

DATA RETENTION POLICY – PERSONAL AND HEALTH INFORMATION

Purpose

The Child Cancer Foundation (the **Foundation**) is required by law to retain certain personal or health information for a specified amount of time. There are also laws that require the Foundation to not retain personal or health information for longer than needed. The Foundation retains data to help its business operate and to have information available when it is needed. However, the Foundation does not need to retain all data indefinitely, and retaining data can expose the Foundation to risk as well as be a cost to its business.

This Policy sets out the legislative requirements for the retention of personal information and health information (as those terms are explained below) that the Foundation collects through its various services. This Policy does not cover other data or information that the Foundation holds or otherwise uses. Failure to comply with this policy can expose the Foundation to fines, penalties and adverse publicity.

This Policy is an internal document that should not be shared with anyone other than Foundation staff.

This Policy supplements and should be read in conjunction with our other policies and procedures in force from time to time, including without limitation our Privacy Policy available [here](#).

Guiding Principles

Through this Policy, the Foundation aims to meet the following commitments:

- compliance with legal and regulatory requirements to retain data;
- compliance with our data protection obligations;
- handling, storing and disposing of data responsibly and securely;
- regularly reminding staff of their data retention responsibilities; and
- regularly monitoring and auditing compliance with this Policy and updating this Policy when required.

Roles and Responsibilities

The Foundation is committed to complying with the laws, rules, and regulations that govern it and aims to achieve recognised data handling good practices. All staff must comply with this Policy, the Record Retention Schedule and any communications and specific instructions from Siobhan Fairweather. An employee's or contractor's failure to comply with this Policy may result in disciplinary sanctions. It is therefore the responsibility of everyone to understand and comply with this Policy. Foundation employees or contractors who are aware of or suspect any violations of this Policy should immediately report such conduct to their managers.

Types of Information

Personal Information

Where the Foundation collects 'personal information' (information about an identifiable individual such as names and email addresses), the Privacy Act 2020 (**Privacy Act**) and its Information Privacy Principles (**IPPs**) require that the Foundation must not hold personal information for longer than is required for the purposes for which the information may lawfully be used. Generally, this means personal information must not be held longer than is necessary for the purpose for which it was collected, unless another law requires the information to be held for longer.

'Health information' is a subset of personal information, which has its own specific retention rules (explained in more detail below). Where personal information is stored with health information and the two categories of information cannot be easily separated, the Foundation should hold the combined information for the period for which it is required to hold the relevant health information.

Health Information and the Code

The Health Information Privacy Code (the **Code**) sets out specific rules for health agencies, such as the Foundation, processing health information. The Code takes the place of the IPPs for the health sector. 'Health information' is defined under the Code and includes information about the health of an identifiable individual (other than a deceased person), including their medical history (for example, information about a child's medical history, disabilities, medical treatment, health status and information in relation to organ donation). Under the Code, 'health information' includes 'incidental' information (ie information about an 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).

Where the Foundation collects health information which is subject to the Code, it must not keep the health information for longer than is required for the purposes for which the information may lawfully be used.

Health Information and the Regulations

The Health (Retention of Health Information) Regulations (**Regulations**) impose an obligation on the Foundation to retain health information relating to identifiable individuals for a period of 10 years beginning of the day after the date shown in the health information as the most recent date on which the Foundation provided services to that individual (the **Minimum Retention Period**).

Under the Regulations 'health information' has the same meaning as that in the Code, except under the Regulations 'health information':

- (a) includes health information about identifiable deceased individuals (whereas the Privacy Act and Code do not generally apply in respect of deceased individuals' personal/health information); and
- (b) does not include 'incidental' information (ie information about an 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).

Health information that is collected before or in the course of, and incidental to, the provision of any health service to that individual is subject to the Code and does not need to be kept for the Minimum Retention Period. The Foundation should not keep the incidental health information for longer than it is required for the purpose it may lawfully be used (which is typically linked to the purpose of collection – ie if the Foundation no longer needs the information for the original purpose for which it was collected, it should be deleted).

Personal Information and Health Information of Deceased Persons

The Regulations require that health information of a deceased person must be held for the Minimum Retention Period. The personal information and health information retention requirements of the Privacy Act and the Code do not apply to deceased persons. Accordingly, for information about deceased persons that is not subject to the Regulations (ie 'incidental' information or personal information), there are no obligations or restrictions in relation to the retention of that information. As such, the Foundation is free to deal with that information as it wishes, although from a 'social expectations' perspective, the Foundation should delete the information if it is no longer required by the Foundation for any of its functions.

