Using the LifeCourse data access request portal: A guide for data users

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Contents

Overview

A key 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. We provide an automated, centralised data access request portal to facilitate this efficient data reuse.

Through this portal, LifeCourse acts as a liaison, connecting potential data users with 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 for the cohort.

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

Summary of the application process

The LifeCourse data access request portal provides a standardised, efficient and transparent gateway for data access requests. This process involves several steps (Figure 1), detailed further below.
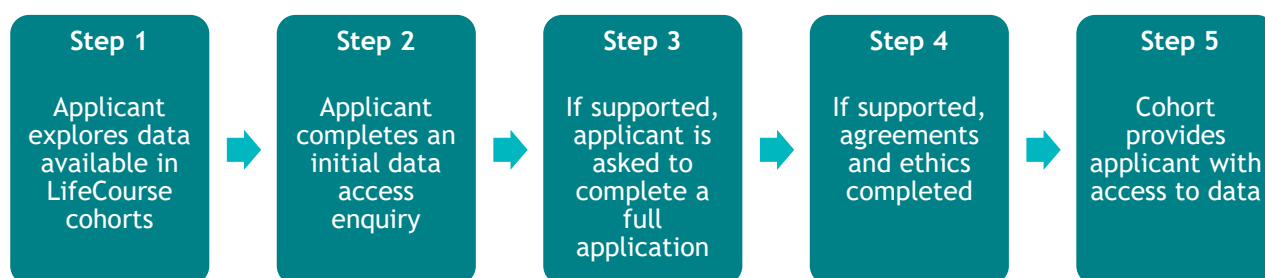
Step 1	Step 2	Step 3	Step 4	Step 5
Applicant explores data available in LifeCourse cohorts	Applicant completes an initial data access enquiry	If supported, applicant is asked to complete a full application	If supported, agreements and ethics completed	Cohort provides applicant with access to data

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

Step 1: Data users are invited to browse the LifeCourse metadata catalogue to identify relevant data available across cohort(s). See 'How can I find out what data are available?' below.

Step 2: At the initial enquiry stage, applicants complete a brief form (accessible here, see Appendix 1), providing researcher contact information and preliminary details of the proposed work (project title, aims and cohort(s) of interest).

The requested cohort(s) indicate initial feasibility of the project. At this stage, cohort custodians may:

- Continue exploring this opportunity by requesting that the applicant completes a full application

- Continue exploring this opportunity by requesting that the applicant completes a full application, but have some additional questions or potential caveats for the applicant to consider

- Decline the request at this stage (for example, because there are issues with data availability that make the project untenable)

For multi-cohort applications, each cohort reviews the application separately. Their responses are collated and a summary is provided to the applicant.

Step 3: If applicable given the outcome to Step 2, the applicant is invited to complete a full application (see Appendix 2). This covers key aspects of the project and the data and/or biosamples required in greater detail, allowing cohort custodians to make a more informed evaluation of the request.

After evaluating the full application, cohorts may:

- Provide in-principle support for the project

- Request further information to assess the application by inviting further discussion, as a next step. LifeCourse will provide an e-introduction, and the applicant and cohort custodian are left to initiate a dialogue

- Decline the request at this stage (for example, after receiving further clarifying information about the project that makes it untenable)

Once an applicant has received the cohort responses to their full application, this concludes the LifeCourse facilitation of the request.

Step 4: Following the provision of in-principle support for the project, direct discussions with the data custodian then occur to progress specific data agreements and clarify any requirements. See 'My application is approved, what happens next?' below.

Step 5: Once agreements have been reached, data access can be arranged. See 'My application is approved, what happens next?' below.

How can I find out what data are available?

The LifeCourse Metadata Catalogue offers a number of ways to discover the available data across our cohorts:

- **Interested in a particular cohort?** For a bird's eye view of our cohorts, start on the Explore our Cohorts page. Delve in deeper on each study's home page from there, including information about the study's design, the measures used by the cohort during each data collection wave and other key information specific to that cohort
- **Already have a set of criteria in mind to address a research question and need to identify cohorts that meet those criteria?** Use the Advanced Search function to search for cohorts based on domain (e.g. Mental health and behaviour problems), construct (e.g. Depression), measure (e.g. Edinburgh Postnatal Depression scale), age at assessment, and/or source or subject of the data (how the data were collected and who it was about)

As a reminder, the LifeCourse metadata catalogue provides a crucial first step in understanding the data available in each cohort but does not take the place of a cohort's full detailed documentation held by each cohort team. Cohorts will typically share this with collaborating researchers once in-principle approval for data access is granted (Step 4 above), to inform development and refinement of the analysis plan.

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, including 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 an administrative facilitator for data applications, while cohorts determine how their data and biospecimens are used in alignment with their ethics and governance protocols.

