

Access LifeCourse data: Guide

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Overview

The aim of the LifeCourse Initiative is to enable researchers to capitalise on the availability of rich cohort data to advance understanding of health and development over the life span.

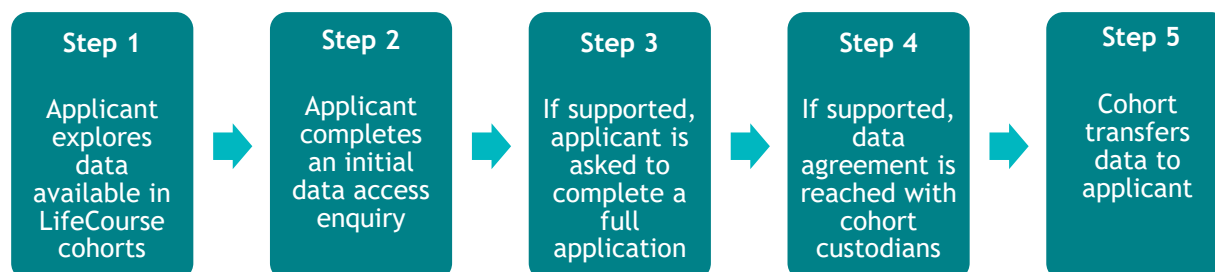
LifeCourse acts as a liaison between potential data users and data custodians, who ultimately approve or reject data access requests. This ensures an efficient process on the applicant side, and that all cohort governance and ethical requirements are maintained.

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

What is involved in the application process?

Requesting access to data from LifeCourse cohorts involves several steps (Figure 1), detailed further below.

Figure 1. Summary of the process for requesting access to data in LifeCourse cohorts.



At the initial enquiry stage (step 2 in Figure 1), applicants complete a brief form (accessible [here](#), see Appendix 1), providing researcher contact information and details of the proposed work (project title, aims, and cohort/s of interest).

The LifeCourse team confirms the in-principle feasibility of your project with the requested cohort/s. At this stage, cohorts may:

- reject the enquiry (for example, because there are issues with data availability that make the project untenable), or
- continue exploring this opportunity by requesting that the applicant completes a full application.

The full application form outlines the formal data access request (see Appendix 2). This covers key aspects of the project and the data and/or biosamples required.

How can I find out what data is available?

[Explore our Cohorts](#) to identify those with data relevant to your research questions. You will find information about what measures have been used by cohorts during each data collection wave, providing a valuable resource in the initial study design phase.

As you move to designing your study in greater detail, it will be necessary to draw on the full study documentation held by each cohort team. Cohorts will typically share this with collaborating researchers once in-principle approval for data access is granted.

Who can apply?

All legitimate researchers are welcome to apply for data access. This includes researchers both internal and external to the Melbourne Children's Campus, as well as to both national and international applicants.

How will cohorts evaluate my application?

The ultimate decision to grant access to data lies with each individual data custodian. LifeCourse acts as a facilitator, while cohorts determine how their data and biospecimens are used in alignment with their ethics and governance protocols.

Your application is likely to be assessed by the data custodians on a range of factors such as:

- suitability given the available data,
- consistency with ethical approvals,
- appropriateness for the purpose and strategic plans of the cohort, and
- redundancy with other planned or in progress work.

My application is approved, what happens next?

Cohorts will usually require researchers to consent to a data agreement which includes details of their specific requirements, such as how data and code should be treated once the project is complete. A Material Transfer Agreement (MTA) and collaborative agreement are also sometimes required.

Many cohorts will encourage, or may even require, that a cohort team member be included as a co-author on the project. This is to ensure that there is appropriate knowledge of the cohort on the project team.

Authorship guidelines from the International Committee of Medical Journal Editors (ICMJE) are available at <http://www.icmje.org>.

Once all approvals and requirements are met, cohorts transfer data according to their preferred platform and protocols. Data users must adhere to the cohort/s protocols and ethical requirements, and the Code of Ethics governing research at MCRI.

Are there any costs involved?

There is no cost associated with submitting a data access request.

Usually, there is no cost associated with access to data. However, in cases where costs do arise (e.g., deriving new data from existing biosamples), these are determined on an individual proposal basis.

Appendix 1. Initial Enquiry

The LifeCourse initial enquiry form is shown below. All possible questions are displayed but may not be required depending on your responses. Access and complete this form at:

<https://redcap.mcri.edu.au/surveys/?s=H47NDMN7EX>.



