

ALBERTA

OFFICE OF THE INFORMATION AND PRIVACY COMMISSIONER

ORDER H2002-004

September 06, 2002

DAVID THOMPSON HEALTH REGION AND DR. S. BESHAI

Review Number H0030 & H0031

Office URL: <http://www.oipc.ab.ca>

Summary: The Applicants made requests to the David Thompson Health Region and to Dr. S. Beshai (“the Custodians”) under the *Health Information Act* (“the Act”), for access to hospital medical records of a deceased minor. One of the Applicants was the biological father of the deceased and the other Applicant was his current wife. The biological parents were divorced and had joint custody of the deceased minor at the time of her death. The Custodians refused to disclose any health information to the Applicants.

The Commissioner found that the Applicants are not personal representatives of the deceased under the Act. Additionally, the Act does not allow Custodians to provide access to or disclosure of the health information of deceased minors even to a personal representative. The Commissioner recommended that the Minister of Alberta Health and Wellness amend the Act to authorize Custodians to provide access to and disclosure of the health information of deceased minors.

Statutes Cited: AB: *Health Information Act*, R.S.A. 2000, c. H-5, ss. 7(1), 8(1), 33, 34(1), 35(1), 79, 104(1)(b), 104(1)(c), 104(1)(d). See appendices for additional statutes cited.

Cases Cited: See appendices for cases cited.

Authorities Cited: See appendices for authorities cited.

I. BACKGROUND

[para 1] This situation involves the right of a parent of a deceased minor to access that minor's health information under the *Health Information Act* ("the Act"). The Applicants made access requests to the David Thompson Health Region ("DTHR") and to Dr. S. Beshai (jointly referred to as the "Custodians"). The Applicants requested copies of all medical records of the deceased from each of the Custodians, including records of the hospitalization from February 21, 2001 until the death. The deceased was a minor who was 15 years of age on the date of her death on April 15, 2001.

[para 2] One Applicant was the biological father of the deceased. The other Applicant was his current wife (jointly referred to as the "Applicants"). The biological parents were divorced and had joint custody. There were complex background issues that were intentionally not addressed at this inquiry such as ongoing civil litigation, whether there was an expressed wish of the deceased not to disclose health information, and whether there was a restraining order against the biological father.

[para 3] The Custodians refused to disclose any information to the Applicants pursuant to section 104(1) of the Act. On October 20, 2001, the Applicants made a request for review of the decisions of the Custodians. Mediation was unsuccessful and the matter was set down for an oral inquiry.

[para 4] The Applicants and Custodians provided written submissions. Seven intervenors provided written submissions (i.e., Alberta Health and Wellness, Alberta Cancer Board, Health Law Institute, Northern Alberta Chapter of the Wills & Estates Section of the Canadian Bar Association and the Alberta Medical Association) that included one joint submission from the College of Physicians and Surgeons of Alberta and the Alberta Mental Health Board.

[para 5] The Applicants and Custodians provided oral submissions at the inquiry. Four of the Intervenors provided oral submissions at the inquiry.

II. RECORDS/INFORMATION

[para 6] There were no records/information before this inquiry. The physician's office record was provided sealed on an 'in camera' basis and remained sealed.

III. ISSUES

[para 7] The following four issues were addressed in this inquiry:

Issue A: Are the Applicants entitled to exercise the right or power of the individual conferred by section 104(1)(d) of the Act?

Issue B: Are the Applicants entitled to exercise the rights or powers of the individual conferred elsewhere in section 104(1) of the Act?

Issue C: Are the Applicants entitled to request the health records/information under any other provision of the Act?

Issue D: Do the Custodians have the authority to disclose the health records/information that was requested, under other provisions of the Act?

[para 8] Where an inquiry relates to a decision to refuse access to records/information, the custodian usually has the onus or burden of proof to show that the applicant has no right of access to the records/information pursuant to section 79 of the Act. However, in this particular inquiry I have not assigned a burden of proof as this inquiry turns on legal argument and interpretation only rather than an examination of specific facts.

[para 9] The legal argument focuses upon whether the Act establishes authority for the Applicants to request the records/information on behalf of the deceased minor, and whether the Act allows the Custodians to provide the health records/information to the Applicants.

IV. DISCUSSION

[para 10] An individual has a right of access to records containing health information about the individual that is in the custody or control of a custodian under section 7(1) of the Act. The records/information requested by the Applicants under section 8(1) of the Act involve 'health information' as defined in the Act. The records/information requested by the Applicants are in the custody and control of the Custodians. However, this is not a request for the Applicant's information, but a request for the health records/information of another individual.

[para 11] A custodian may disclose health records/information to a person who is acting on behalf of another individual, pursuant to sections 104(1)(c) to (i) of the Act. A custodian has the authority to disclose diagnostic, treatment and care information to persons other than the individual who is the subject of the information pursuant to consent of the individual under section 34(1), or without consent of the individual pursuant to section 35(1).

[para 12] Other persons listed in section 104(1) of the Act can exercise any right or power conferred on an individual by the Act. The Applicants requested the health records of the deceased child of one of the Applicants. Both Custodians refused access to the Applicants. The Custodians refused to provide the information to the Applicants on the basis that the Act does not allow them to provide access or to disclose the health records/information of the deceased minor.

Issue A: Are the Applicants entitled to exercise the right or power of the individual conferred by section 104(1)(d) of the Act?

[para 13] The usual way to access health records/information of a deceased individual is through the individual's "personal representative". Section 104(1)(d) of the Act says:

104 (1) Any right or power conferred on an individual by this Act may be exercised

...

(d) if the individual is deceased and was 18 years of age or over immediately before death, by the individual's personal representative if the exercise of the right or power relates to the administration of the individual's estate;

[para 14] "Personal representative" is not defined in the Act. This provision only applies to individuals who are 18 years of age or over, that is, to adults. This provision does not include minors, that is, individuals under the age of 18 years. Section 104(1)(d) is different from other legislative provisions that govern "personal representatives" of deceased individuals that were brought to my attention during this inquiry.

[para 15] The term 'legal representative' appears in some legislation while the term "personal representative" appears in other legislation. There are differences in the definition of "personal representative" in various pieces of legislation. Examples of the legislative provisions that I have canvassed are described in more detail in Appendices I, II and III of this Order.

[para 16] A "personal representative" of a deceased individual typically has authority to access health records/information of the deceased individual, regardless of the individual's age. Section 104(1)(d) of the Act is unique as all minors, that is all individuals under the age of 18 years, are excluded from the "personal representative" provision. This means that even a "personal representative" of a deceased minor does not have authority to access health information of the deceased.

[para 17] I am mindful that most deceased minors do not have estates to administer and there may not even be a "personal representative". It must be kept in mind that the authority of a "personal representative" in the Act is limited to "administration of the individual's estate". This limitation is problematic when the parents of a deceased minor are seeking access to their child's health information for other purposes, such as for a better understanding of how the deceased spent their last days or for working through the grieving process.

[para 18] I find that the Applicants are not entitled to exercise the right or power of a deceased minor that is conferred upon a "personal representative" by section 104(1)(d) of the Act. Neither of the Applicants is a "personal representative" of the deceased.

Issue B: Are the Applicants entitled to exercise the rights or powers of the individual conferred elsewhere in section 104(1) of the Act?

1. General

[para 19] Two provisions in the Act govern access to the health records/information of a minor. Sections 104(1)(b) and 104(1)(c) of the Act say:

104 (1) Any right or power conferred on an individual by this Act may be exercised

...

(b) if the individual is under 18 years of age and understands the nature of the right or power and the consequences of exercising the right or power, by the individual,

(c) if the individual is under 18 years of age but does not meet the criterion in clause (b), by the guardian of the individual,

[para 20] Sections 104(1)(b) and 104(1)(c) of the Act specifically apply to minors or individuals under the age of 18 years. Competent minors are treated differently from incompetent minors. Section 104(1)(b) applies to competent minors, who have the authority to exercise rights or powers on their own behalf. Section 104(1)(c) applies to incompetent minors, where the 'guardian of the individual' has the authority to exercise rights or powers on behalf of the individual.

[para 21] The two provisions that relate to minors do not refer to deceased individuals. However, as these are the only other provisions in section 104(1) of the Act that could possibly provide authority for others to exercise rights or powers on behalf of deceased minors, I will now consider whether these provisions include deceased minors.

2. Competent Minors - Section 104(1)(b)

[para 22] As noted above, section 104(1)(b) applies to competent minors who are individuals who have the authority to exercise rights or powers on their own behalf. There is no provision in the Act for anyone to exercise any right or power of a deceased individual who was a competent minor under section 104(1)(b) of the Act. I emphasize that I have not made a finding about whether or not this particular deceased minor was either a competent or incompetent individual as such a determination is not necessary for the purposes of this inquiry.

[para 23] I find that the Applicants have no authority to exercise the right of access of the deceased minor in this inquiry if the individual was a competent minor, pursuant to section 104(1)(b) of the Act.

3. Incompetent Minors - Section 104(1)(c)

[para 24] "Incompetent" generally means a person who, due to defect of age or understanding or self-control, is considered incapable of administering his or her own affairs. As noted above section 104(1)(c) applies to incompetent minors, that is, to individuals who do not understand the nature or consequences of exercising their rights or powers. A biological parent is the guardian of a child who is an incompetent minor, unless this relationship is altered, for example by an order of a court. The 'guardian of the individual' has the authority to exercise rights or powers on behalf of incompetent minors.

[para 25] It is possible that this provision could apply to deceased minors if the role of the guardian of a minor, as this term is used in the Act, continues after the death of the minor. However, I have heard extensive argument at this inquiry that the role of the guardian of a minor ceases upon the death of the minor. I have considered whether

there might be something different in law about the guardian of a minor than the guardian of an adult or other types of guardians. The Act does not define the terms 'guardian' or 'guardian of the individual' of a minor.

[para 26] If the phrase 'guardian of the individual' was given a broad meaning that includes a guardian of the estate of a deceased minor, a guardian might be entitled to exercise the right or power of the deceased individual. However, at most, the authority of a 'guardian of the individual' could only apply to incompetent minors under the Act. This is a piecemeal approach that does not provide clear statutory authority for others to access health records/information of deceased minors in Alberta.

[para 27] The preponderance of the evidence and argument before me at this inquiry is that the role of the guardian of the individual, as the term is used in the Act, ceases upon the death of the minor. I accept this argument, and find that the 'guardian of the individual', including the guardian of an incompetent minor, does not have authority to exercise rights or powers on behalf of that individual under section 104(1)(c) of the Act.

[para 28] Again, I emphasize that I have not made a finding about whether or not this particular deceased minor was either a competent or incompetent individual as such a determination is not necessary for this inquiry. Similarly, I have not made a finding about whether the Applicants are guardians of this deceased minor. However, I find that even if this individual was an incompetent minor and even if the Applicants were guardians, the Applicants have no authority to exercise the right of access of this deceased minor, pursuant to section 104(1)(c) of the Act.

Issue C: Are the Applicants entitled to request the health records/information under any other provision of the Act?

[para 29] I have read the submissions and listened to extensive oral argument from the participants in this inquiry, which is summarized in Appendix IV of this Order. I find that the Applicants are not entitled to request the health information under any other provision of the Act.

Issue D: Do the Custodians have the authority to disclose the health records/information that was requested, under other provisions of the Act?

[para 30] The authority of custodians to disclose health information may hinge upon the existence of a right or power that can be exercised by an individual on behalf of a deceased minor. Custodians have the authority to disclose health records/information to the persons listed in section 104(1)(c) to (i) who are acting on behalf of the individual, pursuant to section 33 of the Act. Custodians have the authority to disclose health records/information with the consent of the individual pursuant to section 34 of the Act.

[para 31] Custodians have the authority to disclose health records/information to persons other than the individual where the individual has consented to the disclosure. A competent minor has the authority to consent to disclosure under section 104(1)(b).

The guardian of the individual has the authority to consent to disclosure under section 104(1)(c).

