

15 June 2015

Jono Naylor
Acting Chairperson
Justice and Electoral Committee

Dear Mr Naylor

Petition of Hilary Keift and six others

1. You have asked for my advice on this petition, setting out the relevant sections of the Privacy Act 1993 and their application to the petitioner's situation. You have also asked for the current legal position on the rights of under 16-year olds to have their personal medical information protected from disclosure.

2. The petition requests:

"That the Parliament pass legislation providing that the parent of a woman under the age of 16 years has the right to know if that woman has a pregnancy confirmed before she is referred for any resulting medical procedure, and that any consent sought for the medical procedure be fully informed as to procedure, possible repercussions, and after-effects."

Summary of Advice

- The law on this matter is found in the Health Information Privacy Code 1994 ("the Code"), s.22F of the Health Act 1956, the Code of Health and Disability Consumers' Rights and the common law.
- Health Information Privacy Rule 11 ("HIPR 11") prohibits a health agency from disclosing information to another person except where permitted under the listed exceptions, or under another law.
- One of the exceptions is where the disclosure is to, or is authorised by, the individual's representative. The term representative is defined in the Code as *"where that person is under the age of 16 years, that individual's parent or guardian"*.
- That authority applies where the *"individual, ...is unable to exercise his or her rights"*. If a woman under 16 is able to exercise her rights, and does not approve of parental notification, the section would not authorise the health agency to notify the parents of the pregnancy or subsequent care or treatment.

- The preceding paragraphs deal with clinician initiated disclosure, of the sort contemplated by the petition. Slightly different rules apply when the parents request information from a health service. Section 22F of the Health Act 1956 establishes a statutory presumption (not a “right”) that parents are entitled to receive health and medical information about children under the age of 16.
- That presumption is subject to “good reasons” for withholding information in ss.27-29 of the Privacy Act, which includes *“in the case of an individual under the age of 16, the disclosure of that information would be contrary to that individual’s interests”*.
- HIPR 11 is also engaged. A health agency is also entitled to refuse to provide information about a person under the age of 16, to their parents where the agency has reasonable grounds to believe that the individual does not want the information to be disclosed.
- The extent to which the preferences of a person under 16 should be taken into account depend on the clinician’s assessment of their ability to understand the nature and consequences of the decision (“Gillick Competency”).
- Where a health agency refuses to give a parent access to information about a person under 16, that parent is entitled to ask my office to investigate that decision.

Position on Petitioner’s Proposal

3. It is impossible to read of the petitioner’s experience without feeling compassion and profound sympathy for their plight and experience with their daughter. It is not possible to say however whether the petitioner’s proposal if implemented would have avoided the distress and anguish they have suffered.
4. I could not and do not support any proposal to require that medical professionals give information to the parents of a person under 16 in circumstances that might well lead to harm to her. Removing the professional judgement and discretion of medical practitioners is unnecessary under existing law, and would without doubt lead to unintended consequences, such as putting a doctor’s ethical obligations at odds with her legal obligations, leading young women to lie about their age and circumstances, or seek unsafe alternatives to preserve their confidentiality and therefore compromising their care.

Content of this Submission

5. This submission explains the law relating to parents’ rights of access to health information about their children, and children’s rights to privacy.
6. The rights and responsibilities associated with the flows of personal information are secondary to the issue of competence to access or consent to a medical procedure. This submission therefore first sets out my understanding of the respective rights of parents and young persons in relation to accessing health services, and then addresses the legal rules in relation to access to health information.

