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Code of Practice

1 Title

This code of practice is the Health Information Privacy Code 2020.

2 Commencement

This code comes into force on 1 December 2020.

3 Interpretation

(1) In this code,—

disability services includes goods, services, and facilities—

(a) provided to people with disabilities for their care or support or to promote their inclusion and participation in society, and independence; or

- (b) provided for purposes related to or incidental to the care or support of people with disabilities or to the promotion of the inclusion and participation in society, and independence of such people

ethics committee means—

- (a) the Ethics Committee of the Health Research Council of New Zealand or an ethics committee approved by that committee; or
- (b) the National Advisory Committee on Health and Disability Support Services Ethics; or
- (c) an ethics committee required to operate in accordance with the currently applicable Operational Standard for Ethics Committees promulgated by the Ministry of Health; or
- (d) an ethics committee established by, or pursuant to, any enactment

health agency means an agency referred to in subclause 4(2) and, for the purposes of rules 5 to 12, is to be taken to include—

- (a) where an agency holds health information obtained in the course of providing health or disability services but no longer provides such services — that agency; and
- (b) with respect to any health information held by a health agency (being a natural person) at the time of the person's death — their personal representative

health information means information to which this code applies under clause 4(1)

health practitioner has the meaning given to it by section 5(1) of the Health Practitioners Competence Assurance Act 2003

health professional body means an authority empowered to exercise registration and disciplinary powers under the Health Practitioners Competence Assurance Act 2003

health services means personal health services and public health services

health training institution means a school, faculty, or department referred to in subclause 4(2)(d)

personal health services means goods, services and facilities provided to an individual for the purpose of improving or protecting the health of that individual, whether or not they are also provided for another purpose, and includes goods, services, and facilities provided for related or incidental purposes

principal caregiver, in relation to any individual, means the friend of the individual or the member of the individual's family group or whānau who is most evidently and directly concerned with the oversight of the individual's care and welfare

public health services means goods, services, and facilities provided for the purpose of improving, promoting, or protecting public health or preventing population-wide disease, disability, or injury, and includes—

- (a) regulatory functions relating to health or disability matters; and
- (b) health protection and health promotion services; and

- (c) goods, services and facilities provided for related and incidental functions or purposes

representative, in relation to an individual, means—

- (a) where that individual is dead, that individual's personal representative; or
- (b) where the individual is under the age of 16 years, that individual's parent or guardian; or
- (c) where that individual, not being an individual referred to in subclauses (a) or (b), is unable to give their consent or authority, or exercise their rights, a person appearing to be lawfully acting on the individual's behalf in the individual's interests

rule means a health information privacy rule set out in clause 5

the Act means the Privacy Act 2020.

- (2) A term or expression defined in the Act and used, but not defined, in this code has the same meaning as in the Act.

4 Application of code

- (1) This code applies to the following information or classes of information about an identifiable individual—

- (a) information about the health of that individual, including their medical history; or
- (b) information about any disabilities that individual has, or has had; or
- (c) information about any health services or disability services that are being provided, or have been provided, to that individual; or
- (d) information provided by that individual in connection with the donation, by that individual, of any body part or any bodily substance of that individual or derived from the testing or examination of any body part, or any bodily substance of that individual; or
- (e) information about that individual which is collected before or in the course of, and incidental to, the provision of any health service or disability service to that individual.

- (2) This code applies in relation to the following agencies or classes of agency—

Health and disability service providers

- (a) an agency which provides health or disability services; or
- (b) within a larger agency, a division or administrative unit (including an individual) which provides health or disability services to employees of the agency or some other limited class of persons; or
- (c) a person who is approved as a counsellor for the purposes of the Accident Compensation Act 2001; or

Training, registration, and discipline of health professionals, etc

- (d) a school, faculty or department of a tertiary educational institution which provide the training or a component of the training necessary for the registration of a health practitioner; or
- (e) an agency having statutory responsibility for the registration of any health practitioners; or
- (f) a health professional body; or
- (g) persons appointed or designated under the Health and Disability Commissioner Act 1994; or

Health insurance, etc

- (h) an agency which provides health, disability, accident or medical insurance, or which provides claims management services in relation to such insurance, but only in respect of providing that insurance or those services; or
- (i) an accredited employer under the Accident Compensation Act 2001; or