[para 32] These provisions again beg the question of whether another person listed in sections 104(1)(c) to (i) has the authority to exercise a right or power conferred on an individual including the right to consent for disclosure to third parties on behalf of a deceased minor. I have already found that the two provisions that apply to minors in section 104(1) of the Act only apply to living minors. A “personal representative” is usually entitled to exercise a right or power on behalf of a deceased individual, but a “personal representative” under the Act is not entitled to exercise a right or power on behalf of a deceased minor.

[para 33] Custodians have the authority to disclose health records/information without consent in the specific situations prescribed in the Act. Section 35(1) of the Act lists exceptions where custodians have the discretion to disclose without consent. Various disclosure provisions in the Act were examined and argued as a possible means for parents to access health records/information on behalf of deceased minor children.

[para 34] However, I find that none of the disclosure provisions in section 35(1) or elsewhere in the Act provide authority for the Custodians to disclose the health records/information to the Applicants. I find that there is no authority for persons to exercise rights or powers on behalf of deceased minors under the Act. There is no authority for custodians to disclose the health records/information requested under the Act.

V. Recommendation

[para 35] There is no policy reason of which I am aware that absolutely precludes access to and disclosure of the health records/information of deceased minors. These rights existed previously, but disappeared with proclamation of the Act and subsequent consequential amendments to other legislation.

[para 36] I have heard evidence during this inquiry that the loss of the right of access to health records/information has created ongoing hardship for a number of grieving parents of deceased minors. This has also created extensive difficulties for custodians who previously had the legislative authority to provide access to and disclosure of health records/information of deceased minors.

[para 37] In my view the Act should provide authority for custodians to provide access to and disclosure of health records/information of deceased minors. Establishing this legislative authority requires amendment to the Act. This lies outside my powers as Commissioner.

[para 38] Since I have had the benefit of excellent and extensive submissions and argument on this subject during the course of this inquiry, I will take the unusual step of making a specific recommendation to the Minister of Alberta Health and Wellness

regarding the wording of an amendment. I am compelled to do so by the sadness and frustration I have heard from all parties to the inquiry.

[para 39] There are a variety of legislative approaches that could be taken. My recommendations are simple and straightforward. I recommend that section 104(1)(d) be amended to omit the words “and was 18 years of age or over immediately before death”. Section 104(1)(d) of the Act would then read as follows:

104 (1) Any right or power conferred on an individual by this Act may be exercised
...
(d) if the individual is deceased, by the individual’s personal representative if the exercise of the right or power relates to the administration of the individual’s estate;

[para 40] I also recommend that an additional discretionary provision be included in section 35(1) of the Act to authorize disclosure of the deceased’s health information to family members even where disclosure is not for purposes of administration of the deceased’s estate. This provision should balance the privacy of the deceased with the need of family members to have the information, taking into account any relevant factors such as expressed wishes of the deceased.

[para 41] These amendments would be consistent with the extensive argument provided during this inquiry and with other legislative rights of access to and disclosure of health records/information for deceased individuals. I urge the amendments to be made expeditiously due to the urgency of the situation.

VI. ORDER

[para 42] I make the following order under section 80(2) of the Act:

- ❑ I confirm that the Applicants are not entitled to exercise the right or power of the individual conferred by section 104(1)(d), elsewhere in section 104(1) or under any other provision of the Act, and
- ❑ I confirm that the Custodians do not have the authority to disclose the health records/information requested under other provisions of the Act.

Frank Work, Q. C.
Information and Privacy Commissioner

APPENDIX I

Comparison of Health Information Legislation And the Exercise of Rights of Deceased Minors

| Citation & Comments | Legislative Provision (Highlighting added for ease of reference) |
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| <p>Alberta <i>Health Information Act,</i> ("HIA") R.S.A. 2000, c. H-5</p> | <p>7(1) An individual has a right of access to any record containing health information about the individual that is in the custody or under the control of a custodian.</p> <p>8(1) To obtain access to a record, an individual must make a request to the custodian that the individual believes has custody or control of the record.</p> <p>33 A custodian may disclose individually identifying health information to the individual who is the subject of the information or to a person referred to in section 104(1)(c) to (i) who is acting on behalf of that individual.</p> <p>34(1) Subject to sections 35 to 40, a custodian may disclose individually identifying health information to a person other than the individual who is the subject of the information if the individual has consented to the disclosure.</p> <p>35(1) A custodian may disclose individually identifying diagnostic, treatment and care information without the consent of the individual who is the subject of the information</p> <p>...</p> <p>(c) to family members of the individual or to another person with whom the individual is believed to have a close personal relationship, if the information is given in general terms and concerns the presence, location, condition, diagnosis, progress and prognosis of the individual on the day on which the information is disclosed and the disclosure is not contrary to the express request of the individual,</p> |

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| <p>104(1)(b) & (c) – Distinguish between competent and incompetent minors as 104(1)(c) authorizes guardian for incompetent minor but not competent minor</p> <p>104(1)(d) – Personal representative of deceased does not include minors</p> <p>‘Guardian’ and ‘personal representative’ not defined</p> | <p>(d) where an individual is injured, ill or deceased, so that family members of the individual or another person with whom the individual is believed to have a close personal relationship or a friend of the individual can be contacted, if the disclosure is not contrary to the express request of the individual,</p> <p>...</p> <p>(h) for the purpose of a court proceeding or a proceeding before a quasi-judicial body to which the custodian is a party,</p> <p>(i) for the purposes of complying with a subpoena, warrant or order issued or made by a court, person or body having jurisdiction to compel the production of information or with a rule of court that relates to the production of information,</p> <p>...</p> <p>(n) if that individual lacks the mental capacity to provide a consent and, in the opinion of the custodian, disclosure is in the best interests of the individual,</p> <p>(o) to a descendant of a deceased individual, a person referred to in section 104(1)(c) to (i) who is acting on behalf of the descendant or a person who is providing health services to the descendant if, in the custodian’s opinion,</p> <p style="padding-left: 40px;">(i) the disclosure is necessary to provide health services to the descendant, and</p> <p style="padding-left: 40px;">(ii) the disclosure is restricted sufficiently to protect the privacy of the deceased individual,</p> <p>(p) if the disclosure is authorized or required by an enactment of Alberta or Canada,</p> <p>104(1) Any right or power conferred on an individual by this Act may be exercised</p> <p>(a) if the individual is 18 years of age or older, by the individual,</p> <p>(b) if the individual is under 18 years of age and understands the nature of the right or power and the consequences of exercising the right or power, by the individual,</p> <p>(c) if the individual is under 18 years of age but does not meet the criterion in clause (b), by the guardian of the individual,</p> <p>(d) if the individual is deceased and was 18 years of age or over immediately before death, by the individual’s personal representative if the exercise of the right or power relates to the administration of the individual’s estate,</p> <p>(e) if a guardian or trustee has been appointed for the individual under the <i>Dependent Adults Act</i>, by the guardian or trustee if the exercise of the right or power relates to the powers and duties of the guardian or trustee,</p> <p>(f) if an agent has been designated under a personal directive under the <i>Personal Directives Act</i>, by the agent if the directive so authorizes,</p> <p>(g) if a power of attorney has been granted by the individual, by the attorney if the exercise of the right or power</p> |
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| | <p>relates to the powers and duties conferred by the power of attorney, (h) if the individual is a formal patient as defined in the <i>Mental Health Act</i>, by the individual's nearest relative as defined in that Act if the exercise of the right or power is necessary to carry out the obligations of the nearest relative under that Act, or (i) by any person with written authorization from the individual to act on the individual's behalf.</p> |
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| <p>Bill 30, Health Information Protection Act</p> <p>80(1)(b) and (c) – Distinguish between competent and incompetent minors as 104(1)(c) authorizes guardian for incompetent but not competent minor</p> <p>Guardian of minor not defined</p> <p>80(1)(d) Personal representative <u>does not</u> expressly exclude minors</p> <p>30(b) Similar to 35(1)(c) of HIA except restricted to 'immediate' family members but otherwise 35(1)(c) is more qualified</p> <p>30(k) Similar to 35(1)(d) of</p> | <p>80(1) Any right or power conferred on an individual by this Act may be exercised</p> <p>(a) if the individual is 18 years of age or older, by the individual, (b) if the individual is under 18 years of age and understands the nature of the right or power and the consequences of exercising the right or power, by the individual, (c) if the individual is under 18 years of age but does not meet the criterion in clause (b), by the guardian of the individual, (d) if the individual is deceased, by the individual's personal representative if the exercise of the right or power relates to the administration of the individual's estate, (e) if a guardian or trustee has been appointed for the individual under the <i>Dependent Adults Act</i>, by the guardian or trustee if the exercise of the right or power relates to the powers and duties of the guardian or trustee, (f) if a power of attorney has been granted by the individual, by the attorney if the exercise of the right or power relates to the powers and duties conferred by the power of attorney, or (g) by any person with written authorization from the individual to act on the individual's behalf.</p> <p>30 A custodian may disclose health information without the consent of the individual the information is about ... (b) to immediate family members of the individual or to any other individual with whom the individual is believed to have a close personal relationship, if the information is given in general terms and concerns the presence, location, condition, diagnosis, progress and prognosis of the individual on the day on which the information is disclosed and the disclosure is not contrary to the express request of the individual, ... (k) so that the next of kin or a friend of an injured, ill or deceased individual may be contacted if the disclosure is</p> |

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| <p>HIA except does not include 'close personal relationship' but otherwise 35(1)(d) is more qualified</p> <p>30(o) No parallel in 35(1) of HIA</p> | <p>not contrary to the express request of the individual, ...</p> <p>(o) to the personal representative of a deceased individual for the purposes of administering the deceased individual's estate.</p> |
| <p>Manitoba Personal Health Information Act, S.M. 1997, c. 51</p> <p>Personal representative does not exclude minors</p> <p>'Guardian' and 'personal representative' not defined</p> | <p>"representative" in relation to an individual, means a person referred to in section 60;</p> <p>22(2) A trustee may disclose personal health information without the consent of the individual the information is about if the disclosure is</p> <p>...</p> <p>(c) for the purpose of</p> <ul style="list-style-type: none"> (i) contacting a relative or friend of an individual who is injured, incapacitated or ill, (ii) assisting in identifying a deceased individual, or (iii) informing the representative or a relative or a deceased individual, or any other person it is reasonable to inform in the circumstances, of the individual's death; <p>(d) to a relative of a deceased individual if the trustee reasonably believes that disclosure is not an unreasonable invasion of the deceased's privacy;</p> <p>...</p> <p>(f) in accordance with section 23 (disclosure to patient's family),</p> <p>60 The rights of an individual under this Act may be exercised</p> <p>...</p> <p>(e) by the parent or guardian of an individual who is a minor, if the minor does not have the capacity to make health care decisions; or</p> <p>(f) if the individual is deceased, by his or her personal representative.</p> |
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| <p>Saskatchewan <i>Health Information Protection Act, S.S. 1999, c. H-0.021</i> (Enacted but not yet proclaimed)</p> <p>Personal representative does not exclude minors</p> <p>Distinguishes between competent and incompetent minors, s. 56 (d) refers to a guardian or trustee for incompetent minors</p> <p>'Personal guardian', 'legal custodian' and 'personal representative' not defined</p> | <p>56 Any right or power conferred on an individual by this Act may be exercised:</p> <p>(a) where the individual is deceased by the individual's personal representative if the exercise of the right or power relates to the administration of the individual's estate;</p> <p>(b) where a personal guardian has been appointed for the individual, by the guardian if the exercise of the right or power relates to the powers and duties of the guardian;</p> <p>(c) by an individual who is less than 18 years of age in situations where, in the opinion of the trustee, the individual understands the nature of the right or power and the consequences of exercising the right or power;</p> <p>(d) where the individual is less than 18 years of age, by the individual's legal custodian in situations where in the opinion of the trustee, the exercise of the right or power would not constitute an unreasonable invasion of the privacy of the individual;</p> <p>27(4) a trustee may disclose personal health information in the custody or control of the trustee without the consent of the subject individual in the following cases:</p> <p>...</p> <p>(d) where the disclosure is being made to facilitate contact with the next of kin or someone with whom the subject individual has a close personal relationship if the subject individual is injured ill or deceased, unless disclosure is contrary to the express request of the subject individual;</p> <p>...</p> <p>(f) where the disclosure is being made to the personal representative of a deceased individual for the purposes of administering the deceased individual's estate;</p> |
| <p>Ontario <i>Draft Privacy of Personal Information Act, 2002,</i> Ministry of Consumer and Business Services</p> | <p><i>Substitute Decisions Act, 1992, S.O. 1992, c. 30, s. 35</i></p> <p>35 When the Public Guardian and Trustee is the guardian of property for an incapable person who dies, he or she may, until notified of another person's appointment as personal representative, exercise the powers of an executor to whom the incapable person's property is given in trust for the payment of debts and the distribution of the residue.</p> |

