. The common law rule is that a person with decision making capacity may consent to acts which in the absence of consent would be a battery or a trespass to the person. In relation to children's decision making capacity, the common law rule is that a person under the age of majority is capable of giving informed consent to medical treatment when he or she achieves a sufficient understanding and intelligence to enable him or her to understand fully what is proposed and to express his or her consent: *Gillick v West Norfolk AHA* [1986] A.C. 112 (House of Lords) at 169, 188 and 195 and see also 201 in relation to understanding the social and emotional consequences of particular treatment. Compare note 20 below in relation to medical research.

(iii) prevent the person from suffering or continuing to suffer significant pain or distress;[7]

but not if the practitioner is aware that the person has refused that particular medical research procedure either by a valid instructional directive or by any other legally valid informed refusal of treatment;[8] or

(c) the patient does not have decision-making capacity in relation to the treatment and:

(i) the treatment is approved by a previously signed instructional directive (as to which see paragraph 18 on page 10 below);[9] or

(ii) the treatment is palliative care and the health practitioner has had regard to the preferences and values of the patient and has consulted with the patient's medical treatment decision maker, if any;[10] or

(iii) if there is no relevant instructional directive, the treatment is approved by the patient's medical treatment decision maker (as to whom see paragraphs 22 and 23 on page 11 below);[11] or

(iv) if there is no relevant instructional directive and no medical treatment decision maker:

(A) the treatment is routine medical treatment;[12] or

(B) the treatment is significant medical treatment and the Public Advocate consents.[13]

("Significant medical treatment" is any treatment involving significant bodily intrusion, risk, side effects or distress. Routine medical treatment is anything else.)[14]

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[7] See section 53(1) of the Act. Note that as set out in paragraph 11 below, section 53 applies to medical research procedures as well as to medical treatment.

[8] See section 53(2).

[9] See section 60(1)(a).

[10] See section 54.

[11] See section 60(1)(b).

[12] See section 63(1)(a) of the Act. Sections 63(1)(a), 53 and 54 are the only provisions of the Act which authorize clinical treatment without any kind of consent.

[13] See section 63(1)(b).

[14] See the definitions in section 3(1).

8. Before administering medical treatment to a person who does not have decision-making capacity, a health practitioner must make reasonable efforts to ascertain if the patient including a child has an advance care directive or a medical treatment decision maker.[15]

9. The medical treatment provisions of the Act (those contained in Part 4) do not apply to the treatment of the mental illness of an involuntary patient under the Mental Health Act 2014.[16]

Research

10. With one exception, Part 5 of the Act is the only part of the Act that relates to medical research. It does not apply to the administration of a medical research procedure to a person under the age of 18.[17]

11. The exception is that under section 53(1) of the Act a health practitioner may administer a medical research procedure to a person (including a child) if the practitioner believes on reasonable grounds that the medical research procedure is necessary as a matter of urgency to:

    (a) save the person's life; or

    (b) prevent serious damage to the person's health; or

    (c) prevent the person from suffering or continuing to suffer significant pain or distress.

    The health practitioner is not permitted to administer the medical research procedure under this provision if the practitioner is aware that the person has refused that particular medical research procedure either by a valid instructional directive or by any other legally valid informed refusal of treatment.[18]

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[15] See section 50(1).

[16] See section 48.

[17] See section 72(1). The definition of "adult" is in section 3(1) of the Act.

[18] See section 53(2).

12. It is apparent that this exception involves a blurring of the distinction between clinical treatment and medical research. It is thought, however, that if the exception applies, every aspect of the research project could lawfully be conducted in relation to the participant, including a child participant, without consent. This would include, for example, aspects of the research project involving information and sample collection and analysis going beyond the clinical requirements of the relevant procedure.

13. For the purposes of the Act, a "medical research procedure" is "a procedure carried out for the purposes of medical research" not including "non-intrusive examinations", observing a person's activities, undertaking a survey or collecting or using personal information or health information. The full definition is contained in section 3(1) of the Act and is set out in the Appendix on page 20 below. The definition can be varied by the inclusion or exclusion of particular procedures prescribed by the Governor in Council under section 100 of the Act.

14. Part 5 of the Act, which concerns medical research, applies, as mentioned above, to adults, that is, persons of the age of 18 or above.[19] In broad terms, it provides that a medical research procedure (within the meaning of the Act) must not be administered to an adult unless:

    (a) the adult has decision-making capacity and consents;[20] or

    (b) the adult does not have decision-making capacity and the research project has been approved by the relevant human research ethics committee;[21] and

        (i) the procedure has been approved by the adult in a previously signed instructional directive (as to which see paragraph 18 on page 10 below);[22] or

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[19] See note 17 above.

