
Data Access Protocol

Version control

Version	Date approved	Approved by	Reason for change
1.0	28 February 2011	Data Access Committee	Final changes to draft agreed by committee. Document is 'finalised' however remains 'live' and committee may review/amend at any time.
4.0	27 March 2013	Reviewed by Data Access Committee	Further changes to draft reviewed by committee. Document remains 'live' and committee may review/amend at any time.
8.0	21 May 2013	Data Access Committee	Further changes by committee. Document remains 'live' and committee may review/amend at any time.

Growing Up in New Zealand

Data Access Protocol

Background

- 1 The University of Auckland is leading a longitudinal study of children and families called *Growing Up in New Zealand: Longitudinal Study of New Zealand Children and Families*. The Study will collect a significant volume of data on a sample of New Zealand children and their families which will grow over time as progressive waves of data are captured.
- 2 The Data Set generated by the Study will constitute a valuable national resource that will have significant utility for research scholars and social policy analysts who wish to investigate questions concerning child development and family functioning. In providing for access to the data, it is of paramount importance that the privacy of Study Participants and their families is protected.

Purpose

- 3 This protocol describes the process for gaining access to Data collected in the Study for the purposes of undertaking analyses of the Data. The protocol makes provision for Data collected in the Study to be applied to questions of scientific and policy interest, while safeguarding the privacy of Study Participants and their families.
- 4 In particular, the protocol sets out:
 - The principles that will govern the Data access process
 - The process by which researchers may apply for Data access
 - Provisions to safeguard the privacy of Study Participants and their families and ensure the long-run sustainability of the Study
 - The role and function of a Data Access Committee that will oversee the operation of the protocol; and
 - Provisions concerning authorship and publication of papers produced under the protocol
- 5 The longitudinal nature of the Study presents special challenges for the protection of the privacy of individual Study Participants which will need to be carefully managed by the Data Access Committee. As the Study will collect Data across all ethnic groups, the Committee will also need to ensure that the Data are used in appropriate ways. In particular, the Study has obligations to Māori regarding Data access which are set out in the

Kaitiaki/Guardianship principle (clause 9 and clause 10).

- 6 All access to Study Participants' Data by researchers outside the Research Team will be subject to the conditions set out in this protocol and subject to review by the Data Access Committee.

Definitions

- 7 In this document, unless the context otherwise requires:

Approved Researchers means researchers who have applied for—and have been granted—use of External Working Data Sets by the Data Access Committee subject to a Data Access Agreement. This may include government users. The Growing Up in New Zealand Research Team (Research Team) is automatically accorded this status.

Anonymised means having had all names, addresses, and any other Identifying Information removed.

Data means the aggregated information collected about Study Participants in the Growing Up in New Zealand study. For the purposes of this protocol, Data excludes biological samples.

Data Access Agreement means an agreement between an Approved Researcher and Auckland UniServices Limited, approved by the Data Access Committee and setting the terms and conditions of access to an External Working Data Set.

Data Access Committee means the committee described in the Data Access Committee Terms of Reference appointed to consider applications from researchers who wish to use the Internal and External Working Data Sets.

External Working Data Set means an anonymised Data Set drawn from the Internal Working Data Set. All Approved Researchers outside the Growing Up in New Zealand Research Team will work with data of this kind. External Working Data Sets will not contain any Identifying Information.

External Working Data Set Data Access Coordinator means the Data Access Coordinator appointed by Auckland UniServices Limited to manage the Data access process for the External Working Data Set.

External Working Data Set Release Organisation means the organisation which will manage the release of the External Working Data Set to Approved Researchers.

Identifying Information means personal information as defined by the Privacy Act 1993 and includes Data collected about a person from which the identity of that person or a member of his or her family could reasonably be ascertained. This is likely to become greater in volume as Data are collected at several points over time.

Internal Working Data Set means the primary Data Set after the necessary restructuring and cleaning of the raw data collected from Study Participants. This will be a repository for information that accumulates with each wave, together with derived variables and linked data. It will have Identifying Information removed (but will not be anonymised to the same extent as the External Working Data Set) and will only be linkable to data that may lead to identification over time via an identity number. This Data Set will be subject to appropriate security measures. Only the Growing Up in New Zealand team can apply to use the Internal Working Data Set.