LifeCourse Data Access Initial Enquiry

LifeCourse invites researchers from around the world to engage with our cohorts to address new research questions and form new collaborative ventures.

Use this form to submit an initial enquiry regarding access to specific LifeCourse data and/or biospecimens. We understand that your research is still in the planning phase, and only brief, high-level details are required at this time.

As outlined in our [Data Access Guide](#), LifeCourse will liaise with cohort custodians to ensure the in-principle feasibility of your project before asking you to complete a full application.

If you have any questions about this process or would like to discuss your request before starting an application, please contact us at lifecourse@mcri.edu.au.

Not ready to submit your enquiry in full? Save the progress of your form and receive a return code to continue this submission at a later time.

(1) Contact details

Your title

* must provide value

Your first/given name

* must provide value

Your surname/family name

* must provide value

Your email address

* must provide value

Are you a:

* must provide value

Student – answer “Student” question below

Researcher – answer “Researcher” question below

(A)

Other – answer “Other” and “Researcher” questions below

If answered “Student” at (A) above

What degree does this project relate to?

* must provide value

Bachelor and/or honours

Masters

PhD

Other

(“Other”) Please describe your degree type

* must provide value

If answered “Other” at (A) above

Please describe your position

* must provide value

What is your primary institution?

* must provide value

What type of institute is this?

* must provide value

Academic/Research Institute (e.g. university, not-for-profit research)

Government

Private company

Other

(“Other”) Please describe your institution

* must provide value

Where are you located?

* must provide value

(Drop down list of countries)

If answered “Australia”

What state/territory are you in?

* must provide value

What is your ORCID?

* must provide value

Write N/A if you do not have an ORCID account

If answered “Researcher” or “Other” at (A) above

Are you the:

* must provide value

(B)

Lead researcher

Associate researcher on study team

Submitting an enquiry on behalf of the research team – *complete below “lead researcher” fields*

If you answered “Student” at (A) above or “Submitting an enquiry on behalf of the research team” at (B) above

Lead researcher's title

* must provide value

Lead researcher's first/given name

* must provide value

Lead researcher's surname/family name

* must provide value

Lead researcher's email address

* must provide value

Lead researcher's primary institution

* must provide value

What type of institute is this?

* must provide value

Academic/Research Institute (e.g. university, not-for-profit research)

Government

Private company

Other

("Other") Please describe the lead researcher's institution

* must provide value

Where is the lead researcher located?

* must provide value

(Drop down list of countries)

If answered "Australia"

What state/territory are you in?

* must provide value

What is the lead researcher's ORCID?

* must provide value

Write N/A if you do not have an ORCID account

(2) Project details

Project title

* must provide value

Project summary (up to 200 words)

Please tell us about your study including the overall aims.

* must provide value

(3) Details of data and/or biospecimens of interest

Please select the cohort(s) from which data and/or biospecimens are requested (tick all that apply)

Explore which cohorts can meet your study aims [here](#).

* must provide value

(List of LifeCourse cohorts, including "Other" option – select all that apply)

("Other") Other cohort(s), please specify

* must provide value

What are you interested in accessing?

* must provide value

(C)

Data only

Biospecimens only

Data and Biospecimens

If you answered "Data only" or "Data and Biospecimens" at (C) above

Please briefly tell us about the key data you are interested in accessing

* must provide value

If you answered "Data only" or "Data and Biospecimens" at (C) above

If you have any specific questions about data availability, please include them here

If you answered "Biospecimens only" or "Data and Biospecimens" at (C) above

Please briefly tell us about the biospecimens you are interested in accessing, including a brief description of the types of analyses to be performed for each specimen type

* must provide value

If you answered "Biospecimens only" or "Data and Biospecimens" at (C) above

If you have any specific questions about biospecimen availability, please include them here

Thank you for your enquiry

As outlined in our [Data Access Guide](#), LifeCourse will now liaise with the data custodians on your behalf.

Any questions or comments? Contact the LifeCourse team at lifecourse@mcri.edu.au.

Appendix 2. Full Application

The LifeCourse full application form is shown below. All possible questions are displayed but may not be required depending on your responses. Access and complete this form via a unique link provided by the LifeCourse team.



LifeCourse Data Access Full Application

LifeCourse invites researchers from around the world to engage with our cohorts to address new research questions and form new collaborative ventures.

Thank you for submitting an initial enquiry. The cohort custodians would like to continue exploring your project and request that you now complete a full application.

If you have any questions about this process, please see our [Data Access Guide](#) and contact us at lifecourse@mcri.edu.au if you would like to discuss your request further.