[20] This proposition is not found in but is assumed by the Act. It is derived from the common law coupled with section 72(1) of the Act, which provides that Part 5 does not apply to adults with decision making capacity in relation to the relevant medical research procedure. The common law rule is that a person with decision making capacity may consent to acts which in the absence of consent would be a battery or a trespass to the person.

[21] See section 75(a).

[22] See section 75(b)(i).

(ii) if there is no relevant instructional directive, the person's medical treatment decision maker (as to whom see paragraph 23 on page 11 below) has consented;[23] or

(iii) reasonable steps have been made to locate any instructional directive of the person and to identify and contact any medical treatment decision maker of the person (without success)[24] and:

(A) the medical research practitioner believes on reasonable grounds that the inclusion of the person in the research project would not be contrary to the person's values or expressed preferences or the personal and social wellbeing of the person;[25] and

(B) the medical research practitioner believes on reasonable grounds that the human research ethics committee has approved the project in the knowledge that a person may be included without the prior consent of either the person or the person's medical treatment decision maker;[26] and

(C) the medical research practitioner believes on reasonable grounds that one of the purposes of the project is to assess the effectiveness of the procedure being researched;[27] and

(D) the medical research practitioner believes on reasonable grounds that the medical research procedure poses no more of a risk to the person than a risk that is inherent in the person's condition and alternative medical treatment;[28] and

(E) the medical research practitioner believes on reasonable grounds that the relevant research project is based on valid scientific

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[23] See section 75(b)(ii).

[24] See section 79 in Division 3 of Part 5 of the Act. Section 75(b)(iii) refers to authorization under Division 3 of Part 5 if neither of sub-paragraphs (i) or (ii) of section 75(b) applies.

[25] See section 80(1)(a).

[26] See section 80(1)(b).

[27] See section 80(1)(c)(i).

[28] See section 80(1)(c)(ii).

hypotheses that support a reasonable possibility of benefit compared with standard medical treatment.[29]

15. Where a person is included in a medical research project without either his or her approval under an instructional directive or the consent of his or her medical treatment decision maker:

(a) The researcher must continue to take reasonable steps to identify and contact the person's medical treatment decision maker after the research has commenced in order to seek consent to the continuation of the procedure.[30]

(b) The researcher must sign a certificate as to his or her compliance with the above-mentioned requirements before or as soon as practicable after administering the research procedure and, in the case of a procedure lasting longer than 30 days, at intervals of no longer than 30 days.[31]

(c) The researcher must provide copies of the certificate or certificates to:

(i) the relevant human research ethics committee; and

(ii) the Public Advocate;

and retain a copy in the person's clinical records.[32]

(d) The researcher must inform the person, if he or she recovers decision-making capacity, or the person's medical treatment decision maker, if one is subsequently identified, as soon as reasonably practicable of:

(i) the person's inclusion in the research project; and

(ii) the option to refuse continuation of the procedure or withdraw from participation in the project without compromising the person's ability to receive any available alternative medical care.[33]

16. Before administering any medical research procedure to an adult who does not have decision-making capacity, the medical research practitioner must make reasonable

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[29] See section 80(1)(d).

[30] See section 80(2).

[31] See section 81(1).

[32] See section 81(3).

[33] See section 81(2).

efforts to ascertain if the patient has an advance care directive or a medical treatment decision maker.[34]

17. Although Part 5 of the Act does not apply to a medical research procedure administered to a child, it is submitted that the common law would make doing so illegal if the procedure were administered to a child without decision-making capacity and contrary to a valid instructional directive. By hypothesis, in this situation, the child would have had capacity at the time that the instructional directive were made so that there would be a continuing absence of consent notwithstanding the subsequent loss of decision-making capacity.

Instructional Directive

18. An instructional directive is a binding directive included in an advance care directive[35]. An advance care directive may be given by a person, including a child, who has decision-making capacity in relation to every statement made in the advance care directive and who understands the nature and effect of everything in it.[36]

19. An advance care directive must be in writing signed by the patient[37] and witnessed by two adult witnesses, one of whom must be a registered medical practitioner[38]. In the case of a child, one of the witnesses must be a registered medical practitioner or psychologist with prescribed training and experience.[39]

20. Each of the witnesses must certify that:
    (a) the person signing the document appeared to have decision-making capacity;[40] and

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[34] See section 73(1) of the Act.

