What will happen to information collected about me and my child?

By signing the consent form, you are consenting to the BIS research staff to collecting and using information about you and your child for the research project. Any information obtained in connection with this research project that identifies you or your child will remain confidential. Data will be stored in a password protected computer file or in a locked filing cabinet in a lockable office at the Child Health Research Unit.

The information collected about your child will be used in publications in medical or scientific journals. You or your child will not be referred to by name in any study, report or publication. Your identities will remain confidential. Medical and health related information about you and your child will be collected by trained research staff who will employ strict procedures to ensure that these details remain confidential and are not forwarded to any third parties. Any data extracted from medical records will be de-identified prior to analysis and incorporation in any publications.

With your permission, the data collected in the BIS may be used for a range of future projects both in Australia and overseas. It is not possible for us to specify what these projects will be, because as scientific knowledge evolves, the important scientific questions change and new health challenges arise. Future projects that access data collected in the BIS will need to be approved by the BIS Steering Committee and the Hospital Research and The Human Research Ethics Committee at Barwon Health.

If you give consent for you and your child's data to be used in this research project and any other future ethically approved research projects, these will be securely stored in the BIS Cohort Database for an indefinite period.

If you give consent for you and your child's data to be used in this research project only we will store data for 25 years, or seven years beyond your child's 18th birthday, after which paper records will be securely destroyed by shredding. However, electronically stored de-identified data will be maintained in case some aspect of this phase of BIS is required for future analysis.

Does my child have to take part in this research project?

Participation in any research project is voluntary. If you do not want your child to take part in the BIS Data Linkage Project, they do not have to. If you decide that they can take part and later change your mind, you are free to withdraw them from the project at any stage.

What do I do now?

1. Please complete the BIS School Enrolment Screen which was emailed to you (thank you if you have already done this!).
2. Complete the online consent form that will be sent to you by email.
3. Contact the BIS team if you have any questions or concerns.

Any questions or feedback can be directed to BIS@barwonhealth.org.au or the BIS mobile 0400 432 976

Please continue to let us know if there are any other topics you are interested in - we can look to include them in the next Study Update.

The Barwon Infant Study (BIS) is an ongoing collaborative research project conducted by researchers from: Barwon Health the Murdoch Children's Research Institute and Deakin University.

BIS is primarily funded by the National Health and Medical Research Council of Australia.

The BIS Primary School review received additional funding from Deakin University and the Barwon Health Foundation.

Thank you for your child and family's valuable contribution to improving the health of our community.

BIS Data Linkage Info

Barwon Infant Study
EMAIL
bis@barwonhealth.org.au
MOBILE
0400 432 976
WEBSITE
barwoninfantstudy.org.au

A BIS research student on a mission

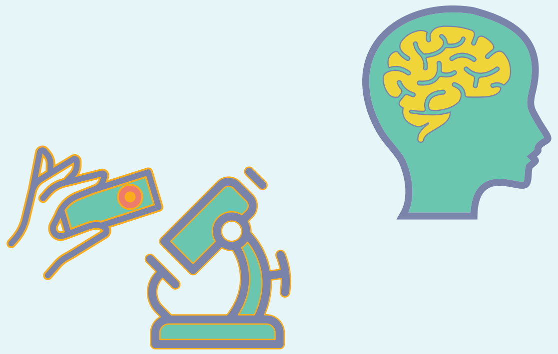
We would like to introduce Solveig, our newest BIS student. She will be spending the year with BIS completing an Honours project, through the School of Medicine at Deakin University. Solveig came to us after studying a Bachelor of Biomedical Science in Melbourne. Having grown up on the sunny beaches of Byron Bay, she now calls Torquay home. Solveig joined the BIS team a year ago as a Research Assistant, helping out with the last of the BIS Preschool Reviews. She is now moving forward in her career with a focus on promoting healthy development and learning.

Solveig's mission is to improve screening for early childhood learning problems, and thus give every school aged child the opportunity to succeed in their education.

Solveig's plan is to analyse data from the BIS Preschool Review and the School Entrant Health Questionnaire (SEHQ). The SEHQ is completed by parents as their kids enter prep.

The SEHQ contains a lot of valuable information. In order to access the SEHQ and additional data that is routinely collected by the Department of Education and other organisations, Solveig will be seeking your consent to undertake a process known as 'data linkage'.

Solveig!



What can you do to help?

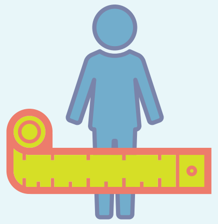
Complete the BIS 2019 School Enrolment Screen that was emailed to you in January. If you did not receive the email containing the survey link, please contact the BIS team at **bis@barwonhealth.org.au** or on **0400 432 976**

BIS Barwon Infant Study

Barwon Health

DEAKIN UNIVERSITY

murdoch children's research institute



What is Data Linkage, and why is it important?