Other

- (j) an agency which provides services in respect of health information, including an agency which provides those services under an agreement with another agency; or
- (k) a district inspector, deputy district inspector or official visitor appointed pursuant to section 94 of the Mental Health (Compulsory Assessment and Treatment) Act 1992; or
- (l) a district inspector or deputy district inspector appointed pursuant to section 144 of the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003; or
- (m) an agency which manufactures, sells, or supplies medicines, medical devices or related products; or
- (n) an agency which provides health and disability services consumer advocacy services; or
- (o) the department responsible for the administration of the Coroners Act 2006, but only in respect of information contained in documents referred to in section 29(1) of that Act; or
- (p) the agencies specified in Schedule 1.

Part 2: Health information privacy rules

5 Health information privacy rules

The information privacy principles are modified in accordance with the Act by the following rules which apply to health information and health agencies—

Rule 1

Purpose of collection of health information

- (1) Health information must not be collected by a health agency unless—
 - (a) the information is collected for a lawful purpose connected with a function or activity of the health agency; and
 - (b) the collection of the information is necessary for that purpose.
- (2) If the lawful purpose for which health information about an individual is collected does not require the collection of an individual's identifying information, the health agency may not require the individual's identifying information.

Rule 2

Source of health information

- (1) If a health agency collects health information, the information must be collected from the individual concerned.
- (2) It is not necessary for a health agency to comply with subrule (1) if the agency believes, on reasonable grounds,—
 - (a) that the individual concerned authorises collection of the information from someone else having been made aware of the matters set out in rule 3(1); or
 - (b) that the individual is unable to give their authority and the health agency having made the individual's representative aware of the matters set out in rule 3(1) collects the information from the representative or the representative authorises collection from someone else; or
 - (c) that compliance would—
 - (i) prejudice the interests of the individual concerned; or
 - (ii) prejudice the purposes of collection; or
 - (iii) prejudice the health or safety of any individual; or
 - (d) that compliance is not reasonably practicable in the circumstances of the particular case; or
 - (e) that the collection is for the purpose of assembling a family or genetic history of an individual and is collected directly from that individual; or
 - (f) that the information is publicly available information; or
 - (g) that the information—
 - (i) will not be used in a form in which the individual concerned is identified; or
 - (ii) will 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) will 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
 - (h) that non-compliance is necessary—

- (i) to avoid prejudice to the maintenance of the law by any public sector agency, including prejudice to the prevention, detection, investigation, prosecution, and punishment of offences; or
 - (ii) for the protection of public revenue; or
 - (iii) for the conduct of proceedings before any court or tribunal (being proceedings that have been commenced or are reasonably in contemplation); or
- (i) that the collection of the information is in accordance with an authorisation granted under section 30 of the Act.

Rule 3

Collection of health information from individual

- (1) If a health agency collects health information from the individual concerned, or from the individual's representative, the health agency must take any steps that are, in the circumstances, reasonable to ensure that the individual concerned (and the representative if collection is from the representative) is aware of—
- (a) the fact that the information is being collected; and
 - (b) the purpose for which the information is being collected; and
 - (c) the intended recipients of the information; and
 - (d) the name and address of—
 - (i) the health agency that is collecting the information; and
 - (ii) the agency that will hold the information; and
 - (e) whether or not the supply of the information is voluntary or mandatory and if mandatory the particular law under which it is required; and
 - (f) the consequences (if any) for that individual if all or any part of the requested information is not provided; and
 - (g) the rights of access to, and correction of, health information provided by rules 6 and 7.
- (2) The steps referred to in subrule (1) must be taken before the information is collected or, if that is not practicable, as soon as practicable after it is collected.
- (3) A health agency is not required to take the steps referred to in subrule (1) in relation to the collection of information from an individual, or the individual's representative, if that agency has taken those steps on a recent previous occasion in relation to the collection, from that individual or that representative, of the same information or information of the same kind, for the same or a related purpose.
- (4) It is not necessary for a health agency to comply with subrule (1) if the agency believes on reasonable grounds,—
- (a) that compliance would—
 - (i) prejudice the interests of the individual concerned, or
 - (ii) prejudice the purposes of collection; or

- (b) that compliance is not reasonably practicable in the circumstances of the particular case; or
- (c) that non-compliance is necessary to avoid prejudice to the maintenance of the law by any public sector agency, including prejudice to the prevention, detection, investigation, prosecution, and punishment of offences.