Minors' ability to consent to a medical procedure

7. Individuals over the age of 16 can give or refuse consent to any medical procedure.¹ The legislation is silent in relation to the position of a minor under 16.
8. It is arguable that because the legislation is explicit with regard to those over 16, that those under 16 could not give effective consent. However, the legislation does not preclude a person under 16 providing an effective consent to receive treatment.
9. In respect of the termination of pregnancies, the current legal position is that a woman "of whatever age" can consent to a termination.² There are no legal requirements to notify a parent when a girl who is a minor requests a termination. Therefore, what becomes important is whether a minor is able to give an informed consent.
10. The Code of Health and Disability Services Consumers' Rights ("the Code") says that every patient has the right to make an informed choice and to give informed consent, except in certain circumstances where treatment may be provided in the best interests of a patient.³
11. The Code presumes that every health services consumer is competent to make an informed choice and give informed consent. The Code does not exclude those under the age of 16 from consenting or refusing consent to a medical treatment.
12. It follows that where a child of "whatever age" has the capacity to understand the nature and possible consequences of a decision, that decision should be understood as being sufficient for legal purposes. This is supported by the common law position in the *Gillick v West Norfolk and Wisbech Area Health Authority* decision – known as the Gillick competency test for minors.⁴
13. The Gillick competency test focuses on the minor's ability to demonstrate "sufficient understanding and intelligence to enable him or her to understand fully what is proposed".⁵ The minor's maturity, intelligence and understanding of implications should be assessed when deciding whether parents should be consulted or give consent. The Gillick competency test supports the view that minors can effectively refuse or consent to a medical treatment.

¹ Care of Children Act 2004, s 36.

² Care of Children Act 2004, s 38.

³ Code of Health and Disability Services Consumers' Rights, r 7.

⁴ *Gillick v West Norfolk and Wisbech Area Health Authority* [1986] AC 112; [1985] 3 All ER 402 (HL). Followed in New Zealand – for example see *Information, choice of treatment and informed consent*, Medical Council of New Zealand, March 2011, [27]-[28]. The test is also reflected in right 7 of the Code, specifically see for example, reference to retaining the right of informed consent to a level appropriate to the consumer's competence with regard to the nature of procedure in right 7(3) and presumption that every consumer is competent to make informed choices and give informed consent in right 7(2).

⁵ *Gillick v West Norfolk and Wisbech Area Health Authority*, per Lord Scarman.

14. New Zealand also recognises children's participation rights by adopting the United Nations Convention on the Rights of the Child ("UNCROC").⁶ The UNCROC recognises legal and social rights of children and young people when seeking consent to health care.⁷

The Privacy Act 1993 – minors' rights to privacy

15. Medical information is universally understood to be sensitive information. Reproductive health information is generally accepted as being particularly so.
16. The Privacy Act sets out twelve principles that manage collection, use, disclosure, storage, disposal and access to personal information relevant to a particular individual.⁸ These principles have been modified into 12 health information privacy rules by the Health Information Privacy Code 1994.
17. Information collected from an individual during their medical treatment attracts a number of rights under the Health Information Privacy Code, including the individual's right to access their information subject to a number of withholding grounds.⁹ Under HIPR 11 a health agency is entitled to disclose information to, or with the consent of a "representative" where the individual is unable to consent. Representative is defined as "*where that person is under the age of 16 years, that individual's parent or guardian*". In most cases then, a health agency is able to disclose health information about a person under 16 to a parent. Where the young person objects or specifically requests privacy, it is open to the health agency to make an assessment of the young person's ability to do so, applying the same or similar grounds as in *Gillick*. The power to disclose in HIPR 11 is discretionary, not mandatory, so the health agency is not required to disclose information to a parent simply by virtue of the fact that the parent may be considered a "representative".
18. Section 22F of the Health Act is also relevant. Section 22F permits the representative of a child to request access to health information about that child, and they are entitled to receive that information except in certain circumstances such as where providing that information to the parent would be contrary to the child's wishes or interests.
19. The New Zealand Medical Council recommends disclosure where it is in the patient's (including minors), best interests.¹⁰
20. In summary, any individual (including a minor) has the right to protect the privacy of their personal information. The Privacy Act provides guidance when disclosure of personal information may be permitted or is required. However, specific legislation or particular ethical or professional duties may also influence whether a doctor is required or is permitted to disclose personal information. This means there is no automatic right to access minor's personal information under the Privacy Act whether by parents or other parties. Even when a

⁶ Adopted and opened for signature, ratification and accession by General Assembly resolution 44/25 (1989).