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| <p>The <i>Health Care Consent Act, 1996</i>, and the <i>Substitute Decisions Act, 1992</i>, in Ontario apply where an individual is not mentally capable or does not have 'capacity' to consent while the individual is alive.</p> <p>A person 16 years or over is presumed to be capable of giving consent to personal care (s. 2(2) <i>Substitute Decisions Act, 1992</i>). That Act refers to 'court-appointed guardians of property' and 'statutory guardians of property' for incapable persons.</p> | <p>59(2) Under an order for full guardianship, the guardian may, ... (d) have access to personal information, including health information and records, to which the person could have access if capable, and consent to the release of that information to another person, except for the purposes of ligation that relates to the person's property or to the guardian's status or powers;</p> <p><i>Health Care Consent Act, 1996</i>, S.O. 1996, c. 2, Schedule A</p> <p>9. In this Part, "substitute decision-maker" means a person who is authorized under section 20 to give or refuse consent to treatment on behalf of a person who is incapable with respect to the treatment.</p> <p>... 20. (1) If a person is incapable with respect to a treatment, consent may be given or refused on his or her behalf by a person described in one of the following paragraphs:</p> <ol style="list-style-type: none"> 1. The incapable person's guardian of the person, if the guardian has authority to give or refuse consent to the treatment. 2. The incapable person's attorney for personal care, if the power of attorney confers authority to give or refuse consent to the treatment. 3. The incapable person's representative appointed by the board under section 33, if the representative has authority to give or refuse consent to the treatment. 4. The incapable person's spouse or partner. 5. A child or parent of the incapable person, or a children's aid society or other person who is lawfully entitled to give or refuse consent to the treatment in the place of the parent. This paragraph does not include a parent who has only a right of access. If a children's aid society or other person is lawfully entitled to give or refuse consent to the treatment in the place of the parent, this paragraph does not include the parent. 6. A parent of the incapable person who has only a right of access. 7. A brother or sister of the incapable person. 8. Any other relative of the incapable person. <p>... (5) If no person described in subsection (1) meets the requirements of subsection (2), the Public guardian and Trustee shall make the decision to give or refuse consent.</p> <p>... (10) Two persons are relatives for the purpose of this section if they are related by blood, marriage or adoption.</p> <p>...</p> |
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| <p>'deceased's estate trustee' does not exclude minors, term is not defined</p> | <p>22. Before giving or refusing consent to a treatment on an incapable person's behalf, a substitute decision-maker is entitled to receive all the information required for an informed consent as described in subsection 11(2).</p> <p><i>Draft Privacy of Personal Information Act, 2002,</i> "guardian of property" means a guardian of property or a statutory guardian of property under the <i>Substitute Decisions Act, 1992;</i></p> <p>"guardian of the person" means a guardian of the person appointed under the <i>Substitute Decisions Act, 1992;</i> ... "substitute decision-maker", in relation to an individual, means a person who is authorized under Part II to consent on behalf of the individual to the collection, use or disclosure of personal information about the individual and who, in accordance with that Part, is capable of giving the consent;</p> <p>10(1) If this Act or any other Act refers to a consent required of an individual to a collection, use or disclosure of personal information about the individual, a person described in one of the following paragraphs may give, withhold or withdraw the consent or provide the information: ... 3. If the individual is deceased the deceased's estate trustee or the person who has assumed responsibility for the administration of the deceased's estate, if the estate does not have an estate trustee.</p> <p>16 (Appointment of representative of an individual who is 16 years or older but incapable of consenting)</p> <p>58. (1) Subject to this Part, an individual is entitled, in accordance with this Part, to access to a record of personal health information about the individual that is in the custody or under the control of a health information custodian unless, ... 59. (1) To exercise a right of access to a record of personal health information, an individual or an authorized person acting on behalf of the individual shall make a written request for access to the health information custodian that has custody or control of the information.</p> |
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| <p>New Zealand <i>Health Information Privacy Code, 1994</i></p> | <p>3.(1) In this code: ... representative, in relation to an individual, means: (a) where that individual is dead – that individual’s personal representative; (b) where that individual is under the age of 16 years – that individual’s parent or guardian; or (c) where the individual, not being an individual referred to in paragraphs (a) or (b), is unable to give his or her consent or authority, or exercise his or her rights – a person appearing to be lawfully acting on the individual’s behalf or in his or her interests;</p> <p>Rule 6 – Access to Personal Health Information (1) where a health agency holds health information in such a way that it can readily be retrieved, the individual concerned is entitled: ... (b) to have access to that health information.</p> <p>Rule 11 – Limits on Disclosure of Health Information (1) A health agency that holds health information must not disclose the information unless the agency believes, on reasonable grounds: (a) that the disclosure is to: (i) the individual concerned; or (ii) the individual’s representative where the individual is dead or is unable to exercise his or her rights under these rules; (b) that the disclosure is authorized to: (i) the individual concerned; or (ii) the individual’s representative where the individual is dead or is unable to give his or her authority under these rules; ... (e) that the information is information in general terms concerning the presence, location, and condition and progress of the patient in a hospital, on the day on which the information is disclosed, and the disclosure is not contrary to the express request of the individual or his or her representative; or (f) that the information to be disclosed concerns only the fact of death and the disclosure is by a registered health professional, or by a person authorized by a health agency, to a person nominated by the individual</p> |

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| | <p>concerned, or the individual's representative, partner, spouse, principal caregiver, next of kin, whanau, close relative or other person whom it is reasonable in the circumstances to inform.</p> <p>...</p> <p>(4) where under section 22F(1) of the <i>Health Act 1956</i>, the individual concerned or a representative of that individual requests the disclosure of health information to that individual or representative, a health agency</p> <p>...</p> <p>(e) may refuse to disclose information to the representative if:</p> <ul style="list-style-type: none"> (i) the disclosure of the information would be contrary to the individual's interests; (ii) the agency has reasonable grounds for believing the individual does not or would not wish the information to be disclosed; ... <p>(5) This rule applies to health information about living or deceased persons obtained before or after the commencement of this code.</p> |
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| <p>Australia <i>Health Records (Privacy and Access) Act, 1997</i></p> | <p>4 In this Act, unless the contrary intention appears -</p> <p>"consumer" means an individual -</p> <p>...</p> <p>(d) where the consumer is a young person or a legally incompetent person - a guardian of the consumer; and</p> <p>(e) where the consumer has died - a legal representative of the deceased consumer;</p> <p>"guardian" means -</p> <ul style="list-style-type: none"> (a) in relation to a young person - a parent or legally appointed guardian of the young person; or (b) in relation to a legally incompetent person - a person who is - <ul style="list-style-type: none"> (i) a legally appointed guardian of the legally incompetent person; or (ii) an attorney, appointed under an enduring power of attorney that has become operative, of the legally incompetent person; <p>and who has power to make decisions about the medical treatment or health care of the legally incompetent person;</p> <p>"legal representative", in relation to a deceased person means a person -</p> <ul style="list-style-type: none"> (a) holding office as executor of the will of the deceased person where probate of the will has been granted or resealed in Australia; or |

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| | <p>(b) holding office in Australia as administrator of the estate of the deceased person;</p> <p>9. (1) A consumer has a right of access, in accordance with this Act, to a health record that is –</p> <p>(a) a health record held by a health service provider;</p> <p>25. Subject to this Act, where a consumer is a young person, a right or power conferred on consumers by this Act–</p> <p>(a) is exercisable on behalf of the consumer by a guardian of the consumer; and</p> <p>(b) is not exercisable by the consumer on his or her own behalf.</p> <p>26. (1) Subject to this Act, where a consumer is a legally incompetent person a right or power conferred on consumers by this Act –</p> <p>(a) is exercisable on behalf of the consumer by a guardian of the consumer; and</p> <p>(b) is not exercisable by the consumer on his or her own behalf.</p> <p>27. (1) The Privacy Principles apply in relation to a deceased consumer so far as they are reasonably capable of doing so in the same way as they apply in relation to a consumer who is not deceased.</p> <p>(2) Subject to subsection (3), where a consumer has died, a right or power conferred on consumers by a provision of this Act is exercisable in relation to the deceased consumer, so far as the circumstances reasonably permit, by a legal representative of the deceased consumer.</p> |
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APPENDIX II

Comparison of FOIP (Freedom of Information and Protection of Privacy) Legislation And the Exercise of Rights of Deceased Minors

| Citation & Comments | Legislative Provision (Highlighting added for ease of reference) |
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| <p>Alberta <i>Freedom of Information and Protection of Privacy Act</i>, R.S.A. 2000, c. F-25</p> <p>84(1)(a) 'Personal representative' does not expressly exclude minors</p> <p>84(1)(e) Does not distinguish between competent and incompetent minors</p> <p>40(1)(s) – Similar to 35(1)(d) in HIA</p> <p>40(1)(cc) – No similar provision in HIA</p> | <p>84(1) Any right or power conferred on an individual by this Act may be exercised</p> <p>(a) if the individual is deceased, by the individual's personal representative if the exercise of the right or power relates to the administration of the individual's estate,</p> <p>(b) if a guardian or trustee has been appointed for the individual under the <i>Dependent Adults Act</i>, by the guardian or trustee if the exercise of the right or power relates to the powers and duties of the guardian or trustee,</p> <p>(c) if an agent has been designated under a personal directive under the <i>Personal Directives Act</i>, by the agent if the directive so authorizes,</p> <p>(d) if a power of attorney has been granted by the individual, by the attorney if the exercise of the right or power relates to the powers and duties conferred by the power of attorney,</p> <p>(e) if the individual is a minor, by a guardian of the minor in circumstances where, in the opinion of the head of the public body concerned, the exercise of the right or power by the guardian would not constitute an unreasonable invasion of the personal privacy of the minor, or</p> <p>(f) by any person with written authorization from the individual to act on the individual's behalf.</p> <p>40(1) A public body may disclose personal information only</p> <p>...</p> <p>(s) so that the spouse, relative, or friend of an injured, ill or deceased individual may be contacted,</p> <p>...</p> <p>(cc) to a relative of a deceased individual if, in the opinion of the head of the public body, the disclosure is not an</p> |

