CONFIDENTIALITY POLICY

## Purpose

The purpose of this Policy is to define the Telethon Kids Institute (**Telethon Kids**) requirements in relation to the disclosure and treatment of Confidential Information (which may include personal, sensitive or identifiable information about individuals or Telethon Kids), which comes into the possession of an Eligible Person during any discussions, collaborations or through Telethon Kids' work.

Telethon Kids requires its employees, volunteers, honouraries, students, consumer representatives, committee members and contractors to respect and maintain the confidentiality of individuals and Telethon Kids' work.

## Scope

This policy applies to all Eligible Persons.

## Definitions

General definitions can be found on the Policy Library website [here](https://telethonkids.sharepoint.com/newIntranet/about-us/PoliciesAndProcedures/Templates/Glossary%20of%20Terms.xls). Other capitalized terms used in this document have the meanings given below.

| Term | Meaning |
| --- | --- |
| Confidential Information | Any information that concerns the research, business, operations, finances, plans of Telethon Kids or Telethon Kids' research partners and/or stakeholders which is by its nature confidential, the recipient knows or ought to know is confidential or is designated by Telethon Kids or Telethon Kids' research partners and/or stakeholders as confidential, but does not include information that:  (a) is or becomes public knowledge other than through the fault of the recipient or any of its officers, employees or agents;  (b) is in the possession of the recipient without restriction in relation to disclosure on or before the date on which it is disclosed to or acquired by the recipient; or  (c) has been independently developed or acquired by the recipient. |
| Eligible Persons | In the case of Telethon Kids, its employees, students, volunteers, honouraries and committee members.  In the case of persons external to Telethon Kids, the person, their employees, students, volunteers, honouraries, external researchers, consumer representative and committee members. |
| Personal Information | Any information or an opinion about an identified individual, or an individual who is reasonably identifiable:   * whether the information or opinion is true or not; and * whether the information or opinion is recorded in a material form or not.   Some Personal Information may include Sensitive Information.  Sensitive Information has the meaning as set out in the Privacy Act 1988 (Cth) and includes health information. |

## Principles

1. Confidential information
   1. Eligible Persons may become aware of Confidential Information during their work with Telethon Kids.
   2. Maintaining the confidentiality of Confidential Information is important given the nature of the information and the work undertaken by Telethon Kids.
   3. Confidential Information may include:
      1. information that is labelled as "Personal Information" or "Confidential" or other similar designations
      2. research results, methods, processes or protocols
      3. trade secrets
      4. designs, diagrams or images
      5. inventions and discoveries
      6. business practices and concepts
      7. computer programming, software and applications
      8. financial and funding information, marketing, technical, scientific, or educational information or strategies
      9. business plans and strategy plans
      10. Personal Information whether from named vital statistics, hospital records, or completed questionnaires.
   4. Disclosure of Confidential Information, even if that disclosure is accidental, may mean that Telethon Kids cannot protect the privacy of any Personal Information or enforce its intellectual property rights in relation to any research or research outcomes. This may mean that Telethon Kids is not given credit for its research or is not able to commercialise the research and generate revenue to continue its work. It may also mean that Telethon Kids is in breach of its contractual obligations to its research partners.
   5. Eligible Persons must not discuss Confidential Information outside Telethon Kids unless they have specific approval from the research project Chief investigator or their line manager. This will include discussing any information such as research results, methods or protocols with scientific peers or at conferences.
   6. Eligible Persons’ obligations in relation to Confidential Information continue even if an Eligible Person’s research has finished or the Eligible Person has left Telethon Kids.
   7. Unapproved disclosure of Confidential Information by an Eligible Person may entitle Telethon Kids to terminate the Eligible Person’s employment or engagement, seek damages from the Eligible Person or seek a court order to stop the use or further disclosure of the Confidential Information.
2. Confidentiality REQUIREMENTS
   1. Eligible persons must not:
      1. Disclose Confidential Information to another person (outside Telethon Kids), or any other organisation or company;
      2. Disclose any Confidential Information for any purpose that is not expressly approved by Telethon Kids during and after your / their engagement;
      3. Remove Confidential Information from the premises of Telethon Kids without express approval by Telethon Kids;
      4. Take, copy, memorise or reproduce, disassemble or reverse engineer any Confidential Information for whatever reason either for themselves or any third party,

except as reasonably required in the ordinary and proper course of employment or engagement with Telethon Kids, where required by law or with the express approval of Telethon Kids.

* 1. Anyone who becomes aware of any unauthorized disclosure of Confidential Information, should immediately contact the research project Chief Investigator or your line manager so that any impacts can be minimized and mitigated. If the unauthorised disclosure involves Personal Information the Data Breach Response Procedure should be followed.
  2. Any serious or material unauthorised disclosure must also be immediately reported to Telethon Kids' Legal Counsel.
  3. If you are required to disclose any Confidential Information by any court, regulatory body or any law, to the extent possible and where permitted by law, you must:
     1. notify Telethon Kids' Legal Counsel in advance of any such disclosure, and follow the directions of Telethon Kids to minimise disclosure; and
     2. if disclosure cannot be avoided, only disclose Confidential Information to the extent necessary, and you must use reasonable efforts to ensure that the Confidential Information when disclosed is kept confidential by any recipient.