⁷ UNCROC, art 12.

⁸ Privacy Act 1993, s 6.

⁹ Health Information Privacy Code 1994, r 6.

¹⁰ *Information, choice of treatment and informed consent*, above n 4, [20] – [24].

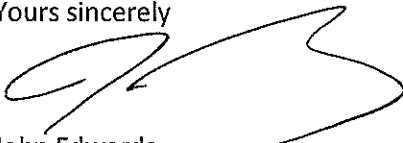
right of access is being exercised by a parent as representative under section 22F of the Health Act, a doctor must still consider whether it is in the best interests of the minor to release their information and what should be considered when assessing best interest considerations.

21. In my view it is appropriate to link the best interest assessment to the Gillick competency test considerations. This means where a minor, who is Gillick competent, is able to consent or refuse medical treatment, he or she should similarly have the ability to keep their personal medical information private from his or her parents. In other words, the views of minors must be considered when deciding whether it is in the minor's best interests to have their medical information disclosed to parents or guardians. Such an approach is consistent with the general purpose of the Privacy Act 1993 and the UNCROC, which recognise individual autonomy and the ability for an individual to control their personal information.

Conclusion

22. In general, doctors cannot treat any person without obtaining their informed consent. Anyone over the age of 16 can refuse or consent to medical treatment¹¹ but legislation does not provide guidance on consent of minors.
23. Section 22F of the Health Act 1956 creates the presumption that certain information about a person under 16 will be available to the parents. The presumption falls short of a "right" by parents to all information about their child, and is limited by right of the clinician involved to withhold information in the best interests of the child.
24. If parents do request access to their child's information and the request is declined, the parents may ask our Office to review that decision.
25. It is my submission that the current privacy laws adequately protect minors' rights to privacy while also giving an appropriate level of discretion to doctors when faced with whether or not to disclose minor's personal information. I would urge caution in widening the law in a way which removes clinicians' ability to make judgment about young persons' ability to make considered decisions about their sensitive information. Where a minor is considered competent to consent to a medical procedure, they should be able to consent or refuse the disclosure of their personal information.
26. I would be happy to appear before the Committee, or to provide any further information that will assist the Committee in relation to this matter.

Yours sincerely



John Edwards
Privacy Commissioner

¹¹ Care of Children Act 2004, s 36.

Appendix

1. Health Act 1956, section 22F;
2. Health Information Privacy Code 1994, rule 11;
3. Care of Children Act 2004, section 36;
4. Care of Children Act 2004, section 38;
5. The HDC Code of Health and Disability Services Consumers' Rights Regulation 1996, right 7;
6. Convention on the Rights of the Child, article 12; and
7. Health Information Privacy Code 1994, rule 6.

1. Health Act 1956

Section 22F Communication of information for diagnostic and other purposes

- (1) Every person who holds health information of any kind shall, at the request of the individual about whom the information is held, or a representative of that individual, or any other person that is providing, or is to provide, services to that individual, disclose that information to that individual or, as the case requires, to that representative or to that other person.
- (2) A person that holds health information may refuse to disclose that information under this section if—
 - (a) that person has a lawful excuse for not disclosing that information; or
 - (b) where the information is requested by someone other than the individual about whom it is held (not being a representative of that individual), the holder of the information has reasonable grounds for believing that that individual does not wish the information to be disclosed; or
 - (c) refusal is authorised by a code of practice issued under section 46 of the Privacy Act 1993.
- (3) For the purposes of subsection (2)(a), neither—
 - (a) the fact that any payment due to the holder of any information or to any other person has not been made; nor
 - (b) the need to avoid prejudice to the commercial position of the holder of any information or of any other person; nor
 - (c) the fact that disclosure is not permitted under any of the information privacy principles set out in section 6 of the Privacy Act 1993—

shall constitute a lawful excuse for not disclosing information under this section.