Rule 4

Manner of collection of health information

- (1) A health agency must collect health information only—
 - (a) by a lawful means; and
 - (b) by a means that, in the circumstances of the case (particularly in circumstances where personal information is being collected from children or young persons),—
 - (i) is fair; and
 - (ii) does not intrude to an unreasonable extent upon the personal affairs of the individual concerned.

Rule 5

Storage and security of health information

- (1) A health agency that holds health information must ensure—
 - (a) that the information is protected, by such security safeguards as are reasonable in the circumstances to take, against—
 - (i) loss;
 - (ii) access, use, modification, or disclosure that is not authorised by the agency; and
 - (iii) other misuse;
 - (b) that, if it is necessary for the information to be given to a person in connection with the provision of a service to the health agency, including any storing, processing, or destruction of the information, everything reasonably within the power of the health agency is done to prevent unauthorised use or unauthorised disclosure of the information; and
 - (c) that, where a document containing health information is not to be kept, the document is disposed of in a manner that preserves the privacy of the individual.
- (2) This rule applies to health information obtained before or after the commencement of this code.

Rule 6

Access to personal health information

- (1) An individual is entitled to receive from a health agency upon request—

- (a) confirmation of whether the health agency holds any health information about them; and
 - (b) access to their health information.
- (2) If an individual concerned is given access to health information, the individual must be advised that, under rule 7, the individual may request the correction of that information.
- (3) The application of this rule is subject to—
- (a) Part 4 of the Act (which sets out reasons for refusing access to information and procedural provisions relating to access to information); and
 - (b) clause 6 (which concerns charges).
- (4) This rule applies to health information obtained before or after the commencement of this code.

Rule 7
Correction of health information

- (1) An individual whose health information is held by a health agency is entitled to request the agency to correct the information.
- (2) A health agency that holds health information must, on request or on its own initiative, take such steps (if any) that are reasonable in the circumstances to ensure that, having regard to the purposes for which the information may lawfully be used, the information is accurate, up to date, complete, and not misleading.
- (3) When requesting the correction of health information, or at any later time, an individual is entitled to—
- (a) provide the agency with a statement of the correction sought to the information (a statement of correction); and
 - (b) request the agency to attach the statement of correction to the information if the agency does not make the correction sought.
- (4) If a health agency that holds health information is not willing to correct the information as requested and has been provided with a statement of correction, the agency must take such steps (if any) that are reasonable in the circumstances to ensure that the statement of correction is attached to the information in a manner that ensure that it will always be read with the information.
- (5) If a health agency corrects health information or attaches a statement of correction to health information, that agency must, so far as is reasonably practicable, inform every other person to whom the agency has disclosed the information.
- (6) Subrules (1) to (4) are subject to the provisions of Part 4 of the Act (which sets out procedural provisions relating to the correction of personal information).
- (7) This rule applies to health information obtained before or after the commencement of this code.

Rule 8

Accuracy, etc, of health information to be checked before use or disclosure

- (1) A health agency that holds health information must not use or disclose that information without taking any steps that are, in the circumstances, reasonable to ensure that the information is accurate, up to date, complete, relevant and not misleading.
- (2) This rule applies to health information obtained before or after the commencement of this code.

Rule 9

Retention of health information

- (1) A health agency that holds health information must not keep that information for longer than is required for the purposes for which the information may lawfully be used.
- (2) Subrule (1) does not prohibit any agency from keeping any document that contains health information the retention of which is necessary or desirable for the purposes of providing health services or disability services to the individual concerned.
- (3) This rule applies to health information obtained before or after the commencement of this code.