1. Declarations of Confidentiality
   1. Eligible Persons are required to:

##### sign the Telethon Kids Declaration of Confidentiality in the form attached in Schedule A; and

##### if requested by Telethon Kids, sign the Request for Access to Telethon Kids Institute Computing Facilities.

1. Confidentiality Agreements
   1. All Eligible Persons disclosing Confidential Information to anyone external to Telethon Kids (for example employees of other organisations, business partners, business associates, research academics) will be required to ensure a Confidentiality Agreement is signed with the external party prior to any disclosure of Confidential Information. Telethon Kids' Legal and Contracts team should be contacted at [contracts@telethonkids.org.au](mailto:contracts@telethonkids.org.au) to obtain confirmation that a Confidentiality Agreement is in place or to request that one is prepared and put in place.
   2. The Confidentiality Agreement must be signed by an authorised representative of Telethon Kids regarding the use and disclosure of Confidential Information.
2. Data security
   1. Eligible Persons must take such steps as are reasonable in the circumstances to protect the Confidential Information they hold from misuse or loss and from unauthorised access or disclosure including ensuring electronic data is stored securely and password protected.
   2. Eligible Persons must also take steps as are reasonable in the circumstances to destroy the Confidential Information once it is no longer required for any purpose for which the information may be used, disclosed or retained under any law.
3. Changes to Telethon KIDS’ Confidentiality Policy
   1. Telethon Kids may change or update parts of this Confidentiality Policy in order to maintain compliance with applicable laws and regulations or following an update to internal practices. We will do this by updating this Confidentiality Policy which is available at [www.telethonkids.org.au](http://www.telethonkids.org.au).
   2. You may not be directly notified of such a change so please ensure that you regularly check this Confidentiality Policy so you are fully aware of any changes or updates.

Schedules

Schedule A - Confidentiality Undertaking

Related Documents

Data Breach Response Procedure

Information Security Classification and Handling Procedure.

Privacy Policy

Information and Data Retention and Disposal Policy

Research Data Confidentiality Policy

Whistleblower Policy

Further Information

Further information about this policy can be obtained by contacting Telethon Kids' Legal Counsel.

Version History

| Version | Approved By | Approval Date | Review Date | Sections Modified | Owner | Implementation Officer | Author |
| --- | --- | --- | --- | --- | --- | --- | --- |
| 1.0 |  | 08/08/2007 |  |  |  |  |  |
| 2.0 | Institute Management Team | 16/06/2015 | 16/06/2018 | Updated titles | Head Research Development | Manager Research Development | Manager Research Development |
| 3.0 | Institute Leadership Team | 03/03/2022 | 03/03/2025 | Full review | Director Governance and Risk | Legal Counsel | Legal Counsel |



CONFIDENTIALITY UNDERTAKING

To Telethon Kids Institute (Telethon Kids):

I, **[Full Name]**, of [address]

being an officer, employee, committee member, student, visitor or volunteer of Telethon Kids, acknowledge that I may receive information from Telethon Kids or its partners, research collaborators or other third parties during my engagement with Telethon Kids that is sensitive and/or confidential (**Confidential Information**) and that is strictly confidential. Confidential Information includes the existence of any research projects that I may undertake during my engagement with Telethon Kids, the identity of any research partners or participants in any research project, and information concerning Telethon Kids and any research partners or participants in any research project, whether disclosed by Telethon Kids or any other person, and whether disclosed before or after the date of this document, but it does not include information that is or becomes part of the public domain through no fault or breach of mine.

I undertake in favour of Telethon Kids to:

* hold in strict confidence all Confidential Information;
* keep the Confidential Information secret and preserve and protect the confidential nature and secrecy of it;
* not, directly or indirectly, communicate or disclose (whether in writing or in any other manner) the Confidential Information to any person or allow or assist any person to observe or have access to any Confidential Information;
* not use or reproduce the Confidential Information except in the proper performance of any duties relating to my tasks as an officer or employee of Telethon Kids;
* not discuss any Confidential Information with any person; and
* comply with Telethon Kids' Confidentiality Policy,

except as required by law or in good faith as directed by Telethon Kids or my Lead Manager (being the person nominated by Telethon Kids). I also undertake not to make any use of the information or any part of it except as required by law or in good faith as directed by Telethon Kids or my Lead Manager.

I further acknowledge that the Confidential Information also includes:

* the existence of or contents of this document or any other agreements entered into or to be entered into in connection with any research project;
* the contents of any discussions between Telethon Kids, research partners or participants in any research project in connection with any research projects;
* the research results or outcomes of any research project undertaken by Telethon Kids or its research partners; and
* personal information, trade secrets, inventions, discoveries, business practices, financial, marketing, technical, scientific or educational information, processes, equipment and techniques used by Telethon Kids.

This document is governed by the laws of the State of Western Australia.

Executed by ……………………………………….

Signature: ………………………………………….

Title: ………………………………………………..

Date: ……………………………………………….

Witnessed by ………………………………………

Signature: ………………………………………….

Title: ………………………………………………..

Date: ……………………………………………….