- (4) Where any person refuses to disclose health information in response to a request made under this section, the person whose request is refused may make a complaint to the Privacy Commissioner under Part 8 of the Privacy Act 1993, and that Part of that Act, so far as applicable and with all necessary modifications, shall apply in relation to that complaint as if the refusal to which the complaint relates were a refusal to make information available in response to an information privacy request within the meaning of that Act.
- (5) Nothing in subsection (4) limits any other remedy that is available to any person who is aggrieved by any refusal to disclose information under this section.

Section 22F: replaced, on 1 July 1993, by section 2 of the Health Amendment Act (No 2) 1993 (1993 No 32).

Section 22F(1): amended, on 1 January 2001, by section 111(1) of the New Zealand Public Health and Disability Act 2000 (2000 No 91).

2. Health Information Privacy Code 1994

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, that—
 - (a) 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; or
 - (b) the disclosure is authorised by—
 - (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 this rule; or
 - (c) the disclosure of the information is one of the purposes in connection with which the information was obtained; or
 - (d) the source of the information is a publicly available publication; or
 - (e) 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) the information to be disclosed concerns only the fact of death and the disclosure is by a health practitioner or by a person authorised by a health agency, to a person nominated by the individual concerned, or the individual's representative, partner, spouse, principal caregiver, next of kin, whānau, close relative, or other person whom it is reasonable in the circumstances to inform; or
 - (g) the information to be disclosed concerns only the fact that an individual is to be, or has been, released from compulsory status under the Mental Health (Compulsory Assessment and Treatment) Act 1992 and the disclosure is to the individual's principal caregiver.
- (2) Compliance with subrule (1)(b) is not necessary if the health agency believes on reasonable grounds that it is either not desirable or not practicable to obtain authorisation from the individual concerned and that—
 - (a) the disclosure of the information is directly related to one of the purposes in connection with which the information was obtained; or

- (b) the information is disclosed by a health practitioner to a person nominated by the individual concerned or to the principal caregiver or a near relative of the individual concerned in accordance with recognised professional practice and the disclosure is not contrary to the express request of the individual or his or her representative; or
- (c) the information—
 - (i) is to be used in a form in which the individual concerned is not identified; or
 - (ii) is to be used for statistical purposes and will not be published in a form that could reasonably be expected to identify the individual concerned; or
 - (iii) is to be used for research purposes (for which approval by an ethics committee, if required, has been given) and will not be published in a form that could reasonably be expected to identify the individual concerned; or
- (d) the disclosure of the information is necessary to prevent or lessen a serious and imminent threat to—
 - (i) public health or public safety; or
 - (ii) the life or health of the individual concerned or another individual; or
- (e) the disclosure of the information is essential to facilitate the sale or other disposition of a business as a going concern; or
- (f) the information to be disclosed briefly describes only the nature of injuries of an individual sustained in an accident and that individual's identity and the disclosure is—
 - (i) by a person authorised by the person in charge of a hospital; or
 - (ii) to a person authorised by the person in charge of a news medium—
for the purpose of publication or broadcast in connection with the news activities of that news medium and the disclosure is not contrary to the express request of the individual concerned or his or her representative; or
- (g) the disclosure of the information—
 - (i) is required for the purposes of identifying whether an individual is suitable to be involved in health education and so that individuals so identified may be able to be contacted to seek their authority in accordance with subrule (1)(b); and
 - (ii) is by a person authorised by the health agency to a person authorised by a health training institution; or
- (h) the disclosure of the information is required—