Rule 10

Limits on use of health information

- (1) A health agency that holds health information that was obtained in connection with one purpose may not use the information for any other purpose unless the health agency believes on reasonable grounds,—
 - (a) that the use of the information for that other purpose is authorised by—
 - (i) the individual concerned; or
 - (ii) the individual's representative where the individual is unable to give their authority under this rule; or
 - (b) that the purpose for which the information is to be used is directly related to the purpose in connection with which the information was obtained; or
 - (c) that the source of the information is a publicly available publication and that, in the circumstances of the case, it would not be unfair or unreasonable to use the information; or
 - (d) that the use of the information for that other purpose is necessary to prevent or lessen a serious threat to—
 - (i) public health or public safety; or
 - (ii) the life or health of the individual concerned or another individual;
 - (e) that 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
 - (f) that the use of the information for that other purpose is necessary—
 - (i) to avoid prejudice to the maintenance of the law by any public sector agency, including prejudice to 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
 - (g) that the use of the information is in accordance with an authorisation granted under section 30 of the Act.
- (2) A health agency that holds health information that was obtained from the testing or examination of a blood sample collected in connection with the Newborn Metabolic Screening Programme shall not use that information unless it believes, on reasonable grounds, that the use is in accordance with Schedule 3.
- (3) This rule does not apply to health information obtained before 1 July 1993.

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 their rights under these rules; or
 - (b) that 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 their authority under this rule; or
 - (c) that the disclosure of the information is one of the purposes in connection with which the information was obtained; or
 - (d) that the source of the information is a publicly available publication and that, in the circumstances of the case, it would not be unfair or unreasonable to disclose the information; or
 - (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 their representative; or

- (f) that 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) that 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—
- (a) that the disclosure of the information is directly related to one of the purposes in connection with which the information was obtained; or
 - (b) that 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 their representative; or
 - (c) that 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) that the disclosure of the information is necessary to prevent or lessen a serious 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 necessary to enable an intelligence and security agency to perform any of its functions; or
 - (f) that the disclosure of the information is essential to facilitate the sale or other disposition of a business as a going concern; or
 - (g) that the information to be disclosed briefly describes only the nature of injuries of an individual sustained in an accident and that the individual's identity and the disclosure is—
 - (i) by a person authorised by the person in charge of a hospital; and
 - (ii) to a person authorised by the person in charge of a news entity;

and for the purpose of publication or broadcast in connection with the news activities of that news entity and the disclosure is not contrary to the express request of the individual concerned or their representative; or

- (h) that the disclosure of the information—
 - (i) is required for the purpose 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
- (i) that the disclosure of the information—
 - (i) is required for the purpose of a professionally recognised accreditation of a health or disability service; or
 - (ii) is required for a professionally recognised external quality assurance programme; or
 - (iii) is required 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

- (j) that non-compliance is necessary—
 - (i) to avoid prejudice to the maintenance of the law by any public sector agency, including prejudice to 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 commenced or are reasonably in contemplation); or
 - (k) that 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
 - (l) that the disclosure of the information is in accordance with an authorisation granted under section 30 of the Act
- (3) A health agency that holds health information that was obtained from the testing or examination of a blood sample collected in connection with the Newborn Metabolic Screening Programme shall not disclose that information unless it believes, on reasonable grounds, that the disclosure is in accordance with Schedule 3.
- (4) Disclosure under subrule (2) is permitted only to the extent necessary for the particular purpose.

- (5) 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.
- (6) This rule applies to health information about living or deceased persons obtained before or after the commencement of this code.
- (7) Despite subrule (6), 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.
- (8) This rule is subject to rule 12.

Rule 12

Disclosure of health information outside New Zealand

- (1) A health agency (A) may disclose health information to a foreign person or entity (B) in reliance on Rule 11(1)(b) or (c) or 11(2)(a), (c), (d), (f), (i) (j) or (l) only if—
 - (a) the individual concerned or, where the individual is dead or unable to exercise their rights under these rules, that individual's representative authorises the disclosure to B after being expressly informed by A that B may not be required to protect the information in a way that, overall, provides comparable safeguards to those in the Act, as modified by this code; or
 - (b) B is carrying on business in New Zealand and, in relation to the information, A believes on reasonable grounds that B is subject to the Act, as modified by this code; or
 - (c) A believes on reasonable grounds that B is subject to privacy laws that, overall, provide comparable safeguards to those in the Act, as modified by this code; or
 - (d) A believes on reasonable grounds that B is a participant in a prescribed binding scheme; or
 - (e) A believes on reasonable grounds that B is subject to privacy laws of a prescribed country; or
 - (f) A otherwise believes on reasonable grounds that B is required to protect the information in a way that, overall, provides comparable safeguards to those in the Act, as modified by this code (for example, pursuant to an agreement entered into between A and B); or
 - (g) that the disclosure of the information is in accordance with an authorisation granted under section 30 of the Act.

