

B. DATA ACCESS, ANALYSIS & PUBLICATION PROTOCOL

Having a Baby in Queensland Survey Program

Last Updated: September 2013

A. Ownership

Data collected by researchers associated with the Having a Baby in Queensland Survey Program are owned by The University of Queensland.

B. Access to Data

1. For people conducting secondary analyses

- (a) Subsets of de-identified Having a Baby in Queensland Survey Program data may be made available to collaborating researchers for valid research purposes where there is a formal request to make use of the material through the Expression of Interest (EOI) process.
- (b) Full acknowledgement of the source of data used must be provided in any publications that arise from access to, and use of, the data as set out in Section D (Guidelines to Publication).
- (c) Where data have been collected through the formative work of an individual researcher, or are regarded as of primary interest to that researcher, and are made available to a Lead Investigator, the original researcher should be invited to participate in any publications that follow from use of the data. Lead Investigators requesting data usage are responsible for contacting the original researcher/s to invite participation at the earliest stage of analysis. The original researcher is not bound to accept co-authorship.
- (d) Numerical data will be continually edited, and the Having a Baby in Queensland Survey Team are obligated to ensure that the data are regularly reviewed and edited. Where permission to use the data has been granted, Lead Investigators will be provided with the most up to date data file and will be notified of any future updates. It is the responsibility of the Lead Investigator to ensure the validity of data used in any publication/s or conference presentation/s and to report the date and source of all data used.
- (e) In order to request Having a Baby in Queensland Survey data and conduct secondary analyses, a formal request must be made through the Expression of Interest (EOI) process (see http://www.qcmb.org.au/survey_program_accessing_survey_data and Document C: Expression of Interest form). Expressions of Interest are assessed by the Having a Baby in Queensland Survey Program Data Manager in consultation with the Queensland Centre for Mothers & Babies Core Contributor Group (Kruske, Miller, Thompson, Gallois, Lee and Watson). For privacy protocol obligations for collaborators using Having a Baby in Queensland Survey Program data see Document E: Privacy Protocol. A request for access to data for analysis (Expression of Interest (EOI)) must be made electronically to the Having a Baby in Queensland Survey Program Data Manager. The request should include the following information:
 - i. Lead Investigator's name, institution, email and phone number

- ii. Name of the liaising Queensland Centre for Mothers & Babies Core Contributor Group member (Kruske, Miller, Thompson, Gallois, Lee and Watson). It is a requirement that a member of the Core Contributor Group be involved as a liaison person on every project. Collaborators must contact a Core Contributor Group member to discuss their project prior to submission of the EOI. Contact details for Core Contributor Group members are available at http://www.qcmb.org.au/our_people/menu/about_us/#Our_investigators.
 - iii. Names of all other people working on the project including all co-investigators, data analysts, and research assistants. Any individual working with Having a Baby in Queensland Survey data must sign the Survey Program Confidentiality Statement stating that they have read and will adhere to the conditions detailed in "Document B. Data Access, Analysis, & Publication Protocol" and "Document E. Privacy Protocol." Individuals are only required to sign one Confidentiality Statement which remains current for any future projects. A Memorandum of Understanding (MoU) must be signed by the Lead Investigator for each approved EOI.
 - iv. Title of the potential project
 - v. Survey datasets requested for the project
 - vi. Rationale, methods, main variables of interest, and proposed analytical plan
 - vii. Expected outputs (papers, PhD, conference papers, further grant applications etc.)
 - viii. Time frame
 - ix. Budget and source of funds
 - x. Names and email addresses of all people who will have access to the raw data
 - xi. Name of person/s who will provide substantive content expertise and input
 - xii. Name of person/s who will advise and/or carry out the statistical analysis and qualitative analysis
 - xiii. A statement declaring if any of the applicants have a conflict of interest (e.g., potential financial gain, employment in maternity services). See "Document E. Privacy Protocol" for information regarding individuals with a conflict of interest.
 - xiv. List of keywords/themes
- (f) Requests for access to data are considered by the Having a Baby in Queensland Survey Program Data Manager, in consultation with the Queensland Centre for Mothers & Babies Core Contributor Group (Kruske, Miller, Thompson, Gallois, Lee and Watson). If approved, the data is provided specifically for the analysis described in the EOI. Lead Investigators will be asked for updates to monitor progress each January and July. Approval will be renewed following interim reports if work is progressing reasonably.
- i. Substantial changes to the project must be notified by submitting a new EOI application form and noting the amendment/s. Substantial changes include; changes to the nature of the analysis, the topic addressed, requests for additional variables, and the addition of an individual to the project with a potential conflict of interest.
 - ii. Minor changes do not require a new EOI application form but must be advised by emailing the Having a Baby in Queensland Survey Program Data Manager (survey@qcmb.org.au). Minor changes include the addition of an individual to the project without a conflict of interest, and the exclusion of a variable from analyses. New collaborators are required to sign a Confidentiality Statement prior to accessing any Having a Baby in Queensland Survey Program data.
- (g) Student projects should follow the EOI procedure as for non-student projects. Upon project completion, the Queensland Centre for Mothers & Babies must be provided with a short summary of the student project. A lay summary is preferred, but a thesis abstract is acceptable. Students should check the intellectual property guidelines for their university/institution before commencing work on Having a Baby in Queensland Survey Program research.