Data Linkage is a process that allows studies to access their participant's 'administrative data'.

Administrative data is routinely generated on everybody when for example you visit a hospital, fill a prescription, get married, have a child or when your child enrolls in school.

Data linkage is a widely used strategy in medical research and has played a crucial role in many public health discoveries. Performing data linkage will help us to address numerous important research questions without placing an added burden on you as a participating BIS family.

How is my information protected?

Maintaining the confidentiality of your family's data is extremely important to the BIS team. When you joined BIS, we allocated you a BIS ID number - a four digit number such as 'C0000'. BIS researchers only see your BIS ID number, not your name or other identifying information. The only people who will have access to identifying information are the BIS personnel, who schedule and conduct your visit.

There are laws designed to protect the confidentiality of administrative data. The information obtained by data linkage is stored securely within each agency, and access to the data is controlled by a data custodian. As with all BIS activities, we must get approval from Barwon Health's Human Research Ethics Committee (HREC) to undertake this research.

Under no circumstances will we forward identified information to other researchers, organizations or individuals.

What is a data custodian?

Data custodians are the people who hold the 'keys' to the administrative data. They store personal information (eg.name, address, date of birth) and also content information (eg.health information such as diagnosis and treatment details). Data custodians have a responsibility to protect the confidentiality of administrative data.

How will my data be linked?

1. If you decide to provide your consent, we will provide the information required to complete accurate data linkage (e.g. name, date of birth, address, gender) to the data custodian or linkage unit (e.g. Centre for Victorian Data Linkage)
2. The data custodian or government linkage unit will then use the information we provide to link with information held in their database.
3. The data custodian or government linkage unit then replaces identifying data with a unique identifier, thus enabling them to provide the BIS team with de-identified linked data.

What is a data linkage unit?

Data linkage can be complicated! So linkage units have been established within state departments to liaise between researchers and data custodians. The linkage units are able to gather data from multiple custodians and link it with a list of research participants provided. This is a secure way for researchers and state departments to work together.

What sort of projects will my data be used for?

The BIS researchers will only use your data for projects that are in the best interest of public health.

For example, the BIS Preschool Review included a tool known as 'The Strengths and Difficulties Questionnaire' (SDQ). In general, parents are also asked to complete the SDQ when their child commences school. By linking these questionnaires we can investigate whether the SDQ completed during preschool can predict the outcome of the SDQ completed at school entry.

This seems simple, but it gives us really useful information about child development and behavior, and may help to identify children with particular needs early on in their schooling.

Recent publications can be found on the BIS website:
www.barwoninfantstudy.org

BIS Brain Games - the journey so far!

Image courtesy of the Raising Children Network

Which records are BIS interested in?

In 2019 we asked what research was most important to BIS parents. Mental health, education, diet, neurodevelopment and allergy were identified as the top priorities, therefore we have integrated all of these themes into the BIS Primary School Review.

Data linkage will enable us to minimize the length of the BIS Primary School questionnaire. Linking to the following records will enable us to address multiple important health questions without added burden to the BIS families.

We are requesting your permission to perform data linkage with the following databases:

> **Victorian Admitted Episodes Dataset** – information on hospital admissions

> **Victorian Emergency Minimum Dataset** – information on emergency room visits

> **Elective Surgery Information System** – information on non-urgent surgical procedures

> **Victorian Integrated Non-Admitted Health Dataset** – information on outpatient hospital services, such as specialist visits

> **Dental Health Data Set** – information from community dental practice visits

> **Maternal and Child Health Data** – information on child and family well-being

> **The School Entrant Health Questionnaire** – a record of parents observations and concerns of their child's health and wellbeing as they enter their schooling years

> **NAPLAN Results** – a measure of learning progress over time

> **Maths and English Online Results** – a measure of learning progress over time

What do we need from you?

In order to undertake data linkage we need 3 things from you:

1. **Your consent**
2. **The name of the school your child attends**, and where they first enrolled
3. **Your child's preferred name** as written on school forms

In the coming weeks we will be contacting you to complete online consent. You will receive an email with a link to this information booklet along with the online consent form.

The data we are seeking your consent to access is Victorian State Data. In the future we may want to access data from the Commonwealth Government, in this case we will give you the opportunity to opt out.

If you have any questions or concerns about the BIS Data Linkage Project, you can contact us on the BIS mobile: **0400 432 976** or email us at bis@barwonhealth.org.au

We are always happy to hear from you.