- (i) for the purpose of a professionally recognised accreditation of a health or disability service; or
 - (ii) for a professionally recognised external quality assurance programme; or
 - (iii) for risk management assessment and the disclosure is solely to a person engaged by the agency for the purpose of assessing the agency's risk—
and the information will not be published in a form which could reasonably be expected to identify any individual nor disclosed by the accreditation, quality assurance, or risk management organisation to third parties except as required by law; or
 - (i) non-compliance is necessary—
 - (i) to avoid prejudice to the maintenance of the law by any public sector agency, including the prevention, detection, investigation, prosecution, and punishment of offences; or
 - (ii) for the conduct of proceedings before any court or tribunal (being proceedings that have been commenced or are reasonably in contemplation); or
 - (j) the individual concerned is or is likely to become dependent upon a controlled drug, prescription medicine, or restricted medicine and the disclosure is by a health practitioner to a Medical Officer of Health for the purposes of section 20 of the Misuse of Drugs Act 1975 or section 49A of the Medicines Act 1981; or
 - (k) the disclosure of the information is in accordance with an authority granted under section 54 of the Act.
- (3) Disclosure under subrule (2) is permitted only to the extent necessary for the particular purpose.
- (4) Where, under section 22F(1) of the Health Act 1956, the individual concerned or a representative of that individual requests the disclosure of health information to that individual or representative, a health agency—
- (a) must treat any request by that individual as if it were a health information privacy request made under rule 6; and
 - (b) may refuse to disclose information to the representative if—
 - (i) the disclosure of the information would be contrary to the individual's interests; or
 - (ii) the agency has reasonable grounds for believing that the individual does not or would not wish the information to be disclosed; or
 - (iii) there would be good grounds for withholding the information under Part 4 of the Act if the request had been made by the individual concerned.

- (5) This rule applies to health information about living or deceased persons obtained before or after the commencement of this code.
- (6) Despite subrule (5), a health agency is exempted from compliance with this rule in respect of health information about an identifiable deceased person who has been dead for not less than 20 years.

Note: *Except as provided in rule 11(4), nothing in this rule derogates from any provision in an enactment which authorises or requires information to be made available, prohibits or restricts the availability of health information, or regulates the manner in which health information may be obtained or made available: Privacy Act 1993, section 7. Note also that rule 11, unlike the other rules, applies not only to information about living individuals, but also about deceased persons: Privacy Act 1993, section 46(6).*

Note: *Rule 11(1)(f) was amended by Amendment No 4. Rule 11(1)(g) was inserted by Amendment No 3, which also amended rule 11(6). The terms "health professional" and "registered health professional" were changed to "health practitioner" by Amendment No 6.*

3. Care of Children Act 2004

Section 36 Consent to procedures generally

- (1) A consent, or refusal to consent, to any of the following, if given by a child of or over the age of 16 years, has effect as if the child were of full age:
 - (a) any donation of blood by the child;
 - (b) any medical, surgical, or dental treatment or procedure (including a blood transfusion, which, in this section, has the meaning given to it by [section 37\(1\)](#)) to be carried out on the child for the child's benefit by a person professionally qualified to carry it out.
- (2) A child's consent, or refusal to consent, to any donation of blood, or to any medical, surgical, or dental treatment or procedure (including a blood transfusion), whether to be carried out on the child or on any other person, has the same effect as if the child were of full age if the child is or has been—
 - (a) married or in a civil union; or
 - (b) living with another person as a de facto partner.
- (3) If the consent of any other person to any medical, surgical, or dental treatment or procedure (including a blood transfusion) to be carried out on a child is necessary or sufficient, consent may be given—
 - (a) by a guardian of the child; or
 - (b) if there is no guardian in New Zealand or no guardian of that kind can be found with reasonable diligence or is capable of giving consent, by a person in New Zealand who has been acting in the place of a parent; or
 - (c) if there is no person in New Zealand who has been so acting, or if no person of that kind can be found with reasonable diligence or is capable of giving consent, by a District Court Judge or the chief executive.
- (4) If a child has been lawfully placed for the purpose of adoption in the home of any person, then, for the purposes of subsection (3), that person must be treated as a guardian of the child.
- (5) Nothing in this section affects an enactment or rule of law by or under which, in any circumstances,—
 - (a) no consent or no express consent is necessary; or
 - (b) the consent of the child in addition to that of any other person is necessary; or
 - (c) subject to subsection (2), the consent of any other person instead of the consent of the child is sufficient.
- (6) Except to the extent that this section enables a blood transfusion to be administered to a child without the consent of any other person, nothing in this section affects [section 37](#).
- (7) Subsection (1) is subject to subsection (6).