Internal Working Data Set Data Access Coordinator means the Data Access Coordinator appointed by Auckland UniServices Limited to manage the Data access process for the Internal Working Data Set.

Research Director means the scientific director of the study. The Research Director, in association with the Research Team, is the guardian of the Data collected in the study.

Research Team means the Research Director, and any other researchers and biostatisticians who are engaged on the Study.

Study means the longitudinal study of children and families known as Growing Up in New Zealand; Research with Children and their Families.

Study Consortium means the wider group of individuals who have contracted, through Auckland UniServices Limited, to contribute to the scientific direction of the Study.

Study Participant means an individual who is a participant in the Study. This includes both children enrolled in the Study sample whose parents or legal guardians have consented to their participation in the Study and parents or other persons linked to the children who have consented to their own participation in the Study.

Principles

Ownership principle

- 8 Information contributed to the Study by an individual Study Participant will remain the property of that Study Participant (or, in the case of minors of the parents of legal guardian of the Study Participant).

Kaitiaki/guardianship principle

- 9 The Research Team will act as guardians of the Data collected from Study Participants, ensure that the Data are held and used in accordance with the principles and provisions of this protocol and ensure that the Data are analysed, interpreted, reported and published in culturally appropriate ways.
- 10 Data contributed to the study by Māori Study Participants, and other contributions to the Study that draw on Māori knowledge and expertise are taonga whose value are to be preserved and protected and used productively and for the benefit of Māori. Data contributed to the study, and other contributions to the study, by members of other cultural groups are to be similarly valued and protected.

Privacy principle

- 11 The Data collected from and about individual Study Participants and their families is for the purposes of approved research only. The privacy of individual Study Participants and their families must be preserved at all times.

Protection of value principle

- 12 Any use of Data from the Study and any published output from the Study must protect the value inherent in the accumulated Data holdings, relationships with Study Participants and community engagement, and must not jeopardise the future integrity of the Study (especially with respect to retention of Study Participants).

Public good principle

- 13 In recognition of the value of the Study for investigating questions of public policy and the significant investment of public funds involved, the Data collected in the Study are considered to be a public good. Accordingly, access to the External Working Data Sets will be provided to Approved Researchers, subject to the principles and provisions of this protocol.

Guardianship of the data and guardianship responsibilities

- 14 In accordance with the Kaitiaki/Guardianship Principle, the Research Team has a number of responsibilities in regard to maintenance of the Internal Working Data Set and use of and facilitation of access to the External Working Data Sets, while the Data Access Committee and the Research Team have responsibilities for protection of individual Study Participants in accordance with the Privacy Principle.

- 15 The Data Access Committee is responsible for ensuring that Data is used in accordance with the Kaitiaki/Guardianship principle.
- 16 The Research Team will maintain the Internal Working Data Set, update it in a timely fashion on completion of each Data collection wave and ensure that it is appropriately documented to facilitate the understanding of those who obtain permission to access the External Working Data Sets.
- 17 The External Working Data Set Release Organisation will manage the release of the External Working Data Set to Approved Researchers.
- 18 The Research Team will ensure the integrity of the Internal Working Data Set by applying best practice quality control methods and will add value to it by developing derived variables.
- 19 The Research Team will work with the External Working Data Set Release Organisation to implement procedures to facilitate access to External Working Data Sets for Approved Researchers in accord with this protocol and as prescribed by the Data Access Committee.
- 20 The Research Team will work with the External Working Data Set Release Organisation to implement best practice security procedures to protect the privacy of individual Study Participants and their families and to protect against unauthorised access to the Data.

Privacy of study participants

- 21 Identifying Information and identity registers will be stored separately from the Internal Working Data Set and all Internal and External Working Data Sets must be password-protected.
- 22 Approved Researchers must adhere to best practice regarding security of Internal and External Working Data Sets and procedures to ensure the privacy of Study Participants and their families. Approved Researchers must take all reasonable steps to prevent unauthorised, either deliberate or unintentional, access to Internal and External Working Data Sets.
- 23 In any publication based on an Internal and External Working Data Set, Approved Researchers must take all care to prevent the identification of any Study Participant or any member of a Study Participant's family, or in any other way compromise the privacy of any Study Participant or any member of a Study Participant's family.

