

E. PRIVACY PROTOCOL

Having a Baby in Queensland Survey Program

Last Updated: August 2012

The Having a Baby in Queensland Survey Program managed by the Queensland Centre for Mothers & Babies at The University of Queensland, collects data on the maternity care experience of women who birth in Queensland. Women have agreed to participate in the program by providing their personal and health information on survey forms (both written and electronic) or over the phone (recorded electronically). This information is currently held in electronic form at The University of Queensland. Many women have also provided consent for the project team to contact them for invitation to participate in further research, and this information is stored electronically at the Queensland Centre for Mothers & Babies at The University of Queensland.

This Privacy Protocol should be read and the Confidentiality Statement signed by:

1. All Queensland Centre for Mothers & Babies staff with access to Having a Baby in Queensland Survey Program data, completed surveys or identifying information.
2. All people who have access to Having a Baby in Queensland Survey Program data.

The Privacy Protocol should be retained and the Confidentiality Statement returned to the Queensland Centre for Mothers & Babies Survey Program Data Manager before any data, completed surveys, or identifying information is accessed.

A. General Principles

The conduct of all projects must comply with the Information Privacy Principles set out in Section 14 of the Privacy Act 1988. The Principles concern the collection, solicitation, security, use and disclosure of personal information. Any person who has access to any personal information pertaining to participants must be made aware of, and undertake in writing to abide by, the Information Privacy Principles, and the National Privacy Principles contained in the 2000 Amendment to the Act. Copies of these documents are available on the Privacy Commissioner's website at <http://www.privacy.gov.au/>.

Access to data is permitted only for approved research purposes, and data may not be used for any other purpose or passed on to third parties.

This document contains three subsections in the Practical Guidelines section:

1. For Queensland Centre for Mothers & Babies internal use of data including staff working with data, consent forms, completed surveys, and personal identifiers;
2. For people conducting secondary analyses;
3. For people conducting substudies.

Your Queensland Centre for Mothers & Babies liaison person or Data Manager will direct you to the appropriate sections for you to read. You must also read "Document B. Data Access, Analysis, & Publication Protocol."

B. Survey Program Privacy Practices

1. Completed Surveys and Survey Files

(a) Completed survey forms and consent to re-contact forms. Completed survey forms are checked and logged on receipt at the Queensland Centre for Mothers & Babies or by external contractors. The consent to re-contact form, which includes identifying information, is removed from the survey prior to data entry. Information from consent to re-contact forms is entered independent of Having a Baby in Queensland Survey responses and is stored separately. Where survey and consent to re-contact forms are sent to an external contractor for scanning and data entry; the contractor undertakes to maintain confidentiality of all files. Consent to re-contact forms and survey data are entered in electronic form and paper copies are scanned to be saved in electronic format for future data quality assurance. Once data are entered in electronic form, a series of data integrity checks are undertaken under the supervision of the Having a Baby in Queensland Survey Program Data Manager. Once the Having a Baby in Queensland Survey Program Data Manager is satisfied that the entered data from the surveys and consent to re-contact forms are accurate, the Having a Baby in Queensland Survey Program Team is asked to endorse a decision to destroy the paper copies. The Data Manager then instructs the data management company to securely destroy the hardcopies of the surveys and consent to re-contact forms in accordance with HREC requirements and as set out in the agreement between the QCMB and the data management company.

Imaged surveys and consent to re-contact forms are stored electronically (in separate files) in protected files by the Queensland Centre for Mothers & Babies. These files can only be accessed by Having a Baby in Queensland Survey Program staff with access to identifiable data (See C. Practical Guidelines). External contractors will delete their copies of all scanned surveys once the Having a Baby in Queensland Survey Program Data Manager is satisfied that they are no longer required. Deletion of files will be confirmed in writing to the Having a Baby in Queensland Survey Program Data Manager.

(b) Electronic files of survey data contain a unique identifier that can be linked to names and addresses only through the consent to re-contact data (stored separately). Access to these data is restricted to Having a Baby in Queensland Survey Program staff with access to identifying data. Electronic files and scanned copies of original data will be archived in accordance with NHMRC guidelines, available at <http://nhmrc.gov.au/publications/synopses/r39syn.htm>

(c) Individual information contained in the surveys must not be divulged to any third party or recorded elsewhere, except as is necessary for legitimate research purposes.

