
Growing Up in New Zealand
Data Access Protocol

Version Control			
Version	Date approved	Approved by	Reason for change
V1.0	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.
V4.0	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.
V5.0	4 April 2013		Incorporating further feedback from Ross
V6.0	18 April 2013		Adding formatting, updating definitions
V7.0	30 April 2013		Internal working dataset definition
V8.0	21 May 2013	Data Access Committee	Further changes by committee. Document remains 'live' and committee may review/amend at any time.
V9.3	10 June 2015	Data Access Committee	Definition update, formatting changes (consistency with ToR). Document remains 'live' and committee may review/amend at any time.
V10.0	21 November 2016	Data Access Committee	Modified wording to reflect new procedures for data access through the e-Research platform
V11.0	16 February 2017		<ul style="list-style-type: none"> -Form numbers have been added in sections 25, 26, and 28 -Section 39 has been modified to reflect new procedures for data access through the e-Research platform -Section 61 has been added that provides information on how to amend existing internal and external DAC applications using forms 1004 (internal) and 1005 and 1003 (external). -A flow diagram for the processes involving DAC applications has been added in Appendix 1.

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 dataset 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 for all data
 - The process by which researchers may apply for data access to Internal and External Working Datasets
 - 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
 - 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 *Growing Up in New Zealand* 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:
- i. *Accredited Researcher* means researchers external to the *Growing Up in New Zealand* research team who have satisfied the criteria and are afforded honorary status as a member of the *Growing Up in New Zealand* research team. Applications to become an Accredited Researcher require endorsement from the Research Director and approval by the Data Access Committee. Accredited Researchers will assume the same level of responsibility for guardianship of the data as is required of the research team.
 - ii. *Approved Researcher* means researchers who have satisfied the criteria to access *Growing Up in New Zealand* datasets, as agreed by the Data Access Committee. Approved researchers include members of the *Growing Up in New Zealand* research team and Accredited Researchers, who are able to apply to access both the Internal and External Working Datasets, and any other researchers who apply and have been approved to access the External Working Datasets.
 - iii. *Anonymised* means having had all nominal information, locality information and any other identifying information removed.
 - iv. *Data* means the aggregated longitudinal information collected about study participants in the *Growing Up in New Zealand* study. For the purposes of this protocol, data excludes biological samples.
 - v. *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 datasets.
 - vi. *Data Access Committee* means the committee described in the Data Access Committee Terms of Reference appointed to consider applications from researchers who wish to become Accredited Researchers, and applications to use the Internal and External Working Datasets.
 - vii. *Data Access Coordinator* means the Data Access Coordinator appointed by Auckland UniServices Limited to manage the data access process.
 - viii. *External Working Dataset* means an anonymised dataset drawn from the Internal Working Dataset. All Approved Researchers working independently of the *Growing Up in New Zealand* research team will work with data of this kind. External Working Datasets will have any identifying information removed to protect participant anonymity.
 - ix. *External Working Dataset Release Organisation* means the organisation which will manage the release of the External Working Dataset to Approved Researchers.
 - x. *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 will likely become greater in volume as data are collected at several points over time.
 - xi. *Internal Working Dataset* means the primary dataset after the initial restructuring and cleaning of the raw data collected from and/or about study participants. This will be a repository for information that accumulates with each wave, together with derived variables and linked data. It will have nominal identifiers removed (but will not be fully anonymised). This dataset will be subject to appropriate security measures. Only members of the *Growing Up in New Zealand* team and Accredited Researchers can apply to use the Internal Working Data Set.
 - xii. *Research Director* means the Principal Investigator and Scientific Director of the study. The Research Director, in association with the research team, is the guardian of the data collected in the study.

- xiii. *Research Team* means the Research Director, and all researchers who are currently bona fide members of the *Growing Up in New Zealand* team.
- xiv. *Study* means the longitudinal study of children and families known as *Growing Up in New Zealand; A longitudinal study of New Zealand Children and their Families*.
- xv. *Study participant* means an individual who is a participant in the study. This includes the 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 or legal guardian of the Study Participant).