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| <p>HIA does not have a parallel to FOIP s. 17 (unreasonable invasion of third party's privacy)</p> | <p>unreasonable invasion of the deceased's personal privacy,</p> <p>17(1) the head of a public body must refuse to disclose personal information to an applicant if the disclosure would be an unreasonable invasion of a third party's personal privacy.</p> <p>...</p> <p>17(4) A disclosure of personal information is presumed to be an unreasonable invasion of a third party's personal privacy if the personal information relates to a medical, psychiatric or psychological history, diagnosis, condition, treatment or evaluation,</p> |
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| <p>British Columbia <i>Freedom of Information and Protection of Privacy Regulation, B.C. Reg. 323/93</i></p> | <p>Who can Act for Young People and Others</p> <p>3. The right to access a record under section 4 of the Act and the right to request correction of personal information under section 29 of the Act may be exercised as follows:</p> <p>(a) on behalf of an individual under 19 years of age, by the individual's parent or guardian if the individual is incapable of exercising those rights;</p> <p>(b) on behalf of an individual who has a committee, by the individual's committee;</p> <p>(c) on behalf of a deceased individual, by the deceased's nearest relative or personal representative.</p> |
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| <p>Ontario <i>Freedom of Information and Protection of Privacy Act, R.S.O. 1990, c. F.31</i></p> <p><i>Municipal Freedom of Information and Protection of Privacy Act, R.S.O. 1990, c. M. 56</i></p> | <p>66. Any right or power conferred on an individual by this Act may be exercised,</p> <p>(a) where the individual is deceased, by the individual's personal representative if the exercise of the right or power relates to the administration of the individual's estate;</p> <p>(b) by the individual's attorney under a continuing power of attorney, the individual's attorney under a power of attorney for personal care, the individual's guardian of the person, or the individual's guardian of property; and</p> <p>(c) where the individual is less than sixteen years of age, by a person who has lawful custody of the individual.</p> <p>54. Any right or power conferred on an individual by this Act may be exercised,</p> <p>(a) if the individual is deceased, by the individual's personal representative if the exercise of the right or power relates to the administration of the individual's estate;</p> <p>(b) by the individual's attorney under a continuing power of attorney, the individual's attorney under a power</p> |

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| | of attorney for personal care, the individual's guardian of the person, or the individual's guardian of property; and (c) where the individual is less than sixteen years of age, by a person who has lawful custody of the individual. |
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APPENDIX III

Comparison of Health Sector and Administration of Estates Legislation And the Exercise of Rights of Deceased Minors

| Citation & Comments | Legislative Provision (Highlighting added for ease of reference) |
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| <p><i>Administration of Estates Act</i>, R.S.A. 2000, c. A-2, s. 1(g)</p> <p>1(g) – Legal representative rather than personal representative as in HIA</p> | <p>1 In this Act, ... (a) “administration” means letters of administration of the property of a deceased person, whether with or without the will annexed and whether granted for general, special or limited purposes; ... (g) “legal representative” means an executor, an administrator, a judicial trustee of the estate of a deceased person or a guardian of the person or estate, or both, of a minor;</p> <p>19 (Estates under \$3000)</p> <p>26 (Public Trustee interim executor or administrator)</p> <p>32 After the issue of a grant, no person other than the legal representative to whom it is issued has power to act in the estate comprised in or affected by the grant until the grant has been recalled or revoked or the legal representative discharged.</p> <p>38- 61 (Duties of Legal Representative)</p> <p>49 On the final passing of accounts, the court may... (a) order that an administrator or guardian be discharged,</p> |

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| <p>Child Welfare Act, R.S.A. 2000, c. C-12</p> | <p>1(1)(d) "child" means a person under the age of 18 years; ... (l) "guardian" means (i) a person who is or is appointed a guardian of the child under Part 7 of the <i>Domestic Relations Act</i>, or (ii) a person who is a guardian of the child under an agreement or order made pursuant to this Act; ... (p) "permanent guardianship agreement" means an agreement entered into under section 12; (q) "permanent guardianship order" means a permanent guardianship order made under section 34; (r) "private guardianship order" means a private guardianship order made under section 56; ... (bb) "temporary guardianship order" means a temporary guardianship order made under section 31 and includes a renewal order.</p> <p>Note - Various types of guardians exist under the CWA and are described in Part 2 (Agreements), Part 3 (Court Orders), Part 5 (Private Guardianship) and Part 6 (Adoption).</p> |
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| <p>Domestic Relations Act, R.S.A. 2000, c. D-14, Part 7, ss. 49-55</p> | <p>Part 7 - Guardianship and Custody of Minors s. 46 - Except where the authority of a guardian appointed or constituted by virtue of this Act is otherwise limited, each guardian during the continuance of the guardian's guardianship (a) may act for and on behalf of the minor, (b) may appear in court and prosecute or defend any proceedings in the name of the minor, (c) after furnishing any security the Court requires under section 54, has the care and management of the estate of the minor, whether real or personal, and may receive any money due and payable to the minor and give a release in respect of it, and...</p> <p>s. 47(1) - Unless a court of competent jurisdiction otherwise orders, the joint guardians of a minor child are (a) the mother, and (b) the father, if (i) the father was married to the mother of the child at the time of birth of the child, (ii) he was married to the mother of the child and the marriage was terminated by</p> |

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| | <p>(A) a decree of nullity of marriage granted not more than 300 days before the birth of the child, or (B) a judgment of divorce granted not more than 300 days before the birth of the child,</p> <p>(iii) he cohabited with the mother of the child for at least one year immediately before the birth of the child, or</p> <p>(iv) he married the mother of the child after the birth of the child and has acknowledged that he is the father of the child.</p> <p>(2) If, on the application of a person declared to be a parent under Part 8, the Court is satisfied that it is in the best interest of the child and that the applicant is able and willing to assume the responsibility of a guardian towards the child, the court may appoint the person as a guardian jointly with any other guardian.</p> <p>48(1) A parent of a minor may by deed or will appoint a person to be guardian of the person and estate, or either, of the minor after the death of that parent.</p> <p>(2) The person appointed guardian of a minor shall act jointly with the other parent or with the guardian appointed by the other parent.</p> <p>49 The Court, may from time to time appoint a guardian of the person and estate, or either, of a minor to act jointly with the father or mother of the minor or with the guardian appointed by the deceased father or mother of the minor.</p> <p>50(1) If on the application of a minor, or of anyone on behalf of the minor, it appears</p> <p>(a) that the minor has no parent or lawful guardian, or</p> <p>(b) that the parent or lawful guardian is not a fit and proper person to have the guardianship of the minor, the Court may appoint a guardian or guardians of the person and estate, or either, of the minor.</p> <p>s. 51(1) A parent of a minor may by deed or will appoint a person to be guardian of the person and estate, or either, of the minor at the death of that parent,</p> <p>...</p> <p>s. 52 (1) Testamentary guardians and guardians appointed by order of letters of guardianship are removable by the Court for the same causes for which trustees are removable.</p> |
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| <p><i>Alberta Surrogate Court Rules, Alta. Reg. 130/95,</i></p> | <p>1 In these Rules, ... </p> |

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| <p>enacted under the <i>Court of Queen's Bench Act</i> and the <i>Dependent Adults Act</i></p> | <p>(i) "minor" includes an unborn child; ... (l) "personal representative" means an executor of a will or an administrator or trustee of an estate to which these Rules apply, and includes a person named as an executor or trustee in a will before a grant is issued,</p> <p>10 (Types of Grants)</p> <p>11(2) Preference must be given to an applicant for a grant of administration in the following order unless the court, on application, orders otherwise: (a) the husband or wife of the deceased; (b) a child of the deceased; (c) issue of the deceased other than a child or grandchild; (d) a parent of the deceased; (e) a brother or sister of the deceased; (f) a child of the deceased's brother or sister if the child is an heir on intestacy; ... Part 1, Division 2, Administration of Estates of Minors, ss. 50-54 50(1) A person may apply for a grant of trusteeship of the estate of a minor.</p> <p>Table - Personal Representatives' Duties (Total of 20 duties) 1 Making arrangements for the disposition of the body and for funeral, memorial or other similar services. ... 9 Retaining a lawyer to advise on the administration of the estate, to apply for a grant from the court or to bring any matter before the court. ... 17 Instructing a lawyer in any litigation.</p> |
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| <p>Public Trustee Act, R.S.A. 2000, c. P-36</p> | <p>4 The Public Trustee may (a) subject to sections 5 and 19, act as guardian ad litem of the estate of a minor; (b) act in the administration of estates; (c) act as custodian of property of missing persons and deceased persons; (d) subject to section 19, on order of the court, act as judicial trustee of the estate of a deceased person;</p> |

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| <p>Public Trustee responsibilities for a minor end with death of the minor (Website, p. 4).</p> <p>However, in the absence of a court appointed trustee, the Public Trustee is by law the trustee of the minor's estate (PTA, s. 6)</p> | <ul style="list-style-type: none"> (e) subject to section 19, accept and carry out a trust where he is appointed for that purpose... (f) act as trustee of the estate of a minor under the guardianship of a director under the <i>Child Welfare Act</i>; (g) act in any other capacity and do any other acts, matters and things that the Public Trustee is authorized or required to do <ul style="list-style-type: none"> (i) subject to section 19, by the Alberta Rules of Court, (ii) subject to section 19, by order of the court, (iii) by order of the LGC, or (iv) subject to section 19, under this or any other Act; (h) if no person has been appointed guardian by the issue of letters of guardianship or appointed as the trustee of the estate of a minor, act as guardian or custodian of the estate of a minor <ul style="list-style-type: none"> (i) who has property vested in him; or (ii) who is entitled either immediately or after an interval either certainly or contingently to property under an intestacy or under a will, settlement, trust deed or in any other manner whatsoever; (i) act as the trustee of the estate of a mentally incompetent person; (j) if no person has been appointed by the court to act for the estate of the unborn minor, act as guardian or custodian of the estate of the minor... <p>5(1) The Public Trustee shall be served with notice of each application made to a court in respect of the property or estate of a minor, missing person or mentally incompetent person.</p> <p>(1.1) Subsection (1) does not apply to applications governed by the Administration of Estates Act.</p> <p>...</p> <p>(3) The Public Trustee is not the guardian ad litem of the estate of a minor, missing person or mentally incompetent person unless the court appoints the Public Trustee as the guardian ad litem.</p> <p>....</p> <p>6(1) Notwithstanding anything in any other Act, any money other than wages or salary and any property to which a minor is entitled under an intestacy or under a will, settlement, trust deed, or in any other manner whatsoever, and for whose estate no person has been appointed guardian by the issue of letters of guardianship or appointed as the trustee of the estate of a minor, shall be paid or transferred to the Public Trustee.</p> <p>11(1) All of the estate of whatever kind, nature or tenure of a mentally incompetent person, in respect of which the Public Trustee is acting as trustee, vests in the Public Trustee on the commencement of his duties as the trustee of the mentally incompetent person.</p> |
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| | <p>15(1) When the Public Trustee is administering an estate of a mentally incompetent person and the mentally incompetent person dies, the Public Trustee shall retain possession of the estate of the deceased pending</p> <ul style="list-style-type: none"> (a) a grant of probate or letters of administration, (b) a grant of letters of administration with will annexed, or (c) the appointment of the Public Trustee by the Minister of Justice and Attorney General <p>...</p> <p>(3) The Minister of Justice and Attorney General, by order, may when he considers it expedient to do so appoint the Public Trustee to be administrator of the estate of the deceased mentally incompetent person, and the Public Trustee when appointed has with respect to the estate the powers and duties of an administrator appointed by the court.</p> <p>(4) (Public Trustee may apply for letters of administration of estate of deceased mentally incompetent person)</p> <p>...</p> <p>(9) Notwithstanding that the Public Trustee is administering the estate of a deceased mentally incompetent person pursuant to any provision of this section, whether by virtue of an order, letters of administration or otherwise, the Public Trustee shall be deemed not to be a legal representative or person having lawful possession of a body within the meaning of and for the purposes of section 55 of the <i>Universities Act</i>.</p> <p>19(1) Where a court or judge is empowered to appoint a trustee, executor, administrator, guardian or guardian ad litem, the Public Trustee may be appointed to any of the appointments.</p> <p>(1.1) If the Minister of Justice and Attorney General is empowered to appoint a trustee, executor, administrator or guardian, the Public Trustee may be appointed by any of the appointments.</p> <p>21 (Estates under \$1000)</p> <p>22 Notwithstanding that the Public Trustee has under section 26 of the <i>Administration of Estates Act</i> the powers of an executor or administrator in respect of the estate of a deceased person, or that he is authorized under section 21 to sell property of a deceased person and apply the proceeds thereof toward payment of the burial expenses of the deceased person, the Public Trustee shall be deemed not to be a legal representative, or person having lawful possession of a body, within the meaning of and for the purposes of section 55 of the <i>Universities Act</i>.</p> |
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| <p><i>Universities Act</i>, R.S.A. 2000, c. U-3, s. 68</p> | <p>68 Every hospital, every penal or correctional institution and every eleemosynary or public institution supported by or receiving financial aid from the government shall on demand hand over to the nearest university or to any</p> |