(2) However, subrule (1) does not apply if the health information is to be disclosed to B in reliance on Rule 11(2)(d) or (j) and it is not reasonably practicable in the circumstances for A to comply with the requirements of subrule (1).

(3) In this rule,—

prescribed binding scheme means a binding scheme specified in regulations made under section 213 of the Act

prescribed country means a country specified in regulations made under section 214 of the Act that are made without any qualification or limitation relating to a class of person that includes B, or to a type of information that includes health information.

Rule 13 **Unique Identifiers**

(1) A health agency (A) may assign a unique identifier to an individual for use in its operations only if that identifier is necessary to enable A to carry out 1 or more of its functions efficiently.

(2) A may not assign to an individual a unique identifier that, to A's knowledge, is the same unique identifier as has been assigned to that individual by another agency (B), unless—

(a) A and B are associated persons within the meaning of subpart YB of the Income Tax Act 2007; or

(b) the unique identifier is to be used by A for statistical or research purposes and no other purpose; or

(c) it is permitted by subrule (3) or (4).

(3) The following agencies may assign the same National Health Index number to an individual—

(a) any agency authorised expressly by an enactment; or

(b) any agency or class of agencies listed in Schedule 2.

(4) Notwithstanding subrule (2) any health agency may assign to a health practitioner as a unique identifier—

(a) the registration number assigned to that individual by the relevant health professional body; or

(b) the Common Provider Number assigned to that individual by the Ministry of Health.

(5) To avoid doubt, A does not assign a unique identifier to an individual under subrule (1) by simply recording a unique identifier assigned to the individual by B for the sole purpose of communicating with B about the individual.

(6) A must take any steps that are, in the circumstances, reasonable to ensure that—

(a) a unique identifier is assigned only to individuals whose identity is clearly established; and

- (b) the risk of misuse of a unique identifier by any person is minimised (for example, by showing truncated account numbers on receipts or in correspondence).
- (7) A health agency may not require an individual to disclose any unique identifier assigned to that individual unless the disclosure is for one of the purposes in connection with which that unique identifier was assigned or for a purpose that is directly related to one of those purposes.
- (8) Subrules 13(1) to (6)(a) do not apply to unique identifiers assigned before 30 July 1994.
- (9) However, subrule 13(2) applies to the assignment of a unique identifier on or after 30 July 1994 even if the unique identifier is the same as that assigned by another agency before that date.

Part 3: Miscellaneous

6 Charges

- (1) For the purposes of charging under section 66 of the Act in relation to information privacy requests concerning health information, a health agency that is a private sector health agency must not require the payment, by or on behalf of any individual who wishes to make a request, of any charges in respect of a matter referred to in section 66(1)(b) and 66(2)(b) of the Act except in accordance with this clause.
- (2) Where an individual makes an information privacy request to a health agency that is not a private sector agency, the agency may, unless prohibited by law other than the Act or this code, make a reasonable charge—
 - (a) where, on a particular day, that agency has made health information available to that individual in response to a request, for making the same or substantially the same health information available in accordance with any subsequent request within a period of 12 months after that day; or
 - (b) for providing a copy of an x-ray, a video recording, an MRI scan photograph, a PET scan photograph or a CAT scan photograph.
- (3) Where an agency intends to make a charge under subclause (2) and the amount of the charge is likely to exceed \$30, the agency must provide the individual with an estimate of the charge before dealing with the request.

7 Complaints of breach of code

- (1) Every health agency must designate a person or persons to deal with complaints alleging a breach of this code and facilitate the fair, simple, speedy, and efficient resolution of complaints.
- (2) Every health agency to which this subclause applies must have a complaints procedure which provides that—
 - (a) when a complaint of a breach of this code is received—