Applications are likely to be assessed by the data custodians on a range of factors, such as:

- Suitability given the available data
- Consistency with ethical approvals
- Alignment with the cohort's overall purpose and strategic plan
- Redundancy with other planned or in-progress work

My application is approved, what happens next?

Congratulations on being provided with in-principle support for your project! The next step is discussing the specifics of the project in greater detail with the cohorts directly, for instance, what variables are required, ethics considerations and what agreements are needed (if any). Cohorts will usually require researchers to consent to a data agreement which includes details of the study's specific requirements, such as how data and code should be treated once the project is complete. A Material Transfer Agreement (MTA) and collaborative agreement can also be 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 Code of Ethics governing research at MCRI, the cohort's protocols and ethical requirements, and the specific project's ethically approved use of the data.

Are there any costs involved?

There is no cost associated with submitting an enquiry or application for data access via LifeCourse. Usually, there is no cost associated with access to data if an application is approved. However, this is determined on an individual cohort basis. This information can be viewed for each cohort by visiting the 'overview' tab on each cohort's home page. Find cohort home pages through the Explore our Cohorts page.

How long does it take?

The thorough evaluation of your request by cohort custodian(s) takes time. In 2022, it took an average of three weeks for an outcome to be provided to a full application. From there, additional time is required to organise agreements and other requirements prior to data transfer. Hence, we recommend accounting for the data access process in your project timelines.

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=KJDP4WDT7XW8JTTE (also available through the LifeCourse Metadata Catalogue Data Access page).

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.

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(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 degree type** * must provide value	
Is your primary institution part of the Melbourne Children's Campus? (Melbourne Children's Campus includes the Royal Children's Hospital, Murdoch Children's Research Institute and The University of Melbourne, Department of Paediatrics) * must provide value *(B)*	Yes No
If answered "No" at (B) above **What is your primary institution?** * must provide value	
If answered "No" at (B) above **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 *(C)*	Lead researcher Associate researcher on study team Submitting an enquiry on behalf of the research team – *complete below "lead researcher" fields*

Appendix

If you answered "Student" at (A) above or "Submitting an enquiry on behalf of the research team" at (C) above, complete the lead researcher details

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

Is the lead researcher's primary institution part of the Melbourne Children's Campus? (Melbourne Children's Campus includes the Royal Children's Hospital, Murdoch Children's Research Institute and The University of Melbourne, Department of Paediatrics) * must provide value *(D)*	Yes No

If answered "No" at (D) above
Lead researcher's primary institution
* must provide value

If answered "No" at (D) above **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?   Data only
* must provide value   Biospecimens only
(E)   Data and Biospecimens

If you answered "Data only" or "Data and Biospecimens" at (E) 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 (E) above
If you have any specific questions about data availability, please include them here

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If you answered "Biospecimens only" or "Data and Biospecimens" at (E) 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 (E) 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, once your initial enquiry progresses.

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 is this application for?
* must provide value

Bachelor and/or honours
Masters
PhD
Other
("Other") **Please describe your position**
* must provide value

If answered "Other" at (A) above
Please describe your position
* must provide value

Is your primary institution part of the Melbourne Children's Campus?

(Melbourne Children's Campus includes the Royal Children's Hospital, Murdoch Children's Research Institute and The University of Melbourne, Department of Paediatrics)
* must provide value
(B)

Yes
No

If answered "No" at (B) above
What is your primary institution?
* must provide value

If answered "No" at (B) above
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
(C)

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 (C) above, complete the lead researcher details

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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

Is the lead researcher's primary institution part of the Melbourne Children's Campus?

(Melbourne Children's Campus includes the Royal Children's Hospital, Murdoch Children's Research Institute and The University of Melbourne, Department of Paediatrics)
* must provide value
(D)

Yes
No

If answered "No" at (D) above
Lead researcher's primary institution
* must provide value

If answered "No" at (D) above
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 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**
(E)

If you answered "Yes" at (E) above
Please provide details of this statistical support (200 words)
* must provide value

If you answered "No" at (E) above
Please provide details of how the necessary statistical expertise will be ensured (200 words)
* must provide value

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**
(F)

If you answered "Yes" at (F) above
Please detail these potential conflicts of interest

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**
(G)

If you answered "Yes" at (G) above
Approval number
* must provide value

murdoch children's research institute
LifeCourse

If you answered "Yes" at (G) above
Name of the ethics approval committee
* must provide value

If you answered "No" at (G) above
Please indicate status and anticipated timeline for approval
* must provide value

(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**
(H)   **Data and Biospecimens**

If you answered "Data only" or "Data and Biospecimens" at (H) 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 (H) above
If you have any specific questions about data availability, please include them here

If you answered "Biospecimens only" or "Data and Biospecimens" at (H) 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 (H) above
Do you anticipate depositing the biospecimens-derived data in   **Yes**
a public data repository?   **No**
* must provide value

If you answered "Biospecimens only" or "Data and Biospecimens" at (H) 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**.