[35] See section 3(1) and section 6(1).

[36] See section 13.

[37] See section 16(1).

[38] See section 17(1).

[39] See section 17(1)(d).

[40] See section 17(2)(a).

(b) the person signing the document was signing it freely and voluntarily;[41] and

(c) the person signing the document appeared to understand the nature and effect of each statement contained in it;[42] and

(d) the witness is not an appointed medical treatment decision maker of the patient[43]; and

(e) the person signed the document in the presence of both witnesses[44].

21. VCAT may revoke or vary an advance care directive if circumstances have changed so that the directive is no longer consistent with the preferences and values of the patient.[45] A health practitioner may refuse to comply with an instructional directive if he or she believes on reasonable grounds that the directive is no longer consistent with the preferences and values of the patient and that the delay that would be caused by an application to VCAT would result in a significant deterioration of the patient's condition.[46]

Medical Treatment Decision Maker

22. In the case of a child, that is, a person below the age of 18, the medical treatment decision maker is the child's parent or guardian or other person with parental responsibility who is reasonably available and willing and able to make a decision.[47]

23. In the case of an adult, that is, a person of or above the age of 18, the first of the following persons who is reasonably available and willing to make a decision is the medical treatment decision maker of a patient or research participant:

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[41] See section 17(2)(b).

[42] See section 17(3).

[43] See section 17(2)(d).

[44] See section 17(2)(c).

[45] See section 22.

[46] See section 51.

[47] See section 55(4). A person who has parental responsibility for a child under a protection order made under Part 4.9 of the Children, Youth and Families Act 2005 would be a person having parental responsibility within the meaning of section 55(4) of the Medical Treatment Planning and Decisions Act 2016. Persons having parental responsibility for a child under some informal arrangement would also be within section 55(4).

(a) a person appointed in accordance with the Act (see paragraph 26 below);[48]

(b) a guardian appointed by VCAT under the Guardianship and Administration Act 1986;[49]

(c) the person's spouse or domestic partner;[50]

(d) the person's primary carer;[51]

(e) an adult child of the person (and if more than one, the oldest);[52]

(f) a parent of the person (and if more than one, the oldest);[53]

(g) a sibling of the person (and if more than one, the oldest).[54]

24. These provisions concerning the identity of the medical treatment decision maker of a patient do not apply while a person is an involuntary patient under the Mental Health Act 2014.[55] In that case, the medical treatment decision maker of an adult patient is the first of the following persons who is reasonably available and willing to make the decision:

(a) a person appointed in accordance with the Medical Treatment Planning and Decisions Act 2016 (see paragraph 26 below);[56]

(b) a person appointed by VCAT to make the particular decision;[57]

(c) a guardian appointed by VCAT under the Guardianship and Administration Act 1986;[58]

(d) the authorized psychiatrist.[59]

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[48] See section 55(1).

[49] See section 55(2) of the Act. Note that a guardianship order cannot be made in relation to a person below the age of 18: see section 19 of the Guardianship and Administration Act 1986.

[50] See section 55(3)(a).

[51] See section 55(3)(b).

[52] See section 55(3)(c)(i).

[53] See section 55(3)(c)(ii).

[54] See section 55(3)(c)(iii).

[55] See section 55(5).

[56] See section 75(1)(a) of the Mental Health Act 2014.

[57] See section 75(1)(b) of the Mental Health Act 2014.

[58] See section 75(1)(c) of the Mental Health Act 2014.

[59] See section 75(1)(e) of the Mental Health Act 2014.

While a child is an involuntary patient under the Mental Health Act 2014, his or her medical treatment decision maker is a parent or guardian or other person with parental responsibility or, failing him or her, the authorized psychiatrist.[60]

25. Part 3 of the Act also provides for the appointment by any person (including a child) of a support person in relation to medical treatment.[61]

26. Both a medical treatment decision maker (for an adult) and a support person (for anyone — adult or child) must be appointed in writing signed by the appointor and are not validly appointed until they formally accept their appointment.[62] The document must be in English[63] and include the full name, date of birth and address of the appointor[64] and the name, date of birth and address of the appointee[65]. The signing of the appointment document must be witnessed by two adult witnesses, one of whom must be an authorized witness.[66] Authorized witnesses are either a registered medical practitioner or a person authorized to take an affidavit in Victoria.[67] Each of the witnesses must certify that:

(a) the person signing the document appeared to have decision-making capacity;[68] and

(b) the person signing the document appeared to be signing it freely and voluntarily;[69] and

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[60] See section 75(2) of the Mental Health Act 2014. See note 47 above in relation to children the subject of a protection order made under Part 4.9 of the Children, Youth and Families Act 2005.