Kaitiaki/Guardianship Principle

- 9. The Research Team will act as guardians of the Data collected from Study Participants, and ensure that the Data are held and used in accordance with the principles and provisions of this protocol to comply with participant consent and protection of participant anonymity. Guardianship requires 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 External Working Datasets will be made available to facilitate access by 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 Dataset and use of and facilitation of access to the External Working Datasets, 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 Dataset and update it in a timely fashion after completion of each data collection wave.
17. The research team will ensure the integrity of the Internal Working Dataset by applying best practice quality control methods and will add value to it by developing derived variables.
18. The research team will anonymise the Internal Working Dataset and provide the External Working dataset with appropriate documentation to facilitate its use by Approved Researchers.
19. An External Working Dataset Release Organisation will be agreed to manage the release of the External Working Dataset to Approved Researchers.
20. The research team will work with the External Working Dataset Release Organisation to implement procedures to facilitate access to External Working Datasets for Approved Researchers in accord with this protocol and as prescribed by the Data Access Committee.
21. The research team will work with the External Working Dataset 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

22. Identifying Information and identity registers will be stored separately from the Internal Working Dataset and all Internal and External Working Datasets must be password-protected.
23. Approved Researchers must adhere to best practice regarding security of Internal and External Working Datasets 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 Datasets.
24. In any publication based on an Internal or External Working Dataset, 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 to become an Accredited Researcher

25. To become an Accredited Researcher, collaboration with the Research Director needs to be agreed to in advance. Applications can be made by completing form 1001. The flow diagram in

Appendix 1 describes this process. The Accredited Researcher Guidelines are provided in the first page of the application form 1001. This form will be submitted to the Data Access Coordinator and will be reviewed by the internal *GUINZ* review team before being submitted to the Data Access Committee for approval to become an honorary member of the *Growing Up in New Zealand* research team. This process will allow use of internal datasets by external users.

Applications for Access to Internal Working Datasets

26. Access to Internal Working Datasets is available to the research team and to those afforded Accredited Researcher status. Researchers who wish to gain access to an Internal Working Dataset must apply to the Data Access Committee in the manner described below using the application form 1002. Applicants must:
- 26.1. Apply via the Internal Working Dataset Data Access Process as coordinated by the Data Access Coordinator and the Research Director.
 - 26.2. Describe the research they intend to carry out using the Internal Working Dataset (the Research Plan).
 - 26.3. Include a statement setting out where and when it is proposed that the results of the research will be published (the Dissemination Plan).
 - 26.4. Demonstrate understanding of the nature and context of the study and the Internal Working Dataset.
 - 26.5. 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.
 - 26.6. Show how they intend to work collaboratively with the research team.
 - 26.7. Provide evidence that the Research Director approves of their request and name the member of the research team who will act as guardian of the data in accordance with the Guardianship Principle.
27. Applicants are expected to seek ethics approval for their application if required but the Data Access Committee will not request information on this matter.

The processes for the submission and review of internal DAC applications are described in the flow diagram in Appendix 1.

Applications for Access to External Working Datasets

28. Researchers who wish to gain access to an External Working Dataset must apply to the Data Access Committee in the manner described below. Applications can be made using application form 1003. Applicants must:
- 28.1. Apply via the External Working Dataset Data Access Process as coordinated by the Data Access Coordinator and the External Working Dataset Release Organisation.

- 28.2. Include a proposal outlining the research they intend to carry out using the External Working Dataset (the Research Plan) and their role in the research.
 - 28.3. Include a statement setting out where and when it is proposed that the results of the research will be published (the Dissemination Plan).
 - 28.4. Show evidence of acquaintance with the context of, and capacity to utilise, the External Working Dataset.
 - 28.5. 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.
 - 28.6. 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.
 - 28.7. Demonstrate that the applicant's organisation or institution approves of their request.
29. Applicants are expected to seek ethics approval for their application if required but the Data Access Committee will not request information on this matter.
30. The research team will provide appropriate documentation about the External Working Dataset set to facilitate applicants' preparation of external data access proposals.

The processes to use the external datasets are described in the flow diagram in Appendix 1.

Research Plans

31. Each research plan must set out the objectives of the proposed research and the proposed broad plan to meet these objectives.
32. Research plans requiring ethnic-specific analyses should be highlighted.
33. The data may only be used for the purpose outlined in the research plan approved by the Data Access Committee.
34. Any change to the purpose and broad plan 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 Data Access Coordinator) without being considered by the full Committee.

Dissemination Plans

35. Dissemination plans must list and describe the intended forms of dissemination of any findings or outputs from the analyses of Internal and External Working Datasets, including planned release dates.
36. 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 Chair of the Data Access Committee (via the Data Access Co-ordinator) in writing for consideration without being considered by the full Committee.