In addition, please advise the Having a Baby in Queensland Survey Program Data Manager of:

- i. Any change of supervisor/s or course
 - ii. Expected submission date
 - iii. The date of award for thesis/degree etc when completed
- (h) A Memorandum of Understanding (MoU) must be signed by the Lead Investigator for each approved EOI, acknowledging responsibility for upholding the requirements set out in this policy and “Document E. Privacy Protocol.” In signing the MoU the Lead Investigator also acknowledges responsibility for ensuring adequate facilities and resources to enable the project to progress in a reasonable manner.
- (i) Details of active and completed EOIs using Having a Baby in Queensland Survey data are available online at (http://www.qcmb.org.au/survey_program_current_approved_analyses).
- (j) Researchers with approval to conduct non-scholarly analysis with the Having a Baby in Queensland Survey data (e.g. for media releases, newsletters, student lectures) must gain approval from the Core Contributor Group for any outputs prior to dissemination.

2. For people conducting substudies

The Queensland Centre for Mothers & Babies can coordinate the selection and invitation of participants for further research (substudies). Contact with substudy participants must be made from the Queensland Centre for Mothers & Babies. There are two ways the Queensland Centre for Mothers & Babies can assist in substudies:

1. Promotion of studies to specific subgroups. Lead Investigators can request to publicise their study to a specific group of women based on their Having a Baby in Queensland Survey responses.
 - (a) Approval. All requests must be submitted to the Having a Baby in Queensland Survey Program Data Manager who will grant approval in consultation with the Queensland Centre for Mothers & Babies Core Contributor Group (Kruske, Miller, Thompson, Gallois, Lee and Watson).
 - (b) Requests from Lead Investigators should be sent to (survey@qcmb.org.au) and include:
 - i. A summary of the study
 - ii. A copy of the study invitation to be sent
 - iii. Details of why selection of specific women for invitation is essential to the project
 - iv. Exact eligibility criteria on which the Lead Investigator wishes women to be selected for invitation
 - v. Details of ethical approval for the study including ethical approval number
 - (c) It is essential that substudies have ethical approval from the Lead Investigator’s institution prior to distribution to women.
 - (d) Women who completed the 2012 Having a Baby in Queensland Survey were able to provide consent to link their provided contact details and survey responses in order to receive tailored invitations for future research. Only women from the 2012 Having a Baby in Queensland Survey, who have provided this consent, can be selected based on survey responses and sent a tailored invitation to participate in the proposed substudy.