[61] See section 31.

[62] See sections 28 and 33.

[63] See sections 28(1) and 33(a).

[64] See sections 28(1)(b) and 33(b).

[65] See sections 28(1)(c) and 33(c) and regulations 6 and 7 of the Medical Treatment Planning and Decisions Regulations 2018.

[66] See section 36(1).

[67] See section 3(1).

[68] See section 36(2)(a)(i).

[69] See section 36(2)(b).

(c) the person signing the document appeared to understand the nature and consequences of it;[70] and

(d) the witness is not an appointee under the document[71]; and

(e) the person signed the document in the presence of both witnesses[72]; and

(f) the witnesses signed the document in the presence of the appointor and of each other.[73]

Appointments under Former Legislation

27. The operation of a medical treatment power of attorney under the former Medical Treatment Act 1988 is preserved by section 102(2) of the Medical Treatment Planning and Decisions Act 2016, which reads as follows (with my underlining):

> "The appointment of an agent or an alternate agent under an enduring power of attorney (medical treatment) under the Medical Treatment Act 1988 that is in force immediately before that Act is repealed is taken, on and after that repeal, to be an appointment of an appointed medical treatment decision maker."

Indeed, an agent appointed under the former legislation continues as if he or she had been appointed as a medical treatment decision maker under the 2016 Act.

28. Since 1 September 2015, enduring powers of guardianship cannot be created. They have been replaced by enduring powers of attorney covering "personal matters". According to section 3(1) of the Powers of Attorney Act 2014 (as amended) (with my underlining):

> "***personal matter***, in relation to a principal under an enduring power of attorney ... , means any matter relating to the principal's personal or lifestyle affairs, and includes any legal matter that relates to the principal's personal or lifestyle affairs, but does not include any matter that relates to medical treatment or medical research procedures;"

The operation of an enduring power of guardianship made before 1 September 2015 under the former Division 5A of Part 4 of the Guardianship and Administration Act 1986 is preserved by section 143(1) of the Powers of Attorney Act 2014, which reads as follows (with my underlining):

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[70] See section 36(2)(a)(ii).

[71] See section 36(2)(d).

[72] See section 36(2)(c).

[73] See section 36(1)(b).

> "The amendments made to the Guardianship and Administration Act 1986 by Division 2 are not to be taken to affect the validity of an old enduring power of guardianship and, subject to subsection (2), the law as in force under the Guardianship and Administration Act 1986, immediately before the commencement of Division 2, is taken to continue to have effect in relation to the old enduring power of guardianship."

Principles, Preferences and Values

29. The Act imposes a duty on all persons making decisions, performing functions or duties, or exercising powers under the Act to act in accordance with the principles set out in section 7. Section 7 is set out in full in the Appendix on page 21 below.

30. The first and most important principle under the Act is essentially that of autonomy. The patient has the right to make informed decisions about his or her medical treatment or participation in a research project[74] and to have his or her decisions respected[75]. The Act gives force to this principle by:

(a) excluding from its provisions all forms of vicarious consent where the patient has decision-making capacity;[76]

(b) giving primacy to valid instructional directives[77] over the decisions and views of medical treatment decision makers and health practitioners in relation to both medical treatment[78] and medical research[79];

(c) requiring medical treatment decision makers in cases where there is no relevant instructional directive to make the medical treatment decision that he or she reasonably believes is the decision that the patient would have made if he or she had had decision-making capacity;[80] and

(d) permitting medical treatment decision makers in cases where there is no relevant instructional directive to consent to medical research if (and

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[74] See section 7(1)(a).

[75] See section 7(1)(b).

[76] See paragraph 3 above.

[77] See paragraph 18 above.

[78] See paragraph 7 above.

[79] See paragraph 14 above and see also paragraph 17 in relation to the significance at common law of a valid instructional directive signed by a child who subsequently lacks decision-making capacity in relation to a medical research procedure.

[80] See section 61(1).

presumably only if) he or she reasonably believes that the patient would have consented if the patient had had decision-making capacity.[81]

31. The decision of a patient who has decision-making capacity or who had previously made an instructional directive (which remains valid) cannot be over-ruled by reference to his or her "best interests" or even by reference to his or her values or preferences.