Provision of External Working Datasets

37. The External Working Dataset Release Organisation will provide, within a reasonable timeframe, External Working Datasets to Approved Researchers.
38. The External Working Dataset will be provided to researchers via the University E-research platform and will be provided, together with documentation, to facilitate Approved Researchers' use of the External Working Dataset. A User Guide will be provided to researchers on how to access the datasets via the E-research platform, once the application is approved.
39. The External Working Dataset 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 dataset and its appropriate use.
40. The access of external datasets by the researchers will be terminated on the end date of the project.
41. Application to extend the date for the access of External Working Datasets can be made by completing an amendment form 1005.

Timeframe for Availability of External Working Datasets

42. After each data collection wave or creation of a new dataset (including data linkage or creation of a longitudinal dataset), the research team will have sole rights of access to the information for a period of six months following cleaning and editing. External Working Datasets will be available to other applicants as soon as is practicable after expiry of this period.
43. The External Working Dataset will be made available for a time-limited period to Approved Researchers. The term of the access period will be specified in each 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. In particular the Data Access Committee will ensure that access complies with the principles set out with regard to guardianship of the data and privacy of study participants.
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 also ensure that the guardianship of the data and 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 Datasets 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 Dataset and require immediate destruction of an External Working Dataset.
51. Any breach of the Data Access Agreement may also be raised with the signatory of the statement of support required under the Data Access Agreement, 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 Datasets 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 Datasets.
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 of research using *Growing Up in New Zealand* datasets 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. All manuscripts or other outputs that include ethnic-specific analyses and findings must comply with the privacy and guardianship principles, and protect the ongoing relationship with the cohort participants.

56. The Data Access Committee will respond to requests for approval for manuscripts or other outputs via the Data Access Coordinator within 14 working days.

Accredited Researcher Eligibility Criteria

The purpose of this section is to outline the eligibility criteria and the process to become an Accredited Researcher.

57. Eligibility criteria to be an Accredited Researcher

- 57.1. Applicants must be from an approved Ministry or research institution and have the skills and appropriate knowledge to make use of the data.
- 57.2. Applicants must justify why they are appropriate to conduct the proposed analysis. This should include:
 - Expertise, recognised by peers, in their policy/research area relevant to the longitudinal study
 - An understanding of the study's over-arching objectives and priorities
 - Familiarity with epidemiological principles of longitudinal data analysis and interpretation, including competency in an appropriate statistical analysis package
 - Experience in preparing high quality reports and publications.
- 57.3. Application should outline why access to the Internal Working Dataset is appropriate, rather than waiting until the fully anonymised External Working Dataset is available.
- 57.4. All approved researchers must sign the Internal Data Access Agreement (and be countersigned by the CEO of their organisation)

58. Process to become an Accredited Researcher

- 58.1. Those considering application are required to have their proposal approved by the Research Director in advance of submitting their application.
- 58.2. An applicant's nomination must be made via their host organisation and include:
 - A statement to support the required criteria for an Accredited Researcher (as outlined above).
 - Where there is a gap in the criteria, a discussion about how to mitigate this.
 - Evidence of support from the host organisation (including from the *GUINZ* Executive Board and Policy Forum member).
 - A plan outlining how the applicant will become up-skilled and knowledgeable about *GUINZ* and the datasets, work with the *GUINZ* team and any resource implications.
 - This plan must be endorsed (in advance) by the Research Director, *GUINZ*.
- 58.3. Recommendation for approval of accredited researcher status by Research Director with ratification by Data Access Committee.

- 58.4. Accredited Researcher signs the Internal Data Access Agreement form (countersigned by the CEO of their organisation).
- 58.5. Accredited Researcher follows process for using Internal Working Dataset, specifies research question and seeks Data Access Committee approval for specific data access and analysis as well as for publication of outputs.

59. Limited numbers of Accredited Researchers

The number of Accredited Researchers will be dependent on available resource and *Growing Up* team capacity, and will be reviewed regularly. Capacity will be discussed by the Research Director and the lead agency in the context of resources available and project deliverables and priorities. This specific aspect should be considered as part of the advance discussions with the Research Director (as per 57.1).

Priority will be given to agencies who have contributed significantly to funding.