- (e) The Having a Baby in Queensland Survey Program Data Manager is responsible for the creation of a database of participants based on the selection criteria and for sending the approved study invitation to these participants.
 - (f) Identifying participant information and will not be available to Lead Investigators or collaborators. Lead Investigators can request a basic description of the invited sample based on participant Having a Baby in Queensland Survey data.
 - (g) Costs associated with Queensland Centre for Mothers & Babies assistance with the conduct of substudies must be covered by the Lead Investigator and collaborators. The agreed costs will be detailed in a MoU developed specifically for each substudy that is approved.
 - (h) Data collected by Lead Investigators and collaborators through the response of participants to Queensland Centre for Mothers & Babies contact is the property and responsibility of the Lead Investigator and collaborators.
2. Linking participants to Having a Baby in Queensland Survey data. Lead Investigators can request to publicise their study to women through the Queensland Centre for Mothers & Babies and subsequently link responses to their new survey materials to existing Having a Baby in Queensland Survey responses.
- (a) Approval. All requests must be submitted to the Having a Baby in Queensland Survey Program Data Manager who will grant approval in consultation with the Queensland Centre for Mothers & Babies Core Contributor Group (Kruske, Miller, Thompson, Gallois, Lee and Watson).
 - (b) An Expression of Interest (EOI) form must be completed for the Having a Baby in Queensland Survey variables requested. The Expression of Interest process as outlined in “1. For people conducting secondary analyses” must be followed, and policies concerning the use of Having a Baby in Queensland Survey data for secondary analyses will be applied (See 1 “For people conducting secondary analysis” and “Document E. Privacy Protocol, B. Practical Guidelines, 2. For people conducting secondary analyses”).
 - (c) Substudies must have relevant ethical approval from the Lead Investigator’s institution prior to distribution to women. Data linkage to Having a Baby in Queensland Survey data must also have ethical approval prior to distribution to women.
 - (d) Intellectual Property. Having a Baby in Queensland Survey data are the intellectual property of the Queensland Centre for Mothers & Babies. New data collected by Lead Investigators and collaborators on specific substudy measures is the property and responsibility of the Lead Investigator and collaborators.
 - (e) Substudy participants must provide consent to link their substudy responses to past Having a Baby in Queensland Survey responses. In addition, substudy participants must be informed of the specific identifying information (e.g., birth date, birth facility) required in order to accurately link to past survey responses. This data, in addition to participant consent forms for data linkage, must be delivered to the Queensland Centre for Mothers & Babies prior to any data linkage.
 - (f) Costs. Costs associated with the Queensland Centre for Mothers & Babies conduct of substudies must be covered by the Lead Investigator and collaborators. The agreed costs will be detailed in a MOU developed specifically for each substudy that is approved.

The Queensland Centre for Mothers & Babies can assist in the general promotion of research studies that do not require the use of Having a Baby in Queensland Survey data for participant selection or data linkage. Lead Investigators can request to publicise their study to the Queensland Centre for Mothers & Babies contact database. This database includes women who have completed a Having a Baby in Queensland Survey (in 2009, 2010 or 2012) or have provided their contact details through other means and have consented to be re-contacted by the Queensland Centre for Mothers & Babies for future research. The management of this database is the responsibility of the Queensland Centre for Mothers & Babies Advocacy and Communication Team and enquires regarding this method of promotion should be directed to info@qcmb.org.au.

