Process for accessing Barwon Infant Study (BIS) data for students and other researchers

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A. Find out what data are available and view data structure

Resources where you can find information about BIS and the data available include the following:

1. The BIS cohort profile paper:
   http://www.barwoninfantstudy.org.au/userfiles/file/bis_cohort_profile.pdf
2. Biological sample collection details:
   http://www.barwoninfantstudy.org.au/userfiles/file/biological_samples_collection_schedule_20150520.pdf
3. The BIS resource document:
   http://www.barwoninfantstudy.org.au/userfiles/file/bis_resource_document_20180816.xls
4. The LifeCourse website:
   https://lifecourse.melbournechildrens.com/cohorts/barwon/
5. Specific questionnaires used in data collection are available on request:
   james.hedley@mcri.edu.au

You should also check the literature for other studies based on the BIS cohort, and to get a better understanding of the data available including each specific variable from other researchers' analysis.

If you need more information before submitting your concept, please contact James Hedley for access to Pooler: james.hedley@mcri.edu.au

B. Submit BIS concept

Once you have decided what data you would like to access, you should develop a concept with a member of the BIS Steering Committee, and submit it via your BIS Steering Committee member.

A template for developing a BIS concept is available here:
http://www.barwoninfantstudy.org.au/userfiles/file/bis_concept_template_v2.pdf

C. Sign a research agreement

When your BIS concept has been approved by the BIS Steering Committee, a signed research agreement will be required. This agreement must always be signed before data will be provided. Additionally, concepts that involve the use of complex data and/or biospecimens may involve legal review.

The research agreement is a governance step to be developed with your BIS Steering Committee link, and Nicola Cooley: nicola.cooley@barwonhealth.org.au

D. Submit a data request

Once you have provided your signed data sharing agreement, you can submit a data request. Most data is available through Pooler, which is an add-in to REDCap and allows you to view data dictionaries, and select each specific variable you would like to include in your request. Instructions for accessing data through Pooler are as follows:

1. Request access to REDCap and/or Pooler (if you do not already have access): james.hedley@mcri.edu.au
2. Build and submit your request for approval. Refer to the Pooler User Guide for detailed instructions: http://www.barwoninfantstudy.org.au/userfiles/file/pooler_user_guide.pdf
3. Additional data not available in Pooler can be provided on request: james.hedley@mcri.edu.au
4. For access to code used in statistical analysis from previous publications, please discuss with your BIS Steering Committee representative
5. For any additional questions or help using Pooler, please contact james.hedley@mcri.edu.au

E. Accessing your data

After you have submitted your data request, and all other documentation has been provided (approved BIS concept, research agreement, materials transfer agreement), your data will be provided.

1. For requests submitted through Pooler, your request must first be approved
2. You can then log in to Pooler to download your data. Refer to the Pooler user guide for detailed instructions: http://www.barwoninfantstudy.org.au/userfiles/file/pooler_user_guide.pdf

F. Returning analysis code and datasets

When you have finalised your analysis (e.g. for a presentation, publication, or thesis submission), you are required to inform the BIS team.

At manuscript submission or when the project is complete, you will need to send in any analysis files and resulting datasets which will be added to the BIS repository, and may be made available to other researchers. Please provide details of your analysis and resulting datasets (including newly derived variables) to james.hedley@mcri.edu.au

If you need assistance or advice on how to format your analysis code, there are templates available here: http://www.barwoninfantstudy.org.au/userfiles/file/stata_templates.zip. You can also contact james.hedley@mcri.edu.au, or you can attend one of the training courses offered by the Clinical Epidemiology and Biostatistics Unit (CEBU): https://www.mcri.edu.au/research/facilities-resources-and-training/cebu-short-courses-and-training

NOTE: If you have biosamples remaining after your analysis, please contact Fiona Collier: fmcol@deakin.edu.au