60. Amendment to existing Data Access Committee applications

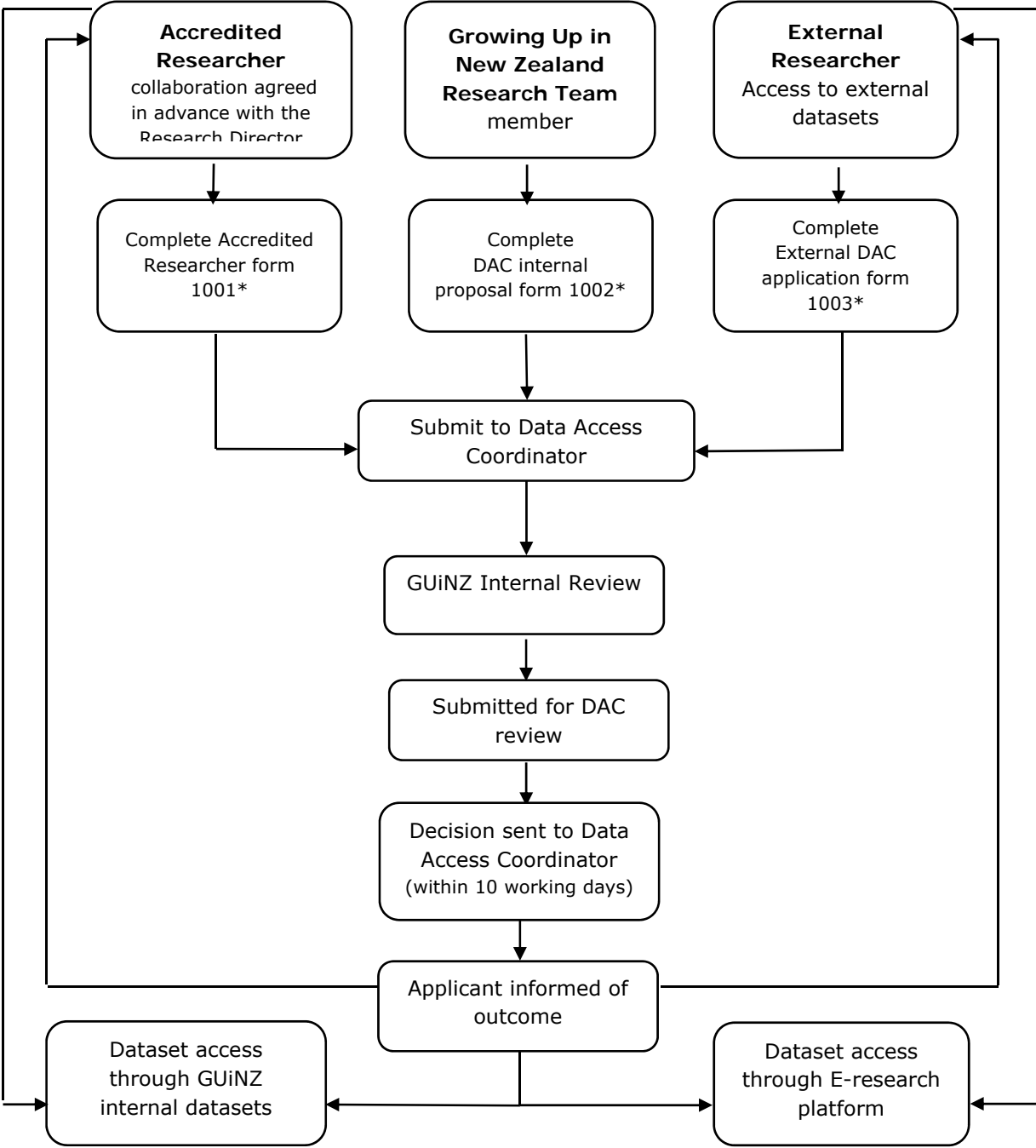
Amendments can be made to existing internal and external Data Access Committee (DAC) applications by completing the appropriate forms.

- Amendments to internal DAC applications use form 1004.
- Amendments to the external DAC applications use form 1005.
- Any change to the project end date use form 1003 completing section on p11.
- Any change to the Principal Investigator or Co-investigators use form 1003 completing sections on p2-3, and p12-13.
- Note: All completed forms must be returned to the Data Access Coordinator.

Appendix 1: Flow diagram describing the processes involving the submission and review of DAC applications.

Access to Growing Up in New Zealand datasets

Application process guidelines



Information required*

All applicants:
 Researcher and project details, analysis approach, dissemination plan and 100 word summary.
 Accredited and External Research applicants also required to include details of expertise and eligibility, and host support.