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| | <p>officers it may appoint for that purpose the bodies of deceased inmates of the institution that are not claimed within a reasonable time by the immediate relatives or the legal representatives of the deceased.</p> |
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| <p><i>Dependent Adults Act</i>, R.S.A. 2000, c. D-11</p> <p>This Act applies to living dependent (incompetent) adults.</p> | <p>In this Act,</p> <p>...</p> <p>(e) "dependent adult" means a person in respect of whom</p> <p>(i) a guardianship order is in effect,</p> <p>(ii) a trusteeship order is in effect, or</p> <p>(iii) both a guardianship order and a trusteeship order is in effect;</p> <p>...</p> <p>(h) "Guardian" means the person named as a guardian in a guardianship order or a person who becomes a guardian by virtue of operation of this Act;</p> <p>(i) "guardianship order" means an order of the Court appointing a person as a guardian pursuant to section 7 or as an alternate guardian pursuant to section 25;</p> <p>...</p> <p>(n) "nearest relative" means, with respect to any person or relative of that person first listed in the following subclauses, relatives of the whole blood being preferred to relatives of the same description of the half-blood and the elder or eldest of 2 or more relatives described in any subclause being preferred to the other of those relatives regardless of sex:</p> <p>(i) husband or wife;</p> <p>(ii) son or daughter;</p> <p>(iii) father or mother;</p> <p>(iv) brother or sister;</p> <p>(v) grandfather or grandmother;</p> <p>(vi) grandson or granddaughter;</p> <p>(vii) uncle or aunt;</p> <p>(viii) nephew or niece</p> <p>...</p> <p>(s) "Public Guardian" means the person appointed as Public Guardian pursuant to section 20;</p> <p>(t) "Public Trustee" means the person appointed as the Trustee under the <i>Public Trustee Act</i>;</p> <p>...</p> <p>(v) "trustee" means the person named as trustee in a trusteeship order or a person who becomes a trustee by</p> |

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| | <p>virtue of the operation of this Act;</p> <p>(w) “trusteeship order” means an order of the Court appointing a person as trustee of the estate of a person pursuant to section 35 or as an alternate trustee of the estate of a person pursuant to section 51.</p> <p>2(1) Subject to this section and section 3, any interested person may apply to the court for an order appointing a guardian in respect of an adult person.</p> <p>10(1) When the Court makes an order appointing a guardian, the Court shall grant to the guardian only the powers and authority referred to in subsection (3) that are necessary for the guardian to make or assist in making reasonable judgements in respect of matters relating to the person of the dependent adult.</p> <p>...</p> <p>10(3) In making an order appointing a guardian, the court shall specify whether all or any one or more of the following matters relating to the person of the dependent adult are to be subject to the power and authority of the guardian:</p> <p>...</p> <p>38 Subject to this Act, when the court makes a trusteeship order the trustee, with respect to the estate or that part of the estate in the trustee’s trusteeship,</p> <p>(a) has the right to and may take possession and control the real and personal property of the dependent adult,</p> <p>...</p> <p>44(1) On the death of a dependent adult, the trustee shall account to the legal representative of the estate of the dependent adult.</p> |
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| <i>Intestate Succession Act</i> , R.S.A. 2000, c. I-9 | No definition of personal representative or guardian or other provisions of relevance. |
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| <i>Wills Act</i> , R.S.A. 2000, c. W-11 | 9(1) A will made by a person who is under the age of 18 years is not valid unless at the time of making the will the person (a) is or has been married, |

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| Applies to adults with limited exceptions | (b) is a member of a component of the Canadian Forces..., or (c) is a mariner or seaman. |
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| <p><i>Personal Directives Act</i>, R.S.A. 2000, c. P-6</p> <p>Applies to adults only</p> | <p>1 In this Act, ... (d) “guardian” means a guardian under the <i>Dependent Adults Act</i>; ... (g) “legal representative” means an attorney under the <i>Powers of Attorney Act</i> or a guardian or trustee under the <i>Dependent Adults Act</i>;</p> <p>3(1) Any person who is at least 18 years of age and understands the nature and effect of a personal directive may make a personal directive. (2) A person who is at least 18 years of age is presumed to understand the nature and effect of a personal directive.</p> <p>10 A personal directive ceases to have effect in the following circumstances: ... (b) on the maker’s death;</p> |
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| <p><i>Powers of Attorney Act</i>, R.S.A. 2000, c. P-20</p> <p>Applies to adults only</p> | <p>2(1) A power of attorney is an enduring power of attorney if (a) the donor is an individual who is an adult at the time of executing the power of attorney,</p> <p>13(1) Except in the case of an irrevocable power of attorney, and notwithstanding any agreement of waiver to the contrary, an enduring power of attorney terminates ... (j) on the death of the donor or the attorney;</p> |
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| <p><i>Age of Majority Act</i>, R.S.A. 2000, c. A-4, s. 1</p> | <p>1 Every person attains the age of majority and ceases to be a minor on attaining the age of 18 years. 2 Section 1 applies for the purpose of any rule of law in respect of which the Legislature has jurisdiction. 3(1) In the absence of a definition or of an indication of a contrary intention, section 1 applies to the construction of “adult”, “full age”, “lawful age”, “infant”, “minor”, “minority” and similar expressions...</p> |
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| <p><i>Hospitals Act</i>, R.S.A. 2000, c. H-12</p> | <p>24(1.1) Except as permitted or required under this Act, a board, an employee of a board, the Minister or a person authorized by the Minister or a physician may disclose health information obtained from hospital records or from persons having access to them only in accordance with the <i>Health Information Act</i>. ... 24(11) Information may be disclosed under subsection (9) only if (a) an officer of an association regulated by a provincial Act makes a written request for it and the patient or the patient’s legal representative consents to the disclosure, or ... 24(18) In this section ... (a.1) “legal representative” means an executor or administrator of the estate of a deceased person, the guardian or trustee of a dependent adult under the <i>Dependent Adults Act</i>, the agent designated in a personal directive made by a person in accordance with the <i>Personal Directives Act</i> or the guardian of a minor; (b) “mentally competent” means able to understand the subject-matter in respect of which consent is requested and able to appreciate the consequences of giving or refusing consent.</p> |
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| <p><i>Hospitals Act</i>, R.S.A. 1980, c. H-11</p> <p>ss. 40(5)(a)(a.1) repealed by HIA, S.A. 1999, c. H-4.8, s. 117(2)(e)(ii), Effective April 25, 2001</p> | <p>40(5) Notwithstanding subsection 3 or any other law, a board or employee of a board, the Minister or a person authorized by the Minister, or a physician or a member of a professional staff may (a) divulge any diagnosis, record or information to the patient to whom the diagnosis, record of information relates or to his legal representative, (a.1) with the written consent of the patient or his guardian or without that consent if the patient is not mentally competent and does not have a guardian, divulge any diagnosis, record or information relating to the patient to any person if in the opinion of the person making the disclosure it is in the best interests of the patient to disclose the information, (13) In this section,</p> |

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| | <p>(a) “legal representative” means an executor or administrator of the estate of a deceased person, the guardian or trustee of a dependent adult under the <i>Dependent Adults Act</i>, the agent designated in a personal directive made by a person in accordance with the <i>Personal Directives Act</i> or the guardian of a minor;</p> <p>(b) “mentally competent” means able to understand the subject matter in respect of which consent is requested and able to appreciate the consequences of giving or refusing consent.</p> |
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| <p><i>Mental Health Act</i>, R.S.A. 2000, c. M-13</p> | <p>1 In this Act, ... (f) “guardian” includes (i) the parent or guardian of a minor, (ii) a director as defined in the <i>Child Welfare Act</i>, in respect of a child who is the subject of a temporary guardianship order or a permanent guardianship agreement or order under the <i>Child Welfare Act</i>, and (iii) a guardian appointed under the <i>Dependent Adults Act</i> with authority over the matters referred to in section 10(3)(g) and (h) of that Act; ... (i) “nearest relative” means, with respect to a formal patient, (i) the adult person first listed in the following paragraphs, relatives of the whole blood being preferred to relatives of the same description of the half-blood and the elder or eldest of 2 or more relatives described in any subclause being preferred to the other of those relatives regardless of gender: (A) spouse; (B) son or daughter; (C) father or mother; (D) brother or sister; (E) grandfather or grandmother; (F) grandson or granddaughter; (G) uncle or aunt; (H) nephew or niece; or (ii) any adult person the board designates in writing to act as the nearest relative if there is no nearest relative within any description in subclause (i) or if, in the opinion of the board, the nearest relative determined under subclause (i) would not act or is not acting in the best interest of the formal patient;</p> |

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| | <p>14(1) When 2 admission certificates or 2 renewal certificates are issued with respect to a patient,</p> <p>(a) the board shall inform the formal patient and make a reasonable effort to inform the patient’s guardian, if any, and, unless the patient objects, the patient’s nearest relative, of</p> <p>(i) the reason, in simple language, for the issuance of the admission certificates or renewal certificates, and</p> <p>(ii) the patient’s right to apply to the review panel for cancellation of the admission certificates or renewal certificates,</p> <p>17(1) In this section,</p> <p>(c) “legal representative” means an executor or administrator of the estate of a deceased person, the guardian or trustee of a dependent adult under the <i>Dependent Adults Act</i>, the agent designated in a personal directive made by a person in accordance with the <i>Personal Directives Act</i> or the guardian of a minor;</p> <p>(d) “mentally competent” means able to understand the subject-matter in respect of which consent is requested and able to appreciate the consequences of giving or refusing consent.</p> |
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| <p><i>Mental Health Act</i>, S.A. 1988, c. M-13.1</p> <p>ss. 17(6)(a)(b) repealed by HIA, S.A. 1999, c. H-4.8, s. 119(2)(f)(iii), Eff. April 15, 2001</p> | <p>17(1) In this section,</p> <p>(c) “legal representative” means an executor or administrator of the estate of a deceased person, the guardian or trustee of a dependent adult under the <i>Dependent Adults Act</i>, the agent designated in a personal directive made by a person in accordance with the <i>Personal Directives Act</i> or the guardian of a minor;</p> <p>(d) “mentally competent” means able to understand the subject-matter in respect of which consent is requested and able to appreciate the consequences of giving or refusing consent.</p> <p>...</p> <p>(6) Notwithstanding subsection (4) or any other law, the Minister, a person authorized by the Minister, a board, an employee of a board or a physician may disclose any diagnosis, record or information relating to a person receiving diagnostic and treatment services in a centre</p> <p>(a) to the person to whom the diagnosis, record of information relates or his legal representative,</p> <p>(b) with the written consent of the person to whom the diagnosis, record or information relates or his legal representative or without that consent if the person is not mentally competent and does not have a legal representative, to any person if in the opinion of the person making the disclosure it is in the best interests of the person to whom the diagnosis, record or information relates to disclose that information,</p> |
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| <p><i>Public Health Act</i>, R.S.A. 2000, c. P-37</p> | <p>1 In this Act, ... (aa) “legal representative” means a lawyer, an executor or administrator of the estate of a deceased person, the trustee or guardian of a dependent adult under the <i>Dependent Adults Act</i>, the agent designated in a personal directive made by a person in accordance with the <i>Personal Directives Act</i> and the trustee or guardian of a minor;</p> <p>63(4) Information obtained by the Chief Medical Officer or by a regional health authority or an employee or agent on its behalf may be disclosed by the Chief Medical Officer or the Regional Health authority, employee or agent ... (b) to the person to whom the information relates or the person’s legal representative;</p> |
| <p><i>Public Health Act</i>, S.A. 1984, c. P-27.1</p> | <p>1(n) “legal representative” means a lawyer, an executor or administrator of the estate of a deceased person, the trustee or guardian of a dependent adult under the <i>Dependent Adults Act</i>, the agent designated in a personal directive made by a person in accordance with the <i>Personal Directives Act</i> and the trustee or guardian of a minor.</p> <p>63(4) Information obtained by the Chief Medical Officer or by a regional health authority or an employee or agent on its behalf may be disclosed by the Chief Medical Officer or the Regional Health authority, employee or agent ... (b) to the person to whom the information relates or his legal representative.</p> |
| <p><i>Confidentiality Regulation</i>, Alta. Reg. 38/99, s. 1(c), under the <i>Ambulance Services Act</i></p> | <p>1 In this Regulation, ... (c) “legal representative” means (i) an executor or administrator of the estate of a deceased person, (ii) the guardian or trustee of a dependent adult under the <i>Dependent Adults Act</i>, (iii) the guardian of a minor, or (iv) an agent as defined in the <i>Personal Directives Act</i> under a personal directive during any time that the</p> |