- (i) the complaint is acknowledged in writing within 5 working days of receipt, unless it has been resolved to the satisfaction of the complainant within that period; and
 - (ii) the complainant is informed of any relevant internal and external complaints procedures; and
 - (iii) the complaint and the actions of the health agency regarding that complaint are documented; and
- (b) within 10 working days of acknowledging the complaint, the agency must—
 - (i) decide whether it—
 - (A) accepts that the complaint is justified; or
 - (B) does not accept that the complaint is justified; or
 - (ii) if it decides that more time is needed to investigate the complaint—
 - (A) determine how much additional time is needed; and
 - (B) if that additional time is more than 20 working days, inform the complainant of that determination and of the reasons for it; and
- (c) as soon as practicable after the agency decides whether or not it accepts that a complaint is justified, it must inform the complainant of—
 - (i) the reasons for the decision; and
 - (ii) any actions the agency proposes to take; and
 - (iii) any appeal procedure the agency has in place; and
 - (iv) the right to complain to the Privacy Commissioner.
- (3) Subclause (2) applies to any health agency specified in clause 4(2)(a), (c), (d), (e), (h), (i) and (j) or items 1 and 5 of Schedule 1.
- (4) Nothing in this clause is to limit or restrict any provision of Part 4 of the Act or sections 49 to 53.

8 Revocation

The Health Information Privacy Code 1994 is revoked.

Schedule 1
Specified Health Agencies

- (1) Accident Compensation Corporation
- (2) Health Research Council
- (3) Institute of Environmental Science and Research Limited
- (4) Ministry of Health
- (5) New Zealand Health Partnerships Limited
- (6) The Interchurch Council on Hospital Chaplaincy

Schedule 2
Agencies Approved to Assign NHI Number

- (1) Accident Compensation Corporation
- (2) Department of Corrections Health Services
- (3) District Health Boards
- (4) Health Practitioners
- (5) Hospitals
- (6) Independent Practitioner Associations
- (7) MedicAlert Foundation – New Zealand Incorporated
- (8) Ministry of Health
- (9) New Zealand Blood and Organ Service
- (10) New Zealand Defence Force Health Services
- (11) Pharmaceutical Management Agency of New Zealand
- (12) Primary Health Organisations
- (13) Any health agency which has a contract with the Accident Compensation Corporation or a District Health Board or the Ministry of Health to provide health or disability services.

Schedule 3

Use and Disclosure of Information Derived from Newborn Babies' Blood Spot Samples

Schedule 3 sets standards for how health information derived from the blood spot samples collected for the Newborn Metabolic Screening Programme may be used and disclosed.

All uses and disclosures of derived information must be—

- (a) for one of the permitted primary or permitted secondary purposes; or
- (b) authorised by the individual concerned or their representative; or
- (c) authorised by a close available relative where the individual is deceased or under 16.

(1) Interpretation

In this Schedule,—

close available relative has the meaning given to it by section 10 of the Human Tissue Act 2008

derived information means health information that was obtained from testing or examination of a blood sample collected in connection with the Newborn Metabolic Screening Programme

permitted primary purpose means a purpose directly connected with conducting and administering the Newborn Metabolic Screening Programme, including to—

- (a) conduct initial and repeat screening for metabolic or genetic disorders of blood samples taken from newborn babies;
- (b) conduct quality assurance and audit; and
- (c) develop new screening procedures

permitted secondary purpose means to—

- (a) assist the New Zealand Police in an investigation where biological material, a body part or a body has been discovered and no other avenue of identifying a person who is deceased or missing is practicable; or
- (b) conduct testing, intending to benefit the individual concerned or their family, that is authorised by—
 - (i) the individual concerned or their representative; or
 - (ii) a close available relative where the individual is dead or under 16; or
- (c) conduct an inquiry pursuant to Part 3 of the Coroners Act 2006; or
- (d) comply with a search warrant or court order; or
- (e) comply with a notice in writing from the chairperson of a mortality review committee pursuant to Schedule 5 of the New Zealand Public Health and Disability Act 2000; or
- (f) carry out research for which approval by an ethics committee and the Ministry of Health has been given.

(2) **Use and disclosure of derived information**

Any health agency that holds derived information about an individual must not use or disclose the information unless it believes, on reasonable grounds, that—

- (a) the individual concerned or their representative has authorised the use or disclosure of derived information about that individual; or
- (b) where the individual is deceased or under 16, a representative or close available relative has authorised the use or disclosure of the individual's derived information; or
- (c) the derived information is to be used or disclosed for a permitted primary purpose or a permitted secondary purpose.

Made at Wellington on 28 October 2020.

John Edwards
Privacy Commissioner

Issued under the authority of the Privacy Act 2020.

Date of notification in *Gazette*: 2 November 2020

This legislation is administered by the Office of the Privacy Commissioner.