

Accessing LifeCourse Data: Guide

This document outlines the steps involved in applying for access to survey and/or biological samples from one (or more) of our LifeCourse cohorts.

What data can I apply for?

The content of the LifeCourse cohorts can be explored at <https://lifecourse.melbournechildrens.com/cohorts/>.

Each of the LifeCourse cohorts hold a wealth of information; much more than could be fully utilised by any one team. In addition, some questions can be answered much more robustly by drawing on data from across multiple cohorts.

As such, custodians of these data are keen to work with other researchers and form new collaborations, while ensuring that all ethical requirements are maintained.

What is the application process?

LifeCourse does not hold these data, but rather acts as a liaison between potential data users and data custodians. The process for requesting data access from LifeCourse cohorts involves several steps (Figure 1), intended to both ensure efficiency on the applicant side and that all ethical and governance requirements are upheld.

The process differs slightly depending on whether requests are single-cohort (i.e. requesting access to data from one LifeCourse cohort), or multi-cohort (requesting access to data from multiple LifeCourse cohorts); and whether access to biological samples is requested. This is detailed further below.

Figure 1. Summary of the application process (solid boxes are applicant-initiated steps).



Specifically, applying for access to LifeCourse data requires applicants to:

1. Complete a brief "[Initial Enquiry form](#)" (see Appendix 1) providing the following details:
 - Applicant (and lead researcher if not applicant) details
 - Proposed project title and aims
 - What data/cohort are you interested in accessing?
 - Any specific questions about data availability you have for the data custodians
2. The LifeCourse team will then confirm the feasibility of your request with the requested cohort(s)
3. Next, you will be asked to submit a "Full application" outlining your formal data access request (see Appendix 2). This form is not intended to be overly onerous, and brief responses consistent with a proposal phase are requested covering:
 - One-page CV for the lead investigator and co-investigator details
 - Level of proposed collaboration with cohort(s)
 - 200 word scientific summary of your research project
 - Key variables
 - Research project significance and justification
 - Proposed methodology and brief analysis plan

- Budget and funding
 - Proposed timeline
 - Ethics approval status
 - Any ethical or contentious issues relating to data use?
 - Potential feasibility issues (e.g. research capabilities, collaborators)
 - For requests to access biological samples only:
 - Amount of material required
 - Planned analyses (and Standard Operating Procedures (SOPs) if available)
 - Whether biospecimen-derived data are to be deposited in a public data repository
4. a) For single-cohort applications, your application will be assessed by the data custodians (or investigator team) for (i) suitability given the available data; (ii) consistency with ethical requirements; and (iii) appropriateness for the purpose and strategic plans of the cohort
- b) For multi-cohort applications, the LifeCourse team will facilitate the assessment of the application by each of the data custodians and the LifeCourse management team.
- The ultimate decision to grant access to data lies with **each individual cohort/data custodian**, with the LifeCourse management team acting in an advisory capacity if required
 - As LifeCourse acts as a facilitator and advisor only, control of how the data and biological samples are used remains with each individual cohort/data custodian (in alignment with their ethics and governance protocols)
 - In the event that an application is rejected by the LifeCourse management team, cohorts are still able to proceed if they choose to, however the project will no longer be facilitated by LifeCourse
 - In the event that a multi-cohort application is approved by one cohort and not the other(s), the decision to proceed will rest with the applicant
5. Once an application has been approved by the relevant parties, a Material Transfer Agreement (MTA) and collaboration agreement will be developed if required.

Additional considerations

- Data users must adhere to the requirements of each cohort, including returning code and data back to the cohort where relevant / required
- We suggest that authorship be determined prior to initiation of the research project and reviewed midway. Data custodians may nominate *Authorship* from their group in accordance with the International Committee of Medical Journal Editors (ICMJE) guidelines (available at <http://www.icmje.org>). Authorship order should be based on consensus across data custodians and the investigator requesting the data for the research project.
- The assistance of the Melbourne Children's LifeCourse Research Initiative should be acknowledged in any publications/presentations arising from the research project (contact lifecourse@mcri.edu.au for format)
- Data users agree to abide by ethics guidelines of the individual cohort studies and the Code of Ethics governing research at MCRI
- In some circumstances, costs may arise to data access (e.g. deriving new data from existing biosamples). In this case, costs are determined on an individual proposal basis

Appendix 1 – Initial Enquiry form information

The initial enquiry form is a relatively brief form covering the following items:

- Associate Researcher (i.e. applicant) and Lead Researcher details
- Proposed project title and aims
- Cohorts and data items required
- Any specific questions for the cohort custodian(s) about data availability?