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| | <p style="text-align: center;">maker of the personal directive lacks capacity.</p> <p>4 An operator, a person employed or engage by an operator, the Minister or a person employed or engaged by the Department of Health who is authorized by the Minister may</p> <p>(a) disclose information respecting a patient to the patient or the patient’s legal representative,</p> <p>(b) disclose information respecting a patient to any person with the written consent of the patient or the patient’s legal representative;</p> <p>(c) disclose information relating to the patient to any person without the written consent of the patient if</p> <p style="padding-left: 40px;">(i) the patient is not able to consent and does not have a legal representative, and</p> <p style="padding-left: 40px;">(ii) in the opinion of the person making the disclosure it is in the best interests of the patient to disclose the information.</p> |
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| <p><i>Human Tissue Gift Act,</i> R.S.A. 2000, c. H-5</p> | <p>4(1) Any adult person may consent,</p> <p>(a) in a writing signed by the person at any time, or</p> <p>(b) orally in the presence of at least 2 witnesses during the person’s last illness,</p> <p>that the person’s body or the part or parts of it specified in the consent be used after the person’s death for therapeutic purposes or medical education or scientific research.</p> <p>5(1) When a person of any age who has not given a consent under section 4 dies, or in the opinion of a physician is incapable of giving a consent by reason of injury or disease and the person’s death is imminent,</p> <p>(a) the person’s spouse of any age, or</p> <p>(b) if none, or if the person’s spouse is not readily available, any one of the person’s adult children, or</p> <p>(c) if none, or if none is readily available, either of the person’s parents, or</p> <p>(d) if none, or if neither is readily available, any person’s adult brothers or sisters, or</p> <p>(e) if none, or if none is readily available, any of the person’s adult next of kin, or</p> <p>(f) if none, or if none is readily available, the person lawfully in possession of the body other than, where the person died in hospital, the administrative head of the hospital, may consent to the body or the part or parts of it specified in the consent being used after death for therapeutic purposes, medical education or scientific research.</p> |
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| <p>Fatality Inquiries Act, R.S.A. 2000, c. F-9</p> | <p>1 In this Act, ... (k)“next of kin” means the mother, father, children, sisters, spouse and common law spouse of a deceased person, or any of them;</p> <p>25(1) A medical examiner may authorize the autopsy of the body of any person who died under the circumstances described in section 10, 11, 12 or 13.</p> <p>28(1) Notwithstanding section 17 of the <i>Cemeteries Act</i>, the Chief Medical Examiner may order a body to be disinterred for the purposes of an investigation under this Act or the <i>Criminal Code (Canada)</i>. (2) copies of an order under subsection (1) shall be sent by registered mail at least 48 hours before the disinterment to (a) the spouse, common law spouse or, if there is no spouse or common law spouse, any other adult next of kin of the deceased who is resident in Alberta,</p> |
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| <p>Limitations Act, R.S.A. 2000, L-12</p> | <p>s. 1 In this Act ... (h) “person under disability” means (i) a minor who is not under the actual custody of the parent or guardian, (ii) a dependent adult pursuant to the <i>Dependent Adults Act</i>, or (iii) an adult who is unable to make reasonable judgments in respect of matters relating to the claim;</p> <p>5 Persons under disability 5(1) The operation of the limitation periods provided by this Act are suspended during any period of time that the claimant is a person under disability. (2) Where a claimant brings an action against (a) a parent or guardian of the claimant, or (b) any other person for a cause of action based on a sexual nature including, without limitation, sexual assault, and the claim arose when the claimant was a minor, the operation of the limitation periods provided by this Act is suspended during the period of time that the claimant is a minor.</p> |

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| <p><i>Fatal Accidents Act</i>, R.S.A. 2000, c. F-8</p> | <p>s. 1 In this Act, (a) “child” includes a son, daughter, grandson, granddaughter, stepson, stepdaughter and illegitimate child; ... (d) “parent” includes a father, mother, grandfather, grandmother, stepfather and stepmother;</p> <p>Persons entitled to benefits</p> <p>3(1) An action under this Act (a) shall be for the benefit of the wife, husband, cohabitant, parent, child, brother or sister of the person whose death has been so caused, and (b) shall be brought by and in the name of the executor or administrator of the person deceased, and in the action the court may give to the persons respectively for whose benefit the action has been brought those damages that the court considers appropriate to the injury resulting from the death. (2) If there is no executor or administrator, or if the executor or administrator does not bring the action within one year after the death of the party injured, then the action may be brought by and in the name of all or any of the persons for whose benefit the action would have been, if it had been brought by or in the name of the executor or administrator. (3) Every action so brought shall be for the benefit of the same persons and is as nearly as possible subject to the same regulations and procedure as if it were brought by and in the name of the executor or administrator.</p> <p>Death of person liable for damages</p> <p>5(1) If a person dies who would have been liable to an action in damages under this Act had the person continued to live, then, whether the person died before or after or at the same time as the person whose death was caused by wrongful act, neglect or default, an action may be brought and maintained or, if pending, may be continued against the executor or administrator of the deceased person. (2) If neither probate of the will of the deceased person mentioned in subsection (1) nor letters of administration of the person’s estate have been granted in Alberta, a judge of the court of Queen’s Bench may, on the application of any party intending to bring or to continue an action under this section and on the terms and on the notice that the judge may direct, appoint an administrator ad litem of the estate of the deceased person and on that appointment being made, (a) the administrator ad litem is an administrator against whom an action may be brought or continued under subsection (1) and by whom it may be defended,</p> |

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| | <p>(b) the administrator ad litem may take any steps that a defendant may take in an action, including third party proceedings and the bringing, by way of counterclaim, of any action that survives for the benefit of the estate of the deceased person, and</p> <p>(c) a judgement in favour of or against the administrator ad litem in that action has the same effect as a judgement in favour of or against as the case may be, the deceased person, but it has no effect whatsoever for or against the administrator ad litem in the administrator's personal capacity.</p> <p>Damages for Bereavement</p> <p>8(1) In this section,</p> <p>(a) "child" means a son or daughter, whether legitimate or illegitimate;</p> <p>(b) "parent" means a mother or father.</p> <p>(2) if an action is brought under this Act, the court, without reference to any other damages that may be awarded and without evidence of damage, shall award damages for grief and loss of the guidance, care and companionship of the deceased person of</p> <p>...</p> <p>(b) \$43,000 to the parent or parents if</p> <p>(i) the deceased is a minor child, or</p> |
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| <p><i>Survival of Actions Act</i>, R.S.A. 2000, c. S-27</p> | <p>s. 3 A cause of action existing against a person who dies after January 1, 1979, survives against the person's estate.</p> <p>Administrator ad litem</p> <p>s. 8(1) If a cause of action survives under this Act and there is a personal representative of the deceased person against whom the action may be brought or continued in Alberta, the Court of Queen's Bench</p> <p>...</p> |
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| <p><i>Black's Law Dictionary</i>, 5th edition, 1979</p> | <p>Legal Representative - A term in its broadest sense, means one who stands in place of, and represents the interests of, another. A person who oversees the legal affairs of another. Examples include the executor or administrator of an estate and a court appointed guardian of a minor or incompetent person. Term "legal representative", which is almost always held to be synonymous with term "personal representative" ...</p> |

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| <p>In Alberta both parents are guardians under the <i>Domestic Relations Act</i>.</p> | <p>Guardian - A person lawfully invested with the power, and charged with the duty, of taking care of the person and managing the property and rights of another person, who, for defect of age or understanding, or self-control, is considered incapable of administering his own affairs. One who legally has the care and management of the person, or the estate or both, of a child during its minority.</p> <p>A <i>general guardian</i> is one who has the general care and control of the person and estate of his ward; while a <i>special guardian</i> is one who has special or limited powers and duties with respect to his ward, e.g., a guardian who has the custody of the estate but not of the person or vice versa or a <i>guardian ad litem</i>.</p> <p>A <i>guardian ad litem</i> is a special guardian appointed by the court to prosecute or defend in behalf of an infant or incompetent a suit to which he is a party, and such guardian is considered an officer of the court to represent the interests of the infant or incompetent in the litigation.</p> <p>A <i>guardian by nature</i> is the father and on his death, the mother, of a child. This guardianship extends only to the custody of the person of the child to the age of majority. Sometimes called '<i>natural guardian</i>'.</p> |
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APPENDIX IV

Highlights of Inquiry Submissions

A. Applicants

- The *Health Information Act* (“HIA”) does not allow health information to be provided to the parents of a deceased child, or for anyone under the age of 18 years.
- The Applicants want closure. For example, they want to know more about the circumstances of how the deceased died.
- The Commissioner should read in an interpretation into HIA that allows access to the health information as HIA has a gap, although they are not sure how the Commissioner could do this.
- Until this is done the parents of a deceased child have no right to the health information of their child.
- Alternatively, HIA should be amended to allow access and disclosure of health information to parents of deceased minors.

B. Custodians

1. David Thompson Health Region

- When interpreting HIA, the purposes of the Act must be considered, e.g., protecting individual privacy and confidentiality and individuals that are the subject of the health information should have control over their information.
- Any interpretation of HIA should err on the side of privacy protection.
- HIA provides a complete code governing access to and collection, use and disclosure of health information in Alberta.
- HIA does not allow Custodians to provide access to or disclosure of health information of a deceased minor to anyone including the Applicants.
- Before HIA this situation would have been covered by legislation such as the *Hospitals Act*. In the past, Custodians considered a variety of factors such as the status of the legal representative and the relationship with the deceased individual and used their discretion to decide whether to disclose the health information of a deceased minor.
- With HIA there are now many difficult situations where Custodians are asked for health information of deceased minors, but the HIA message is clear that this information cannot be disclosed.

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- Part 2 of HIA codifies a fundamental principle described in the *McInerney v. MacDonald* [1992] 2 S.C.R. 138 (S.C.C.) (“McInerney”) decision that health information collected about an individual belongs to that individual.
 - Part 2 of HIA creates a right of access by individuals or representatives of individuals. The purposes for which health information can be accessed are not limited under Part 2.
 - Section 11(2)(a) of HIA requires Custodians to refuse to disclose health information to Applicants if the health information is about another individual.

- Section 104 of HIA creates authority for the substituted exercise of individual rights or powers on behalf of individuals.
- Section 104 identifies limited classes of representatives and a restricted the scope of authority for representatives, e.g., personal representatives are limited to matters relating to administration of the individual's estate.
- Section 104(1)(d) creates a 'three screen' access test to exercise rights of a deceased individual: 1. Individual must be 18 years or over, 2. Must be a personal representative, and 3. Must be for purposes of administration of the individual's estate.
- Under section 104(1)(d) the Applicants do not have a right of access to the health information of the deceased minor.