B. Practical Guidelines

1. For Queensland Centre for Mothers & Babies internal use of data, including staff working with data, consent forms, completed surveys, and personal identifiers.

All members of staff working on the Queensland Centre for Mothers & Babies project are required to sign a Confidentiality Statement issued by The University of Queensland stating that they will observe the privacy principles (stated above) at all times. All members of staff working on the Queensland Centre for Mothers & Babies Having a Baby in Queensland Survey Program with access to data, completed surveys, or consent to re-contact forms must also sign the Survey Program Confidentiality Statement attached to this document stating that they have read, and will adhere to, the policies outlined in this privacy protocol and the "Data Access, Analysis, & Publication Protocol".

(a) Identifying Data

- (i) Electronic files that contain data allowing personal identification are stored in a password protected folder on a network drive which is also password protected. The Having a Baby in Queensland Survey Program Data Manager and Senior Data Analyst are the only individuals allowed access to these files or copies of these files. Copies may only be taken for the purpose of secure archiving and backup. This includes scanned copies of completed surveys, the full set of electronically entered survey data, and consent to re-contact forms and data.

(b) De-identified Data

- (i) De-identified data files are stored in a password protected folder on the Queensland Centre for Mothers & Babies network drive which is also password protected.
- (ii) Access to de-identified data files will be granted to authorised Queensland Centre for Mothers & Babies personnel by the Survey Program Principal Investigators (as listed on the current ethical approval; Miller, Thompson, Kruske).
- (iii) Staff granted access to de-identified survey data are required to undertake appropriate orientation under the guidance of the Having a Baby in Queensland Survey Program Data Manager to ensure they are familiar with established data management and analysis protocols.
- (iv) Personnel must be vigilant in ensuring that data files are secure. Files may be stored only on a password protected computer hard drive, password protected external hard drive or password protected USB drive.
- (v) The Queensland Centre for Mother's & Babies Advocacy and Communications Team are provided with a list of names and personal contact details for participants who have given permission to be contacted for future research, or have requested to receive the Queensland Centre for Mothers & Babies newsletter. These details are added to the Queensland Centre for Mothers & Babies contact database, which also includes the names and details of other individuals who have not responded to the Having a Baby in Queensland survey but have consented to be contacted for future research, or to receive the Queensland Centre for Mothers & Babies newsletter. The Advocacy and Communications Team are not provided with any survey data, or information regarding the source of individuals in the database.

2. For people conducting secondary analyses

Subsets of de-identified Having a Baby in Queensland Survey Program data may be requested for valid research purposes. See "Document B. Data Access, Analysis & Publication Protocol," and the Queensland Centre for Mothers & Babies website (http://www.qcmb.org.au/survey_program_accessing_survey_data) for further details regarding the Expression of Interest Data Access process.

Researchers internal to the Queensland Centre for Mothers & Babies may have access to data prior to the submission of an Expression of Interest (EOI) form but must undertake the same process as external researchers prior to the dissemination of findings. Researchers external to the Queensland Centre for Mothers & Babies must undertake the Expression of Interest process to request data for secondary analyses.

- (a) Approval to conduct an analysis must be sought from the Queensland Centre for Mothers & Babies Core Contributor Group (Kruske, Miller, Thompson, Gallois, Lee, and Watson). Approval is for analysis on a specific topic as outlined in an approved Expression of Interest (EOI) and other analyses may not be conducted without seeking further approval. Further details regarding the Expression of Interest process are outlined in "Document B. Data Access, Analysis, & Publication Protocol."