B. Guidelines to Analysis

1. Data analysis must be conducted according to recognised standards. Collaborators should familiarise themselves with the datasets, as well as the original surveys and technical reports. Where a standard derived variable exists, or the Having a Baby in Queensland Survey Program team have developed a standard method of categorising variables, these should be used unless there are sound methodological reasons for using a different derivation. When using Having a Baby in Queensland Survey qualitative data, all data must be anonymised in reporting (see 2).
2. Qualitative data. Individual comments must be appropriately used in qualitative research. It is imperative that participants cannot be identified through individual comments. Qualitative variables include the verbatim responses of women to open-ended questions within the survey. These variables may contain identifying information including names of individuals and facilities. It is the responsibility of the Lead Investigator to ensure the anonymity of survey respondents in all output. When using individual comments, researchers must:
 - i. Indicate clearly in all written and verbal presentations that specific details have been changed to avoid recognition of individuals
 - ii. Use false names, if names are used. Names can also be replaced with the person's relationship to the participant or their title. For example, {son}, {mother}, {family member}, {friend}, {family doctor}, {midwife}.
 - iii. Remove the names of towns and suburbs. Town and suburb names can be replaced with short descriptors as per the five ARIA categories. For example, {Major City}, {Inner Regional}, {Outer Regional}, {Remote}, {Very Remote}.
 - iv. Change place names. Names of places can be replaced by a short descriptor. For example: Nambour General Hospital replaced by {regional centre hospital}.
 - v. Change specific details such as numbers and ages of children, and precise details of diagnosed conditions, family circumstances, employment details, or other unique characteristics. These should be altered in a way which does not substantially alter the point being made but disguises the actual participant and her circumstances.

C. Guidelines to Publication and Conference Presentations

1. Researchers should follow their institutions' guides as well as the NHMRC guidelines pertaining to publications and conference presentations. The current NHMRC Australian Code for the Responsible Conduct Research can be found at <http://www.nhmrc.gov.au/publications/synopses/r39syn.htm>
2. There must be no honorary or courtesy authorship: i.e., no person may be listed as an author when he/she has not participated in a substantial way in conceiving and/or executing and/or

interpreting at least part of the work described in the publication. The QCMB Liaison person for a project does not automatically have authorship rights.

3. Minimum requirement for authorship is participation in conceiving and/or executing and/or interpreting at least part of the publication in a co-author's field of expertise, sufficient for him or her to take public responsibility for it.
4. All publications must include the following acknowledgement:

The research on which this paper (book, monograph, abstract, or report) is based was conducted as part of the Having a Baby in Queensland Survey Program of the Queensland Centre for Mothers & Babies at The University of Queensland. We are grateful to Queensland Government for funding and to the women who provided survey data. The Queensland Registry of Births, Deaths and Marriages contacted women to invite them to participate on behalf of the Queensland Centre for Mothers & Babies to ensure women's privacy was protected.

5. Additional funding agencies should also be acknowledged if this is applicable.
6. The acknowledgement may refer to any other persons who have provided comments, advice, support or other input into the paper, who are not already listed as authors. Permission should be sought from these persons before including their names.
7. Due recognition of all contributors is part of the proper research process. Authors should ensure that research assistants, technical officers, and other 'non-authors' who contribute, including community members involved in supporting the project, are properly acknowledged.
8. Publication of multiple papers based on the same set(s) or subset(s) of data is improper unless full cross-referencing occurs within the papers, for example, by reference to a preliminary publication at the time of publication.
9. Lead Investigators must take overall responsibility for publications. In the event that a member of the Queensland Centre for Mothers & Babies Core Contributor Group (Kruske, Miller, Thompson, Gallois, Lee and Watson) is not a co-investigator on the project, publications and journal submissions (including abstracts for conference presentations) must be reviewed by the Queensland Centre for Mothers & Babies liaison person (i.e., specified member of the Core Contributor Group) before submission to a journal or editor.
10. In the event that a member of the Queensland Centre for Mothers & Babies Core Contributor Group is not a co-author on a publication, authors must provide copies of publications to the Queensland Centre for Mothers & Babies Survey Program Data Manager when they are submitted, reviewed, re-submitted and accepted. An electronic copy of the published paper, report, conference abstract, and/or conference presentations (poster or slides used) should be provided to the Queensland Centre for Mothers & Babies Survey Program Data Manager as they occur (for example, conference abstracts should be provided as soon as the abstract has been accepted, conference presentation slides or posters should be provided as soon as the presentation has been given).