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- The principles of statutory interpretation should be considered together with the ordinary meaning of the legislative provisions.
 - The first step is to examine the words used in the statute. If the words are not ambiguous, the words are to be given their ordinary meaning (R. Sullivan, *Driedger on the Construction of Statutes*, 3rd ed., Toronto: Butterworths, 1994, p. 1).
 - The wording of s. 104 is "clear and unambiguous" and provides comprehensive parameters for the exercise of rights on behalf of an individual.
 - The provisions in section 104(1) clearly distinguish between the exercise of rights for living and deceased individuals.
 - Alternatively, if s. 104 has more than one possible meaning, the statute should be interpreted as a whole in a purposive manner and in context. The interpretation should be chosen that is most plausible, acceptable and efficacious (R. Sullivan, *Supra*, p. 131).
 - Where a statute sets out a specific exception or process for one situation but is silent on an analogous situation, it is reasonable to conclude that the Legislature did not intend to create an analogous exception or process.
 - It is presumed that silence is deliberate and reflects an intention to exclude those items that are not mentioned (R. Sullivan, *Supra*, pp. 168-70).
 - Section 104 makes provision for deceased adults but is silent and does not provide a process for the exercise of a right or power on behalf of deceased minors.
 - It should be presumed that this was a deliberate act and the exercise of a right or power on behalf of deceased minors was intentionally excluded from HIA.
 - The common law should also be considered when interpreting this provision.
 - In *Re Professional Institute of the Public Service of Canada v. Northwest Territories (Commissioner)* (1988) 53 D.L.R. (4th) 530 (NWT CA), aff'd [1990] 2 S.C.R. 367 (SCC), Justice Kerans said that ordinarily courts (and in that case a Commissioner) should not fill legislative gaps. The exception is a rare case where the alteration meets, beyond a doubt, four criteria:
 - 1. The problem arose only by reason of legislative oversight,
 - 2. The change is that which the legislature would have made had it addressed the issue,
 - 3. No harm is done by the proposed change to legal rights created by the legislation, and
 - 4. Harm will be done to legal rights created by the statute if the change is not made (pp. 535-536).
 - Is this a situation where it is "beyond a doubt" that the "problem arose only by reason of legislative oversight"?
 - It is not clear whether or not this was a legislative oversight in section 104(1). However, it is such an obvious omission that it is unlikely to be an unintentional error.
 - The Legislature could have addressed this issue but for some reason they did not, so a legislative vacuum has been created.
 - Applying the established principles of statutory interpretation the Applicants have no right of access to the deceased's health information.

- Custodians must refuse access under s. 104(1)(d) because HIA does not create a right of access on behalf of deceased minors. Without an explicit provision, Custodians would be in breach of HIA.
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- Section 104(1)(b) applies to the guardian of a minor and s. 104(1)(c) applies to a competent or mature minor.
 - The role of a parent as guardian of a minor child ends with death of the child. Parental guardianship does not survive the death of a child.
 - Both of the s. 104(1) provisions relating to minors clearly refer only to individuals living at the time the right is exercised.
 - Even if there were a patch for guardians of incompetent minors, this would solve one problem but create other problems, for example for competent minors who do not have guardians.
 - The Applicants have no other right or power to access the information under section 104 or elsewhere.
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- Part 5 of HIA creates authority to disclose health information but does not require Custodians to disclose. Part 5 restricts the exercise of discretion by Custodians.
 - No provisions in section 35 including sections 35(1)(b), 35(1)(d) or 35(1)(o) apply to this situation.
 - No provisions elsewhere in HIA permit Custodians to disclose the health information to the Applicants.
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- Bottom line – A plain reading of the legislation creates an obstacle for access and disclosure of health information of deceased minors, Custodians cannot by-pass the legislation. A legislative gap or a vacuum exists. Only an interpretation or an amendment of s. 104 could solve this issue of the right to access or disclosure of health information of a deceased minor. This is a situation for the Legislature to fix.
- Personal representatives of deceased minors should be treated in the same manner as personal representatives of adults.
- There is no general harm in granting access to health information of deceased minors although general exceptions to access or disclosure should be considered.
- Although there are situations where health information should not be disclosed, Custodians could exercise discretion as they currently do under other provisions of HIA.
- HIA should define “personal representative” and describe the activities that are included in the “administration of the individual’s estate”.
- HIA should give Custodians the authority to disclose health information on behalf of deceased minors.
- What can the Commissioner do to rectify this situation?
 - The Commissioner cannot read in an interpretation as this is a “gap or oversight” that is a “conceptual error as opposed to an error in expression”. This is a failure to create a direction or plan, as opposed to a failure to accurately communicate an intended direction or plan.
 - This is a situation where the Legislature needs to amend the legislation.
- The Commissioner should send a strong message to the legislature to amend HIA.

2. Dr. S. Beshai

- **This Custodian raised a number of arguments that were similar to the arguments raised by the other Custodian, which I will not repeat in this summary.**
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- The right to privacy survives death. For example, the *Freedom of Information and Protection of Privacy Act*, R.S.A. 2000, c. F-25 (“FOIP” Act) protects privacy of personal information (s. 17(4)) even after death and personal information may only be disclosed for specified purposes such as for notifying relatives of the death (s. 40(1)(s)). The protection of privacy of the deceased’s personal information continues for 25 years following an individual’s death (s. 17(2)(i)).
 - The concept that privacy rights continue on after death under the FOIP Act has been described in earlier orders of the Commissioner (e.g., Order 2000-012, paragraph 31).
 - HIA demonstrates a continued intent to protect privacy rights for health information that survive an individual’s death.
 - Custodians must not disclose health information except in accordance with section 31 of HIA.
 - HIA creates a \$50,000 fine for improper disclosure of health information under s. 107.
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- Section 104(1)(d) is the only provision in HIA that applies to the exercise of rights on behalf of deceased individuals. The Applicants do not fall within this provision.
- None of the three criteria in section 104(1)(d) have been met in this case; 1) the deceased was under 18, 2) the Applicants were not the “personal representative”, 3) no evidence suggested that the Applicants were accessing the information to “administer the estate” of the deceased.
- HIA does not provide for any representation or substitutes that can exercise rights to health information on behalf of deceased minors in s. 104(1).
- When a provision specifically mentions one or more items as exceptions to the general rule and is silent on other items, it is presumed that the silence is deliberate and reflects an intention to exclude items that are not mentioned.
- This maxim of statutory interpretation is known as *expressio unius est exclusio alterius* (to express one thing is to exclude another) (R. Sullivan, *Supra*, pp. 168-170; *Ramawad v. Minister of Manpower and Immigration* [1978] 2 S.C.R. 375 (S.C.C.) at 382).
- This maxim of implied exclusion applies here. The Legislature purposely wanted to exclude the exercise of rights on behalf of deceased minors.
- Other statutory interpretation principles are applicable here such as giving ordinary meaning to words in the absence of absurdity and the presumption against adding or deleting words to the express words of a statute (R. Sullivan, *Supra*, pp. 275-278, P. Cote, *The Interpretation of Legislation in Canada*, 3rd ed., Scarborough: Carswell, 2000, pp. 275-278).
- A “personal representative” is a legally appointed status. “Personal representative” is not defined in HIA.
- The HIA provision is similar to the Ontario legislation, which was judicially considered in the court decision of *Adams v. Ontario (Information and Privacy Commissioner)* (1996) 136 D.L.R. (4th) 12 (Ont. G.D.) (“Adams” case). The Adams case considered the application of “personal representative”, which is not defined in the Ontario FOIP Act either.
- In the Adams case, the husband wanted access to the hospital records of his deceased wife, which were requested under the Ontario FOIP Act. The husband had not been appointed as personal representative of his wife’s estate.
- The Adams court said the husband was not allowed to access the health information for two reasons: 1. The husband was not legally appointed as administrator of the estate and the

provision did not include persons “akin to that of a personal representative” and 2. The husband was seeking the records for a purpose not expressly included in the legislation, i.e., not for the exercise of a right that related to the administration of the individual’s estate.

- The Adams case took a literal reading of the provision and rejected compassionate reasons for disclosure to close family members where the information requested was sought for personal reasons.
 - Section 104(1)(d) should be interpreted in a similar way to the approach taken by the Adams court in Ontario.
 - Compassion is not a good enough reason to provide access to or for disclosure of health information under HIA.
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- A minor who is capable should enjoy the right of confidentiality and privacy under section 104(1)(b).
 - Section 104(1)(c) allows parents who are guardians of living minor children, i.e. individuals under 18 years, to access their child’s health information.
 - Guardians need to have a right of access so they can make health decisions for the child, to maintain the best interest of the child. The existence of a guardian to exercise rights over health information on behalf of a young child is a logical basis for section 104(1)(c).
 - Section 104(1)(c) is there to make decisions for a living child, but does not create rights to access to health information after a child has died.
 - Section 104(1)(c) does not apply to circumstances such as the present circumstance where the child is deceased. The section is drafted in the present tense, and refers to a living individual.
 - Upon the death of a child, a parent is no longer a guardian of the child.
 - The parent cannot deal with the child’s estate unless and until the parent is appointed as a personal representative of the estate.
 - The appointment of an administrator of a deceased child’s estate requires an application to the Court and is governed by the Alberta Surrogate Rules, Alta. Reg. 130/95, ss. 50-54.
 - The Surrogate Court determines who is the proper person to administer the estate, which is usually the parent of a minor.
 - The person who administers an estate is usually the Executor or Administrator of the estate.
 - The Applicants have not made an application to the Surrogate Court for letters of administration to become the Administrator of the estate.
 - Section 104(1) does not give a right of access to health information of deceased minors even to a personal representative of the deceased.
 - It would have been easy to include deceased children in section 104(1)(d) of HIA.
 - A parent does not have carte blanche rights over a child.
 - HIA is not providing for the rights of parents but rather for the rights of the individual or the minor child.
 - Even if section 104(1)(c) gave rights to a guardian of a child after death this does not solve the issue for mature minors. There is still a legislative gap.
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- Section 104(1)(d) should take out the part about ‘over age 18’, as this then would not exclude the situation of an individual who is a minor.
- This is not a situation where the Commissioner can omit these words or read into this provision.
- Remediating this situation is a matter of policy for the Legislature, not a matter of interpretation for the Commissioner.

C. Intervenors

Note: Many of the Intervenors raised arguments that were similar to the arguments raised by the parties, which will not be repeated in this summary.

1. Alberta Health and Wellness (AHW)

- The policy position of HIA is that an adult individual's right to privacy extends beyond death, as disclosure of health information of a deceased adult is restricted.
 - For example, s. 104(1)(d) permits only a personal representative to exercise a deceased adult's rights to health information.
 - Further, this right of access only exists if "the exercise of the right or power relates to the administration of the individual's estate".
 - From a policy perspective, the ability to access a deceased child's health information should not be significantly different from that of a deceased adult.
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- Other HIA provisions that may authorize the disclosure of health information in relation to a deceased individual include section 3 (information otherwise available by law to a party in legal proceedings) (AHW, *Health Information Act – Guidelines and Practices Manual*, AHW, 2001, pp. 17-18).
- Section 35(1)(o) of HIA allows Custodians to disclose health information of a deceased individual for the provision of health services to a descendant of the deceased if the privacy of the deceased is protected (AHW, *Health Information Act – Guidelines and Practices Manual*, *Supra*, pp. 211-212).
- Section 35(1)(p) of HIA allows Custodians to disclose health information of a deceased individual where an enactment authorizes the disclosure (AHW, *Health Information Act – Guidelines and Practices Manual*, *Supra*, pp. 212-213).

2 & 3. College of Physicians and Surgeons of Alberta (CPSA) & Alberta Mental Health Board (AMHB)

- A physician has a duty to a patient to honor their express instructions, even after death.
 - Even if a guardian of the deceased became the Executor or Administrator of the estate, the physician should still honor the wishes of a deceased patient who did not want their records released.
 - Common law and statute exist side-by-side and where HIA is silent, the common law continues to exist.
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- Section 104(1) of HIA refers to "any right or power conferred on an individual by this Act".
- *Southam Inc. v. Attorney General of Canada et al* (1990) 73 D.L.R. (4th) 289 (S.C.C.) ("Southam"), said that when something is conferred by an Act of the Parliament of Canada, the Act of Parliament must be the source of the jurisdiction or power that is being conferred.
- In the Southam case, Mr. Justice Iacobucci said "The privileges, immunities and powers of the Senate are *conferred* by the Constitution, not by a statute, although the latter defines or elaborates upon the privileges, immunities, and powers. Such a statute then is the manifestation of Senate privileges but it is not its source; the source is section 18 of the Constitution Act, 1867" (p. 299).