- (b) The Lead Investigator is responsible for ongoing communication with the Queensland Centre for Mothers & Babies through a specified liaison person who must be a member of the Queensland Centre for Mothers & Babies Core Contributor Group.
- (c) All individuals who will have access to data must be listed on the EOI form. 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 this document and “Document B. Data Access, Analysis, & Publication Protocol.”
- (d) After the Privacy Protocol has been read and the Confidentiality Statement signed, these individuals will receive a copy of the relevant data files and associated documentation via USB or CloudStor (secure online) transfer. Data should be obtained from the Having a Baby in Queensland Survey Program Data Manager at the Queensland Centre for Mothers & Babies, and not from other sources, to ensure that the most up-to-date data are provided. Copies of datasets previously provided by the Queensland Centre for Mothers & Babies for other analyses conducted by the collaborator must not be used.
- (e) Individuals requesting access to Having a Baby in Queensland Survey Data must declare any conflict of interest (e.g., potential financial gain, employment in Queensland maternity services). Clinicians, or individuals who have worked in maternity services, are considered to have a conflict of interest if it would be possible for them to identify one or more survey participants for whom they provided clinical care. Requests for access to Having a Baby in Queensland Survey Data by clinicians with a potential conflict of interest will be considered on a case by case basis by the Queensland Centre for Mothers & Babies Core Contributor Group (Kruske, Miller, Thompson, Gallois, Lee, and Watson). In the event that a care provider is denied access to raw data on the basis of a conflict of interest, projects may still be approved with provisions made for other individuals to conduct data analysis.
- (f) Data files must be copied to a password-protected area of a computer or network that is not accessible to others who have not signed the Confidentiality Statement. Copies of data files may not be made except for the purpose of backup.
- (g) Identifiers. Data files will contain a numerical Unique Identifier for each case which must be used to link data sets (for example, linking additional variables that may be provided separately).
- (h) Completion. The Lead Investigator must inform the Queensland Centre for Mothers & Babies Survey Program Data Manager once analysis is complete. All data must be removed from computers, and networks on which they were stored and archived in accordance with the Lead Investigator’s research institute guidelines. The data and associated documentation referred to in (d) must be returned to the Having a Baby in Queensland Survey Program Data Manager at The University of Queensland. In addition, updated data files that contain new variables derived for the specific analysis in that project, as well as Technical Reports for these new variables, must be provided.
- (i) Publications and journal/conference submissions. 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/conference submissions must be reviewed by the QCMB Liaison person prior to submission.
- (j) Acknowledgement. All publications should contain acknowledgements as outlined in the “Data Access, Analysis & Publication Protocol” (Document B).

3. For people conducting substudies

The Queensland Centre for Mothers & Babies can coordinate the selection and invitation of participants for further research (substudies). Document B, the “Data Access, Analysis & Publication Protocol” outlines the procedure for the request and conduct of substudies.

- (a) Approval. Approval to conduct a substudy must be sought from the Having a Baby in Queensland Survey Program Data Manager consistent with the process specified in “Document B. Data Access, Analysis & Publication Protocol.”
- (b) Intellectual Property. Results of the Having a Baby in Queensland Survey 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.
- (c) For Lead Investigators who have requested to contact participants through the Queensland Centre for Mothers & Babies and also link new participant responses to existing Having a Baby in Queensland Survey responses, additional privacy procedure requirements include:
 - (i) Confidentiality. Where the results of research using Queensland Centre for Mothers & Babies data are published or presented in public, information must be presented in a form that does not permit the identification of any individual participant.
 - (ii) An Expression of Interest (EOI) must be submitted for the Having a Baby in Queensland Survey variables requested. All policies specified in “2. For people conducting secondary analyses” apply to the use of these variables.
 - (iii) Acknowledgement. All publications should contain acknowledgements as outlined in the “Data Access, Analysis & Publication Protocol” (Document B).

C. Publication of Findings

- 1. In the event that a member of the Queensland Centre for Mothers & Babies Core Contributor Group is not a co-author on a publication, publications and journal submissions must be reviewed by the Queensland Centre for Mothers & Babies liaison person before submission to a conference, journal or editor.
- 2. Acknowledgement. All publications should contain acknowledgements as outlined in the “Data Access, Analysis & Publication Protocol” (Document B).
- 3. Where the results of research using Queensland Centre for Mothers & Babies data is presented in public, information must be presented in a form which does not permit the identification of any individual participant.

CONFIDENTIALITY STATEMENT

I have read the document "Document B. Data Access, Analysis, & Publication Protocol" and agree to abide by its conditions.

I have read the Privacy Protocol (Document E) and agree to abide by its conditions.

Title

.....

Name

.....

Organisation and Address

.....

.....

Email address

.....

Signature Date

Affiliation

- ☐ Collaborator
- ☐ QCMB staff member (NB: You will also need to supply a signed University of Queensland Confidentiality Form)
- ☐ Student (NB: You will also need to sign a University of Queensland transfer of Intellectual Property form)
- ☐ QCMB Investigator/Liaison
- ☐ Consultant / company (NB: You will also need to supply a signed University of Queensland Confidentiality Form)