Initial enquiry form fields

*Compulsory field

1. Contact details for Applicant (Primary contact)

- Name (Title*, first name*, surname*)
- Email address*
- Phone number* (landline or mobile)
- Primary Institution*
- Requestor type: *
 - Student
 - Degree type (tick one) :*
 - Bachelor & honours
 - Masters
 - PhD
 - Other
 - If Other, please specify*
 - ORCID iD*
 - Researcher
 - ORCID iD*
 - Policy Analyst
 - Other
 - If other, please specify*
- Is the Lead Investigator (or Supervisor, if applicant is a student) for the project the same as the Applicant/Primary contact provided?*:
 - Yes (Section 2 below is hidden/skipped by applicant)
 - No (Section 2 below is displayed/completed by applicant)

2. Lead Investigator details (or Supervisor, for students)

- Name (Title*, first name*, surname*)
- Email address*
- Phone number* (landline or mobile)
- Primary Institution*
- ORCID iD*

3. Resources requested

- Access request type: *
 - Data access:
 - Checked (Sections 5 and 6 below is displayed/completed by applicant)
 - Not checked (Section 6 below is hidden/skipped by applicant)
 - Biospecimen access
 - Checked (Section 5 and 7 below is displayed/completed by applicant)
 - Not checked (Section 7 below is hidden/skipped by applicant)

4. Project Description

- Project Title*
- Study Aims*
- (If biospecimens requested) List of proposed laboratory analyses*

5. Resources requested

- List of studies/cohorts available
 - Tick all that apply

6. Data request details *[For each study/cohort selected]*

- Domains (as listed on LifeCourse website)
 - Tick all that apply
- Raw data (if applicable)
 - Tick all that apply
- Featured measures (if applicable)
 - Tick all that apply
- If you have any specific questions about data availability, please include them here

7. Biospecimen request details *[For each study/cohort selected]*

- Sample population required*
 - Tick all that apply
 - Children
 - Parents
 - Others
 - If Others, Please specify.*
- Biospecimens requested*
 - Tick all that apply

Appendix 2 – Full Application form information

The full application is a continuation of the initial enquiry form. The answers supplied in the initial enquiry are pre-filled. If updates are required to this pre-filled information, please contact lifecourse@mcri.edu.au. This form will ask you to provide the following additional information:

- *Co-investigator details, and upload one-page CV for the Lead Investigator*
- *Level of collaboration with cohort(s) proposed*
- *200 word scientific summary of the research project (Optional: 200 word lay summary)*
- *Brief description of the variables that will be created*
- *Research project significance and justification.*
- *Methodology and brief analysis plan*
- *Budget and funding*
- *Proposed timeline*
- *Ethical approval granted, yet to be granted or not needed?*
- *Any ethical or potentially contentious issues relating to data use?*
- *Potential feasibility issues (research capabilities, collaborators)*

Full application form fields (additional questions not including those in the initial enquiry)

*Compulsory field

1. Proposed Co-Investigators and Collaboration

- Number of co-investigators to list (select one)*
 - None
 - 1
 - 2
 - 3
 - 4
 - 5
 - more than 5
 - For each co-investigator*: Name, Primary Institution, Role in proposed project, ORCID iD, email address)
 - If more than 5, free text box is provided for details of additional co-investigators
- Proposed level of collaboration with MCRI*
 - No collaboration
 - Early-stage consultation only
 - Details for proposed scope and duration of collaboration*
 - On-going co-development of the project
 - Details for proposed scope and duration of collaboration*

2. Additional Project Details

- Please upload a short (one-page) CV for the Lead Investigator (or Supervisor, for students)
- Permission to publish a lay summary on the MCRI/study website if application approved?
 - Yes
 - Lay Summary of research project
 - No
- Scientific summary of research project (Up to 200 words)*
- Research project significance and justification. (If applicable, what value will the new variables add to the dataset, eventually made available to other researchers?)*
- Methodology and brief analysis for data items*
- Funding of proposed project
- Estimated timeline for project completion*

- Ethical approval granted for proposed project?*
- Yes
 - Approval number*
 - Name of ethics approval committee*
 - Please upload the ethics approval certificate, if available. If unavailable, the Access Co-ordinator will contact you about providing this certificate prior to material release.
- No
 - Ethical considerations and potentially contentious issues
- Potential feasibility issues (e.g. researcher capabilities, collaborators)*

3. **Biospecimen additional details**

- *[For each specimen type selected in the initial enquiry]:*
 - Amount of material required from each sample type request*
- Describe briefly the laboratory analysis to be completed for each sample type*
- If you have Standard Operating Procedures (SOPs) already available for the laboratory analyses, please upload them here.
- Do you anticipate depositing the biospecimen-derived data in a public data repository?*
- Yes
 - Please describe where you anticipate depositing the biospecimens-derived data, and the justification for this.*
- No