- The Legislature intended s. 104 of HIA to apply only to a power or right that was created by HIA (i.e., where no prior right existed), not to a right or power that was merely manifested by HIA.
 - The right of access to health information is derived from the common law and was not a right or power that was created or conferred by the HIA.
 - In *McInerney* the Supreme Court of Canada confirmed that under common law there is a right of individual access to health information.
 - Due to the wording of s. 104, and the omission of guiding language, the matter of access to and disclosure of health information on behalf of another individual should default to the common law.
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- The estate of a deceased has a right of ownership over intangible personal property, such as medical records.
 - This right of ownership would transfer to an Executor or Administrator of an estate should one exist.
 - A personal representative is subject to supervision and direction of the Court of Queen's Bench of Alberta under the Surrogate Rules of Court.
 - If Section 104(1)(d) provided a personal representative with power to access the deceased's health information for administration of the estate, then Custodians would need to have an understanding of many pieces of legislation including the *Wills Act*, *Administration of Estates Act*, *Trustee Act* and the Surrogate Rules of Court as well as relevant case law to ensure that the information was being used for the purpose of administering the estate.
 - In situations where section 104(1)(d) does apply, this creates problems for Custodians because they must understand what constitutes the administration of the estate.
 - Section 104(1)(d) places onerous requirements on custodians to define, interpret and enforce the purpose of administration of an individual's estate when providing access to health information of deceased individuals.
 - Practically and functionally, the Legislature should not have expected a custodian to fully understand all legislation, Rules of Court and case law that governs the administration of estates.
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- In regards to a remedy for exercising the rights of deceased minors for health information, the Commissioner should not read in meanings that do not exist in the wording of HIA.

4. Alberta Cancer Board (ACB)

- This submission provided a broader perspective of the issues at hand rather than legal argument.
- Before HIA, the legal representative definition given in the *Hospitals Act* was used.
- Requests for deceased individual's health records are an "ongoing challenge" due to the volume and complexity of the requests received.
- A two-tier system of access that included the common law and statute law would be difficult for custodians to follow.
- Where there is no executor or administrator, the next of kin should be able to access deceased individual's health records
- Implementing a hierarchy for access would be useful, but Custodians would still need to consider the express wishes of the individual.

- HIA is unclear regarding who can and cannot access deceased individual's records. This is an area that needs clarification due to the emotional, economical, and secondary affects that these health records provide.
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- Examples of Requests for Access to or Disclosure of a Deceased's Health Information that are problematic under HIA are as follows:

- **Family member's of the deceased wanting access to the deceased's health information as part of the bereavement process. The requesting family members are neither the executor, administrator, nor the authorized representative of the deceased. They want the information for purposes other than administrating the deceased's estate.**

- The deceased's family is from another country. The deceased's sister wants the ACB to release the deceased's information to the deceased's brother who resides outside of Canada. The deceased's brother is a physician who would like to review the deceased's chart.
- An ACB patient, when alive, consented to the release of his ongoing progress reports to a named relative. The patient has deceased, and the relative requests access to the deceased's final information.
- Daughter of the deceased signed a consent to perform an autopsy and requests the autopsy information so that she may have an accurate diagnosis that can be passed on to siblings and other descendants of the deceased.
- Family members have been kept informed, in a general way, about the condition, progress, and prognosis of the ACB patient on the day in which the information is disclosed. This disclosure to the family members was not contrary to the express wishes of the individual. The ACB patient deceased and family members want further details.

- **Family members of the deceased wanting access to the deceased's health information for the purposes of administrating the deceased's estate. The requesting family members are not the executor, administrator, nor the authorized representative of the deceased.**

- The wife is the beneficiary of her husband's life insurance. She requires his information to process the insurance claim. The insurance company may reside outside of Alberta. The ACB suggested she apply for letters of administration from the Surrogate Court. She found the paperwork too complicated. She cannot afford a lawyer to assist her with this process (estimated cost \$2000.00 for a lawyer and the Court's charges are further based on the value of the estate). She requires the money from the insurance claim to pay living expenses and to apply for letters of administration etc. Note: claims for life insurance are time limited.
- A son of the deceased requests that a "proof of death statement" be completed by the ACB and returned to him. The statement is required for insurance purposes. The statement contains detailed health information of the deceased.
- A husband of the deceased requests the ACB to release his deceased wife's dates of treatment in order to file her final income tax submission.

- **Disclosures of the deceased individual's health information to other health service providers.**
 - An Alberta family physician is treating the wife of a deceased individual. The deceased's estate has been settled a while ago. The wife asked the physician to request the deceased charts on her behalf. She wants to know what happened to her husband. The purpose of the disclosure is to share this information with the wife and to provide health services to the wife. Obviously, the wife is not the "descendant" of the deceased. The disclosure is to a custodian under 35(1)(a), for the purpose of providing health services under s. 27(1)(a), but for providing health services to someone other than the individual that information is about. It is unclear whether s. 27(1)(a) allows a custodian to use the health information of a deceased in order to provide health services to someone other than the deceased.
 - A Cancer Genetics Clinic in British Columbia requests disclosure of a deceased health information for the purposes of providing health services to a descendant of a deceased. "Health services" is defined under HIA as meaning a service that is provided to an individual for any of the following purposes and is directly or indirectly and fully or partially paid for by the Department of Health and Wellness of the Government of Alberta.
 - An ACB patient deceased at another custodian's facility. The patient informed an affiliate of that custodian that he wanted his body "donated to science." The affiliate requested the ACB to disclose the deceased chemotherapy and radiation therapy administration to assess whether or not his body could be donated to science. A next-of-kin was not identified. The information may be released under s. 35(1)(a), but the authority for the purpose under s. 27 is unclear.
 - A patient consented to be on a clinical trial. Consent to participate in the research may not include a consent to release information following death of the participant. The sponsor of the clinical trial requests information about the participant's death. The clinical trial sponsor requires this information on the cause of death as it relates to the outcome of the drug trial.
 - The Canadian Blood Services requested that the ACB disclose health information of an identified individual for the purposes of performing "look-back" investigations. The individual identified was deceased. The disclosure of the deceased health information to the Canadian Blood Services is not authorized or required under an enactment of Alberta or Canada. The Canadian Blood Services Standard Operating Procedures are based on the US Food and Drug Administration Requirements for look-back investigations. However, there may be Canadian case law that applies to these types of disclosures. The issue of following-up a deceased recipient is very much a medical one, based on the likelihood that the recipient may have passed a transfusion transmitted infection on to contacts.
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- In particular the following issues should be addressed:
 - Define what the term "personal representative" means.
 - Allow the deceased's next-of-kin to access records. The next-of-kin under the *Human Tissue Gift Act* have control over what happens to the deceased's body with respect to scientific research and testing. If the next-of-kin can make this decision, shouldn't they also be able to access health information of the deceased?
 - Establish a time limit on the deceased individual's right of privacy.

5. Health Law Institute (HLI)

- Representatives of deceased minors should be included in section 104(1)(d).
- A mature minor should be treated the same way as an adult under 104(1)(c).
- Representatives of patients need access to records in order to ensure that they have been treated fairly and for legal actions under the estate.
- It is unfair to restrict access to health information of deceased individuals to purposes of “administering” an estate.
- The substitute of an individual often has curtailed rights in HIA, which may be unfair. When the substitute is to be acting with the same rights and powers as the individual it does not make sense to limit those rights and powers unless there is a good reason.
- The rights of a substitute are further limited by s. 58(2), which deals with “expressed wishes of the individual” and “any other factors the custodian considers relevant”.
- A substitute may have rights limited by restrictions that exist for the “personal representative” and “administration of the individual’s estate”.
- “Administration of the estate” should be given a broad meaning and should clearly include situations such as legal actions on behalf of a deceased’s estate.
- The term “personal representative” could be defined according to the Surrogate Court Rules in s. 1 (l), as this would be an appropriate definition.
- Unless these terms are defined in HIA they may be interpreted in a variety of ways based on the judgement of the custodian. The question is whether variation in interpretation and inconsistency is just.
- It is difficult for a custodian to know whether a particular individual is administering the deceased individual’s estate.
- Applying for a grant of administration may be time consuming and expensive for the family of the deceased individual and could damage relations between the family and custodian.

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- The differences between Part 2 and 5 of HIA must be considered. In Part 5 of HIA a right, but not a requirement, of access exists for example in sections 33 and 35. Part 2 sets out a scheme for how a Custodian should decide what to disclose
 - The Applicants might be entitled to request the health information under another provision of HIA.
 - Section 35(1) allows a custodian to disclose health information.

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- The Commissioner should apply the *Interpretation Act* to HIA for the authority to order access and disclosure of health information of deceased minors under HIA.
 - The *Interpretation Act*, R.S.A. 2000, c. I-8, says that an enactment shall be construed as being remedial and shall be given the fair, large and liberal construction and the interpretation that best ensures the attainment of its objects (s. 10).
 - The Commissioner should interpret HIA to maintain the rights of individuals that existed prior to HIA, specifically the right of others to exercise the rights of deceased minors.
 - It is difficult to amend legislation.
 - If the Commissioner waits for the legislation to be amended, many affected people will run out of time to access health information of deceased minors.

6. Canadian Bar Association, Wills & Estates Section, Northern Alberta (CBA)

- Any agent named in a personal directive, or any attorney named in an enduring power of attorney, should automatically have full access to the medical records by virtue of their position as an agent or attorney, unless an agent's or attorney's access is specifically excluded in the personal directive or the enduring power of attorney.
- The "personal representative" in s. 104 (1)(d) should be defined to include the individuals appointed personal representative, or if no personal representative has been appointed by a will, a Grant or Probate or a Grant of Administration, the person who is entitled to apply to become the personal representative pursuant to Section 11 of the Surrogate Court Rules ought to have access to the health information automatically, even if they have not applied for a Grant of Administration.
- In regards to s.104 (1)(f) and (g), the agent named in the personal directive or attorney named in the enduring power of attorney should have automatic rights to all health information so long as the personal directive or power of attorney does not specifically restrict access to the information.
- HIA should not make it a requirement for the personal directive or power of attorney to state a right to access health information. Rather, access should be provided unless specifically excluded.

7. Alberta Medical Association (AMA)

- Prior to HIA various pieces of legislation and case law governed the access to and disclosure of health information of deceased individuals.
- Prior to HIA, the *Hospitals Act* sections 40(5)(a), 40(10) and 40(13) provided a mechanism for patients and third parties to obtain hospital or medical records. Prior to HIA, the primary legislation that governed access to health records of a deceased individual, was s. 40(5)(a) of the *Hospitals Act*, which was subsequently repealed by HIA.
- Section 40 of the *Hospitals Act* did not mention third party access to a deceased person's health records unless they were a legal representative or administrator of the estate.
- The *Public Health Act*, section 63(4)(b), still allows a legal representative, which includes an executor or an administrator of an estate, to have access to health information of a deceased individual.
- The *McInerney* decision says that a patient does not own their health record, although a patient does have a right of access to the information. The fiduciary relationship between the physician and patient creates an obligation to keep health records and to make information available to the patient unless there is a reason the patient should not have the information.
- In *Re Meyers and Wellesley Hospital* [1986] O.J. No. 995 (Q.L.) ordered production of a wife's hospital records to the husband when the wife went into a coma after an operation.
- In *Mitchell v. Aldrete* [1981] N.J. No. 2 (Q.L.) C.A., the Court held that a hospital should release records to the personal representative of a deceased patient.