32. The next group of "principles" provide that:

(a) a patient has a right to be shown respect for his or her culture, beliefs, values and personal characteristics[82];

(b) a patient's preferences, values and personal and social wellbeing should direct decisions about the person's medical treatment or participation in medical research procedures;[83]

(c) a patient should be supported to enable him or her to make decisions about his or her own medical treatment or participation in medical research procedures;[84]

(d) a patient may "exercise autonomy" by making decisions, setting out preferences and values in advance, appointing medical treatment decision makers and support persons, and making collaborative decisions with family or community.[85]

The last of these four principles is an explicit statement about the exercise of "autonomy".

33. It is suggested that the concept of personal and social wellbeing is equivalent to "best interests" and is very different from the concept of preferences and values.

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[81] See section 77(1).

[82] See section 7(1)(c).

[83] See section 7(1)(d).

[84] See section 7(1)(e).

[85] See section 7(1)(f).

34. The remaining principle in section 7 is of a different character: it is an assertion that a partnership between a patient and the patient's family and carers and health practitioners is important to achieve "the best possible outcomes".[86]

35. The Act provides an explicit mechanism for a person to state in advance the person's "preferences and values" in relation to medical treatment decisions (including a statement about acceptable outcomes) and medical research procedures. Statements of these kinds constitute a "values directive"[87] if they are included in an advance care directive (as to which see paragraph 18 on page 10 above). The Act gives as a possible example the following statement: "If I am unable to recognise my family and friends, and cannot communicate, I do not want any medical treatment to prolong my life."[88]

36. A values directive is not the only way that the preferences and values of a person may be expressed for the purposes of the Act. The requirement in the principles set out in section 7 of the Act that a person's preferences and values should direct decisions about the person's medical treatment or participation in medical research procedures is not limited to preferences and values contained in a values directive in an advance care directive. In deciding what medical treatment decision or medical research decision should be made where there is no relevant instructional directive, a medical treatment decision maker must first consider any preferences or values set out in a values directive and next any other preferences or values of the patient known to the medical treatment decision maker.[89]

37. It is only if a medical treatment decision maker is unable to decide what medical treatment decision or medical research decision the patient or research participant would have made if he or she had had decision-making capacity on the basis of the preferences and values of the patient that the medical treatment decision maker may resort to a consideration of the personal and social wellbeing of the patient for the

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[86] See section 7(1)(g).

[87] See section 6(2).

[88] Ibid.

[89] See sections 61(2) and 77(2) for medical treatment and medical research respectively.

purpose of reaching a conclusion as to that issue and thereby make the relevant medical treatment decision or medical research decision on behalf of the patient.[90]

ETHICS

Ethical Guidance

38. Ethics and the law are quite distinct concepts. Something can be legal but not ethical or ethical but not legal. Nevertheless, there are areas where decisions about what is ethical should be considered by reference to the law; where ethics should follow the law.

39. It is suggested that the Medical Treatment Planning and Decisions Act 2016 contains sophisticated provisions which should provide guidance to human research ethics committees in relation to at least the following areas:

(a) decision-making capacity — see paragraph 3 above and the full text of section 4 of the Act set out in the Appendix on page 20 below;

(b) participation in possibly life or health saving emergency research procedures — see paragraph 11 above;[91]

(c) participation in a medical research project in circumstances where the patient has no decision-making capacity and there is no relevant instructional directive or any medical treatment decision maker — see sub-paragraph (b)(iii) of paragraph 14 on page 8 above; and

(d) the articulation of principles in relation to the ethical concept of "autonomy" — see sub-paragraph (d) of paragraph 32 above and the full text of section 7(1)(f) set out in the Appendix on page 21 below.

40. It is submitted that in each of these areas, the Act provides better guidance and more readily applicable analytical principles than the *National Statement on Ethical Conduct in Human Research*. It is also interesting to observe that the Act's approach to decision-

[90] See sections 61(3) and 77(3) for medical treatment and medical research respectively.

[91] Section 53 of the Act.

making capacity is both more elaborate and more complete than the approach to capacity to give consent set out in section 85(3) of the Health Records Act 2001.

41. It does not follow, however, that in areas to which the Act does not apply, such as research involving non-intrusive examinations, observations, surveys or the collection or use of information, the priority given by the Act to "autonomy" should be copied by human research ethics committees: that remains a matter for judgment on a case by case basis having regard to other ethical values including the ones set out in the *National Statement*.