Not ready to submit your enquiry in full? Save the progress of your form and receive a return code to continue this submission at a later time.

Fields previously completed have been auto-filled, but can be modified as necessary.

(1) Review your contact details

Your title

* must provide value

Your first/given name

* must provide value

Your surname/family name

* must provide value

Your email address

* must provide value

Are you a:

* must provide value

(A)

Student – answer “Student” question below

Researcher – answer “Researcher” question below

Other – answer “Other” and “Researcher” questions below

If answered "Student" at (A) above

What degree does this project relate to?

* must provide value

Bachelor and/or honours

Masters

PhD

Other

("Other") Please describe your degree type

* must provide value

If answered "Other" at (A) above

Please describe your position

* must provide value

What is your primary institution?

* must provide value

What type of institute is this?

* must provide value

Academic/Research Institute (e.g. university, not-for-profit research)

Government

Private company

Other

("Other") Please describe your institution

* must provide value

Where are you located?

* must provide value

(Drop down list of countries)

If answered "Australia"

What state/territory are you in?

* must provide value

What is your ORCID?

* must provide value

Write N/A if you do not have an ORCID account

If answered "Researcher" or "Other" at (A)

above

Are you the:

* must provide value

(B)

Lead researcher

Associate researcher on study team

Submitting an enquiry on behalf of the research team - *complete below "lead researcher" fields*

If you answered "Student" at (A) above or "Submitting an enquiry on behalf of the research team" at (B) above

Lead researcher's title

* must provide value

Lead researcher's first/given name

* must provide value

Lead researcher's surname/family name

* must provide value

Lead researcher's email address

* must provide value

Lead researcher's primary institution

* must provide value

What type of institute is this?

* must provide value

Academic/Research Institute (e.g. university, not-for-profit research)

Government

Private company

Other

("Other") Please describe the lead researcher's institution

* must provide value

Where is the lead researcher located?

* must provide value

(Drop down list of countries)

If answered "Australia"

What state/territory are you in?

* must provide value

What is the lead researcher's ORCID?

* must provide value

Write N/A if you do not have an ORCID account

(2) Project details

Project title

* must provide value

Project summary (up to 200 words)

Please tell us about your study including the overall aims.

Feel free to elaborate on your previous answer (listed below).

* must provide value

Research project significance and potential benefits (up to 200 words)

What is the end goal of the proposed research?

* must provide value

Methodology and analytic approach

Do you have the support of a statistician? **Yes**
 * must provide value **No**

If already developed, what are the key aspects of your statistical analysis plan? Specifically, what are the main measures and expected challenges in deriving them, and what are the main analytical methods that will be used? (up to 400 words)
 * must provide value

Funding source

What is the funding source for this project?
 * must provide value

Are there any potential conflicts of interest to report? **Yes**
 * must provide value **No**

What is your estimated timeline for project completion?
 * must provide value

Has ethical approval been granted for your proposed project? **Yes**
 * must provide value **No**

(3) Data and/or biospecimens request details

Please select the cohort(s) from which data and/or biospecimens are requested (tick all that apply)
 Explore which cohorts can meet your study aims [here](#).
 * must provide value

(List of LifeCourse cohorts, including "Other" option – select all that apply)
 ("Other") Other cohort(s), please specify
 * must provide value

What are you interested in accessing? **Data only**
 * must provide value **Biospecimens only**
(C) **Data and Biospecimens**

If you answered "Data only" or "Data and Biospecimens" at (C) above
Please briefly tell us about the key data you are interested in accessing
 If known, elaborate on key domains or specific measures, at what age or wave of data collection, in each cohort.
 * must provide value

If you answered "Data only" or "Data and Biospecimens" at (C) above

If you have any specific questions about data availability, please include them here

If you answered "Biospecimens only" or "Data and Biospecimens" at (C) above

Please briefly tell us about the biospecimens and analyses of interest

If known, elaborate on number of participants and amount of biospecimen at what age or wave of data collection required for analysis in each cohort.

* must provide value

If you answered "Biospecimens only" or "Data and Biospecimens" at (C) above

Do you anticipate depositing the biospecimens-derived data in a public data repository?	Yes
	No

* must provide value

If you answered "Biospecimens only" or "Data and Biospecimens" at (C) above

If you have any specific questions about biospecimen availability, please include them here

Thank you for your request

As outlined in our [Data Access Guide](#), LifeCourse will now liaise with the data custodians on your behalf.

Any questions or comments? Contact the LifeCourse team at lifecourse@mcri.edu.au.