Applications for access to external working Data Sets

- 24 Researchers who wish to gain access to an External Working Data Set drawn from the Internal Working Data Set must apply to the Data Access Committee in the manner described below. Applications must:
 - 24.1 Apply via the External Working Data Set Data Access Process as coordinated by the External Working Data Set Data Access Coordinator and the External Working Data Set Release Organisation.
 - 24.2 Include a proposal outlining the research they intend to carry out using the External Working Data Set (the Research Plan).
 - 24.3 Include a statement setting out where and when it is proposed that the results of the research will be published (the Dissemination Plan).
 - 24.4 Show evidence of acquaintance with the context of the External Working Data Set.
 - 24.5 Provide an account of how the applicant will act to ensure compliance with the principles of Ownership, Kaitiaki/Guardianship, Privacy, and Protection of Value (clauses 8-12), including descriptions of safeguards to prevent the identification of Study Participants through publication of results of sub-groups of the sample.
 - 24.6 Specify details of the applicant's organisation or institution, where applicable (including name and location), and a statement of support from the Chief Executive, or equivalent, of that organisation or institution or his or her delegated nominee.
 - 24.7 Demonstrate that the applicant's organisation or institution approves of their request.
- 25 Applicants are expected to seek ethics approval for their application if required but the Data Access Committee will not request information on this matter.
- 26 A step by step guide for External Data Set Data Access applications including details of timelines, costs and committee response times will be made available to applicants by the External Working Data Set Data Access Coordinator.
- 27 The Research Team will provide information on the available data set to assist applicants in preparing proposals.
- 28 Decisions made by the Data Access Committee will be reached by consensus of all members present and will be final.

Applications for access to internal working Data Sets

- 29 Researchers who wish to gain access to an Internal Working Data Set must apply to the Data Access Committee in the manner described below. Applications must:
- 29.1 Apply via the Internal Working Data Set Data Access Process as coordinated by the Internal Working Data Set Data Access Coordinator and the Research Team.
 - 29.2 Include a proposal outlining the research they intend to carry out using the Internal Working Data Set (the Research Plan).
 - 29.3 Include a statement setting out where and when it is proposed that the results of the research will be published (the Dissemination Plan).
 - 29.4 Show evidence of acquaintance with the context of the Internal Working Data Set.
 - 29.5 Provide an account of how the applicant will act to ensure compliance with the principles of Ownership, Kaitiaki/Guardianship, Privacy, and Protection of Value (clauses 8-12), including descriptions of safeguards to prevent the identification of Study Participants through publication of results of sub-groups of the sample.
 - 29.6 Specify details to show they are part of the Research Team.
 - 29.7 Demonstrate that the Research Director approves of their request.
- 30 Applicants are expected to seek ethics approval for their application if required but the Data Access Committee will not request information on this matter.
- 31 Decisions made by the Data Access Committee will be reached by consensus of all members present and will be final.

Research plans

- 32 Each Research Plan must set out the objectives of the proposed research and the proposed analyses to meet these objectives.
- 33 Research Plans involving ethnic-specific presentations will need to be highlighted.
- 34 The Data may not be used for any other purpose other than that outlined in a Research Plan approved by the Data Access Committee.
- 35 Any change to the proposed analyses in a Research Plan must be provided to the Data Access Committee in writing. Changed plans, including the justification for the changes, will be treated as new

applications under this protocol and therefore must be approved by the Data Access Committee before any work is undertaken. Minor changes that do not materially alter the research questions, planned analytical approach or outputs may be approved by the chair of the Committee (via a request to the appropriate Data Access Coordinator) without being considered by the full Committee.