Advance Care Directives by Children in Relation to Research

42. As mentioned in paragraph 18 above, a child with sufficient capacity can make an advance care directive. On the other hand, because Part 5 of the Act, which covers medical research, does not apply to children, the requirement that reasonable efforts be made to ascertain if the patient has an advance care directive or a medical treatment decision maker before a medical research procedure is administered[92] is not applicable to children. As mentioned in paragraph 17 above, however, the administration of a medical research procedure in breach of an instructional directive to a child who does not, at the time, have decision-making capacity might well be illegal.

43. It is suggested, therefore, that although there is no statutory obligation to make reasonable efforts <u>before</u> administering a medical research procedure to a child who does not have decision-making capacity to ascertain whether an instructional directive exists (or whether there is any parent or person in loco parentis), it is ethically necessary to do so.

[92] The requirement is contained in section 73(1) and is mentioned above in paragraph 16 on page 10.

APPENDIX

Section 4 of the Medical Treatment Planning and Decisions Act 2016

(1) A person has ***decision-making capacity*** to make a decision to which this Act applies if the person is able to do the following —
- (a) understand the information relevant to the decision and the effect of the decision;
- (b) retain that information to the extent necessary to make the decision;
- (c) use or weigh that information as part of the process of making the decision;
- (d) communicate the decision and the person's views and needs as to the decision in some way, including by speech, gestures or other means.

(2) For the purposes of subsection (1), an adult is presumed to have decision-making capacity unless there is evidence to the contrary.

(3) For the purposes of subsection (1)(a), a person is taken to understand information relevant to a decision if the person understands an explanation of the information given to the person in a way that is appropriate to the person's circumstances, whether by using modified language, visual aids or any other means.

(4) In determining whether or not a person has decision-making capacity, regard must be had to the following —
- (a) a person may have decision-making capacity to make some decisions and not others;
- (b) if a person does not have decision-making capacity for a particular decision, it may be temporary and not permanent;
- (c) it should not be assumed that a person does not have decision-making capacity to make a decision —
  - (i) on the basis of the person's appearance; or
  - (ii) because the person makes a decision that is, in the opinion of others, unwise;
- (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.

  Examples

  Practicable and appropriate support includes the following —
  - (a) using information or formats tailored to the particular needs of a person;
  - (b) communicating or assisting a person to communicate the person's decision;
  - (c) giving a person additional time and discussing the matter with the person;
  - (d) using technology that alleviates the effects of a person's disability.

(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.

Definition of "medical research procedure" in section 3(1) of the Medical Treatment Planning and Decisions Act 2016

medical research procedure means —
- (a) a procedure carried out for the purposes of medical research, including, as part of a clinical trial —
  - (i) the administration of pharmaceuticals; or
  - (ii) the use of equipment or a device; or
- (b) a prescribed medical research procedure —

but does not include any of the following —
- (c) any non-intrusive examination including —
  - (i) a visual examination of the mouth, throat, nasal cavity, eyes or ears; or
  - (ii) the measuring of a person's height, weight or vision;
- (d) observing a person's activities;
- (e) undertaking a survey;
- (f) collecting or using information, including either of the following —
  - (i) personal information within the meaning of the **Privacy and Data Protection Act 2014**;
  - (ii) health information;

(g) any other procedure prescribed not to be a medical research procedure;

Section 7 of the Medical Treatment Planning and Decisions Act 2016

(1) A person exercising a power or performing a function or duty under this Act must have regard to the following principles —

(a) a person —

(i) has the right to make informed decisions about the person's medical treatment or medical research procedures that may be administered to the person; and

(ii) should be given, in a sensitively communicated and clear and open manner, information about medical treatment or medical research procedure options, including comfort and palliative care, to enable the person to make informed decisions;

(b) the informed decisions of a person made under paragraph (a) should be respected and given effect to;

(c) a person has the right to be shown respect for the person's culture, beliefs, values and personal characteristics;

(d) a person's preferences, values and personal and social wellbeing should direct decisions about the person's medical treatment or medical research procedures that may be administered to the person;

(e) a person should be supported to enable the person to make decisions about the person's medical treatment or medical research procedures that may be administered to the person;

(f) a person may exercise autonomy with regards to medical treatment or medical research procedures that may be administered to the person by —

(i) making decisions; and

(ii) setting out preferences and values in advance; and

(iii) appointing a medical treatment decision maker; and

(iv) appointing a support person; and

(v) making collaborative decisions with family or community;

(g) a partnership between a person and the person's family and carers and health practitioners is important to achieve the best possible outcomes.

(2) In subsection (1), the reference to a person exercising a power or performing a function or duty under this Act includes VCAT.