Compare: 1968 No 63 s 25

Section 36(2)(a): amended, on 1 July 2005, by [section 3](#) of the Care of Children Amendment Act 2005 (2005 No 5).

4. Care of Children Act 2004

Section 38 Consent to abortion

- (1) If given by a female child (of whatever age), the following have the same effect as if she were of full age:
 - (a) a consent to the carrying out on her of any medical or surgical procedure for the purpose of terminating her pregnancy by a person professionally qualified to carry it out; and
 - (b) a refusal to consent to the carrying out on her of any procedure of that kind.
- (2) This section overrides section 36.

Compare: 1968 No 63 s 25A

5. The HDC Code of Health and Disability Services Consumers' Rights Regulation 1996

RIGHT 7 Right to Make an Informed Choice and Give Informed Consent

- 1) Services may be provided to a consumer only if that consumer makes an informed choice and gives informed consent, except where any enactment, or the common law, or any other provision of this Code provides otherwise.
- 2) Every consumer must be presumed competent to make an informed choice and give informed consent, unless there are reasonable grounds for believing that the consumer is not competent.
- 3) Where a consumer has diminished competence, that consumer retains the right to make informed choices and give informed consent, to the extent appropriate to his or her level of competence.
- 4) Where a consumer is not competent to make an informed choice and give informed consent, and no person entitled to consent on behalf of the consumer is available, the provider may provide services where -
 - a) It is in the best interests of the consumer; and
 - b) Reasonable steps have been taken to ascertain the views of the consumer; and
 - c) Either, -
 - i. If the consumer's views have been ascertained, and having regard to those views, the provider believes, on reasonable grounds, that the provision of the services is consistent with the informed choice the consumer would make if he or she were competent; or
 - ii. If the consumer's views have not been ascertained, the provider takes into account the views of other suitable persons who are interested in the welfare of the consumer and available to advise the provider.
- 5) Every consumer may use an advance directive in accordance with the common law.
- 6) Where informed consent to a health care procedure is required, it must be in writing if -
 - a) The consumer is to participate in any research; or
 - b) The procedure is experimental; or
 - c) The consumer will be under general anaesthetic; or
 - d) There is a significant risk of adverse effects on the consumer.
- 7) Every consumer has the right to refuse services and to withdraw consent to services.
- 8) Every consumer has the right to express a preference as to who will provide services and have that preference met where practicable.

- 9) Every consumer has the right to make a decision about the return or disposal of any body parts or bodily substances removed or obtained in the course of a health care procedure.
- 10) No body part or bodily substance removed or obtained in the course of a health care procedure may be stored, preserved, or used otherwise than
 - (a) with the informed consent of the consumer; or
 - (b) For the purposes of research that has received the approval of an ethics committee; or
 - (c) For the purposes of 1 or more of the following activities, being activities that are each undertaken to assure or improve the quality of services:
 - (i) a professionally recognised quality assurance programme:
 - (ii) an external audit of services:
 - (iii) an external evaluation of services.

6. Convention on the Rights of the Child

Article 12

1. States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.
2. For this purpose, the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative or an appropriate body, in a manner consistent with the procedural rules of national law.

7. Health Information Privacy Code 1994

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—
 - (a) to obtain from the agency confirmation of whether or not the agency holds such health information; and
 - (b) to have access to that health information.
- (2) Where, in accordance with subrule (1)(b), an individual is given access to health information, the individual must be advised that, under rule 7, the individual may request correction of that information.
- (3) The application of this rule is subject to—
 - (a) Part 4 of the Act (which sets out reasons for withholding information); and
 - (b) Part 5 of the Act (which sets out procedural provisions relating to access to information); and
 - (c) clause 6 (which concerns charges).
- (4) This rule applies to health information obtained before or after the commencement of this code.