Dissemination plans

- 36 Dissemination Plans must list and describe the intended forms of dissemination of any findings or outputs from the analyses of Internal and External Working Data Sets, including intended release dates.
- 37 Any changes to the Dissemination Plan must be notified in writing to the Data Access Committee and approved by the Committee. Minor changes that do not materially alter the Dissemination Plan may be submitted to the Data Access Chair (via the appropriate Data Access Co-ordinator) in writing for consideration of approval by the chair of the Committee without being considered by the full Committee.

Provision of external working Data Sets

- 38 The External Working Data Set Release Organisation will provide, within a reasonable timeframe, External Working Data Sets as required to meet approved Research Plans.
- 39 The External Working Data Set will incorporate all variables requested for approved Research Plans, including derived and linked Data where available, together with documentation to facilitate Approved Researchers' understanding of the External Working Data Set.
- 40 The External Working Data Set will be made available to Approved Researchers in a format that is widely accessible via commonly used statistical packages and in a manner suitable for ensuring the security and integrity of the Data Set and its appropriate use.
- 41 Approved Researchers must then destroy the External Working Data Sets on or before the termination date of the Data Access Agreement once analyses are complete and must provide a signed letter to the External Working Data Set Data Access Coordinator confirming that they have done so.

Timeframe for availability of external working Data Sets

- 42 After each Data collection wave or creation of a new Data set (including Data linkage or creation of a longitudinal Data set), the Research Team will have sole rights of access to the information for a period of either eighteen months following cleaning and editing, or until the first set of major research outputs are accepted for publication, whichever is the shorter, unless otherwise agreed. External Working Data Sets will be available to other applicants after expiry of this period.
- 43 The External Working Data Set will be made available for a time-limited period. The term of the access period will be specified in the Data Access Agreement.

The Data Access Committee

- 44 The purpose of the Data Access Committee is to facilitate the provision of access to Data collected in the Study by Approved Researchers under the terms and conditions of this document.
- 45 The Data Access Committee will operate under the Terms of Reference.
- 46 The Data Access Committee will follow the agreed process to ensure any manuscripts or other outputs ensure that the privacy of Study Participants is protected.
- 47 The Data Access Committee may from time to time undertake an audit of research projects to ensure compliance with the terms of use for data access.

Data access agreement

- 48 Approved Researchers will enter into a Data Access Agreement with Auckland UniServices Limited requiring them to adhere to all of the principles and provision of this protocol as well as the requirements of the Data Access Agreement.
- 49 The Data Access Agreement will include stipulations regarding protection against the identification of Study Participants, destruction of External Working Data Sets once analyses are completed, a prohibition on making the Data available to third parties, a prohibition on using the Data to attempt to identify Study Participants and proper acknowledgment of the Data source.

- 50 In case of any breach of the Data Access Agreement, the Data Access Committee may terminate an Approved Researcher's right of access to an External Working Data Set and require immediate destruction of an External Working Data Set.
- 51 Any breach of the Data Access Agreement may also be raised with the signatory of the statement of support required under clause 24.7, which is the Chief Executive, or equivalent, of the Approved Researcher's organisation or institution, or his or her delegated nominee.
- 52 Approved Researchers must comply at all times with the security requirements stipulated by the Data Access Committee in the Data Access Agreement. In particular, Approved Researchers must adhere to best practice regarding security of External Working Data Sets and procedures to ensure the privacy of Study Participants. Approved Researchers must take all reasonable steps to prevent unauthorised, either deliberate or unintentional, access to External Working Data Sets.
- 53 Members of the *Growing Up in New Zealand* research team are required to adhere to all of the principles and provision of this protocol as well as the requirements of the Data Access Agreement (Internal).

Approval of outputs

- 54 All manuscripts or other outputs intended for a public domain must be approved by the Data Access Committee before they are submitted for publication to ensure that the publication is consistent with this protocol, and in particular that it neither breaches the Privacy principle nor jeopardises the long-run value, integrity and sustainability of the Study.
- 55 The Data Access Committee will respond to requests for approval for manuscripts or other outputs via the Internal or External Data Set Data Access Coordinator within 14 working days.
- 56 Any manuscripts or other outputs that include analyses involving ethnic-specific presentations must be highlighted.



Growing Up in New Zealand

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