

Will you give my data to a third party?

The BIS team will never pass any of your identifiable information on to a third party. This includes insurance companies.

What sort of records are you accessing?

We are asking permission to access records from the Department of Education, and health data from Victorian hospitals and maternal health nurses.

We will NOT accessing any sensitive records, such as criminal records, Centrelink and welfare information or sexual assault services.

Will the data have our names on it?

Your child's name will be provided to the data custodian in order for them to locate your data within their files, your name will then be replaced by your 'BIS ID' before it is returned to the BIS researchers. This means that your data is not identifiable to the researchers but is connected with the samples and information we have collected in the past.

But you know our names and our ID's?

The BIS team is made up of:

Research assistants – who you will have met during your BIS visits, and who book your BIS appointments, so they know both your name and BIS ID

Research officers – who work in the laboratory and process your biological samples, who only see your BIS ID

Researchers – which can include clinicians, public health physicians, statisticians and more. These team members do analysis and only receive your data de-identified by BIS ID.

How will you link our data?

1. First we had to write a document that we felt explained data linkage, what we wanted to use linkage for, and how we were going to access and store the data. This is called a 'participant informed consent form' or PICF. You will have received a copy of our PICF on data linkage through the post.
2. Then we had to consult with the data custodians of the data we wish to access, to make sure that they agree our PICF is sufficient.
3. We then take the PICF to the Human Research Ethics Committee (or HREC) at Barwon Health, where a panel of impartial ethics members decide whether or not the project is in the public interest and complies with the ethics guidelines set out by the Australian Research Council.
4. Once the PICF has been approved, we seek participant consent.
5. Once we have your consent, we provide the data custodian or linkage unit with your 'identifiers' and BIS ID. Identifiers are your name, date of birth, sex and any other information needed to find your individual data in a data set.
6. Once the data custodian has found your data, they remove your identifiers and replace them with your BIS ID.

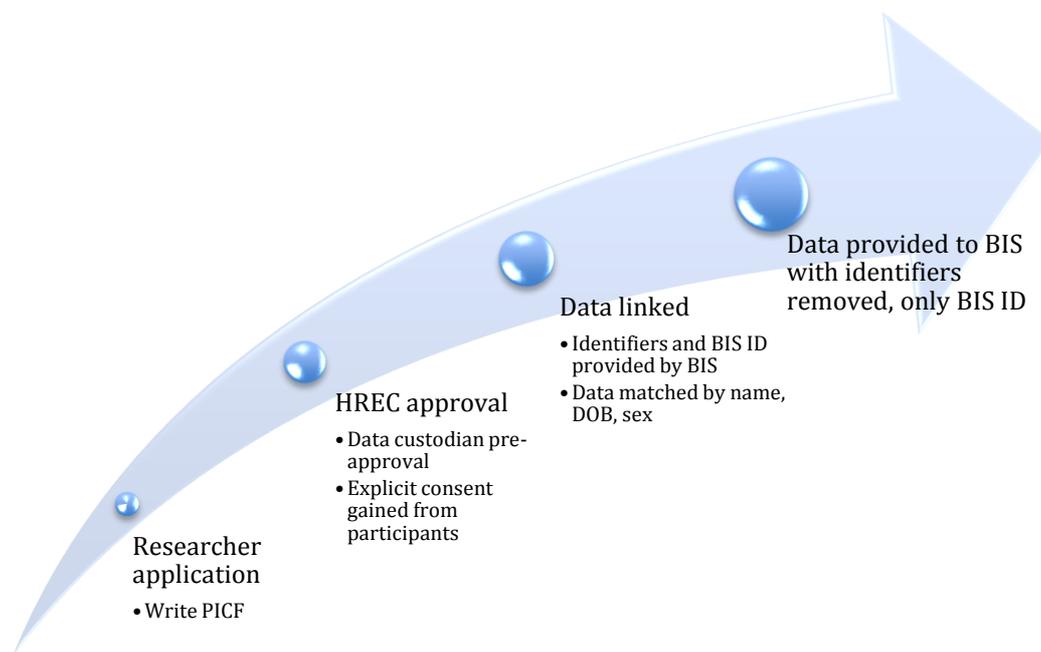
What do you do with the data once you have it?

The de-identified data is kept by the BIS Data Manager, and secured within the BIS offices in the Child Health Research Unit.

If a BIS project requires data, the data manager provides the necessary information to the researcher.

In the case of Solveig's project this would be information such as:

- Strengths and Difficulties Questionnaire answers de-identified by BIS ID
- Brain Games results from the pre-school review de-identified by BIS ID



Who is involved in the Data Linkage process? *Adapted from the Menzies Institute*

- **Data Custodians** – effectively the 'owners' of data. Data custodians work within an organisation or agency (such as government departments) and are responsible for the collection, use and dissemination of data. Data custodians may manage administrative or research datasets and collect and store personal information (such as name, address, date of birth) as well as information about the person (eg. health diagnosis or treatment details).
- **Data Managers** – Receive and store de-identified data for use by researchers within the BIS research group
- **Researchers** - the people who use the anonymised linked data for the purpose of analysis and research. Research projects undergo an extensive application process and must be approved by a relevant Human Research Ethics Committee (HREC) as well as relevant data custodians.

- **Data Linkage Units** - the organisations who link datasets together and create Linkage ID's, which allow data from different sources and organisations to be linked together.

Is data linkage new? *from SA-NT Datalink website*

Data linkage has been used for many years by researchers primarily looking at the relationship between disease and lifestyle factors such as smoking and coronary disease. It is thought that the discovery of the relationship between Thalidomide and congenital defects is an early (and renowned) example of data linkage.

Technological advances and the ability to link large, seemingly unconnected, databases now provides the means for health and social researchers to examine relationships that may not be clearly evident but nonetheless just as important. For example a researcher may wish to investigate whether there is a relationship between early literacy scores and criminality? By linking education and justice records, the researcher will be able to investigate this relationship.

A recent study undertaken in France linking data between educational levels and cancer mortality over a fifteen year period demonstrated a strong relationship between lower educational levels and certain types of cancer in men but not in women. The researchers commented:

"Recently, it was made possible to carry out a mortality follow-up of a representative sample of the French population, through record linkage between population census records and the national French cause-of-death file. This linkage possibility allowed for the first time in France analyses of social inequalities by cause of death that did not suffer from the previous methodological problems."

Menvill, G., et al (2005) Social inequalities and cancer mortality in France 1975-1990. *Cancer causes and control*. June 2005 #13.

Technological advances are now also enabling researchers to work with data bases whose sizes are measured in terabytes, or trillions of bytes, thereby allowing for the comparison of very large sets of data.