SCHEDULE – RECORD RETENTION SCHEDULE

The following table identifies the documents created/maintained by the Foundation that include ‘personal information’ and/or ‘health information’ which is subject to legislative retention/deletion requirements.

Document category	Document description	Personal/health information contained	Legislative requirement	Retention period recommendation
Whānau Connect Group registration form	Registration form for individuals to be a part of the Whānau Connect Group, which involves their families sharing experiences through social events.	<i>Personal information:</i> name, contact details, date of birth, gender, ethnicity, spoken language and preference of an interpreter.	<i>Privacy Act, IPP 9</i> – Foundation cannot keep personal information for longer than is required for the purpose for which the information may be used.	Personal information should be deleted on the earlier of: <ul style="list-style-type: none"> when the relevant individual ceases to be a member of the Whānau Connect Group; when the patient whose family has joined the Whānau Connect Group turns 20 years old; and the date of when a discharge letter (if any) is sent to a family member.
Family support services registration form	Registration form to receive support from the Foundation via a Family Support Coordinator.	<i>Personal information:</i> name, contact details, date of birth, gender, ethnicity, spoken language, preference for interpreter, relationship details for siblings. <i>Health information:</i> diagnosis, diagnosis date.	<i>Privacy Act, IPP 9</i> - Foundation cannot keep personal information for longer than is required for the purpose for which the information may be used. <i>Regulations</i> - Foundation must keep the Health Information for the Minimum Retention Period. <i>Code, Rule 9</i> - Foundation cannot keep the health information longer than is required for the purpose for which the information may be used.	Personal information and incidental health information should be deleted on the earlier of: <ul style="list-style-type: none"> when the provision of support services ceases; when the patient whose family has registered for the services turns 20 years old; and the date of when a discharge letter (if any) is sent to a family member. Health information subject to the Regulations must be kept for the Minimum Retention Period. On the expiry of the Minimum Retention Period, health information subject to the Regulations must be deleted on the earlier of: <ul style="list-style-type: none"> when the individual turns 20 years old; and where a discharge letter has been issued, on the date of the discharge of the letter.
Membership registration form	Registration to become a member of our organization to be able to vote in the AGM.	<i>Personal information:</i> name, contact details, date of birth, gender, ethnicity, spoken language, preference for interpreter.	<i>Privacy Act, IPP 9</i> – Foundation cannot keep personal information for longer than is required for the purpose for which the information may be used.	Personal information should be deleted when the individual ceases to be a member of the Foundation.
Volunteer registration form	Registration to become a volunteer for our organisations (eg our Whānau Connect Group).	<i>Personal information:</i> name, contact details, date of birth, gender, ethnicity, emergency contact, commencement date, volunteer role.	<i>Privacy Act, IPP 9</i> - Foundation cannot keep personal information for longer than is required for the purpose for which the information may be used.	Personal information should be deleted when the individual ceases to be a volunteer for the Foundation.
File notes from family support sessions	Chronological documentation of all interactions with families,	<i>Personal and health information:</i> information provided by parents of supported children which could	<i>Privacy Act, IPP 9</i> - Foundation cannot keep personal information for longer than is required for the purpose for which the information may be used.	Personal information and incidental health information should be deleted on the earlier of: <ul style="list-style-type: none"> when the provision of support services ceases;

	<p>phone calls, emails, messages and records of face to face visits.</p>	<p>include information about the child's treatment and health status. Reports can also include information about parents' mental health.</p>	<p><i>Regulations</i> - Foundation must keep the Health Information for the Minimum Retention Period.</p> <p><i>Code, Rule 9</i> - Foundation cannot keep the health information longer than is required for the purpose for which the information may be used.</p>	<ul style="list-style-type: none"> • when the patient whose family has registered for the services turns 20 years old; and • the date of when a discharge letter (if any) is sent to a family member. <p>Health information subject to the Regulations must be kept for a minimum of 10 years from the most recent date on which Foundation provided services to the individual.</p> <p>On the expiry of the Minimum Retention Period health information subject to the Regulations must be deleted on the earlier of:</p> <ul style="list-style-type: none"> • when the individual turns 20 years old; and • where a discharge letter has been issued, on the date of the discharge of the letter.
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