

DATA LINKAGE PARTICIPANT INFORMATION & CONSENT

HUMAN RESEARCH ETHICS COMMITTEE APPROVAL NUMBERS: HREC/13/SAH/106

INVESTIGATORS: BetterStart and Goodstart Research Team

Dear Parent/Guardian

Goodstart is a non-profit organisation, committed to strengthening the Australian evidence base by commissioning and collaborating research and evaluation to ensure children have the outcomes they need for school and life.

Goodstart is seeking your consent to use and disclose information collected about you and your child to create de-identified data (not linked to a name) which can be linked with data from other agencies and organisations held by BetterStart's ethically approved, Better Evidence, Better Outcomes, Linked Data platform (BEBOLD), led by Professor John Lynch at the University of Adelaide. The goal of 'joining up' Goodstart information with the BEBOLD platform is to help improve the services that Goodstart offers and support healthy child development for all children.

1. Introduction

This form tells you about the project to help you decide if you want to take part in the research. Please read this information carefully and ask questions about anything that you do not understand or want to know more about.

After reading this information, if you agree to take part in the project, please confirm your consent at the end of the form.

There are no costs associated with participating in this research project, nor will any payment be made for participation.

2. What does participation in this research project involve?

Data linkage is the process of identifying, matching and merging records that correspond to the same person from several datasets or even within one dataset.

Goodstart proposes to disclose limited information required to link individuals across multiple datasets, being your and your child's full name, address, date of birth, gender and date of enrolment, to SA NT DataLink. SA NT DataLink's role is only to link records using this information. They have no access to any other information nor any further role in the project. Their job is to match individual's records and create a "project specific linkage key" – essentially a random number - that is then passed back to Goodstart.

Goodstart will use the project specific linkage key provided by SA NT DataLink to attach records, remove names and Goodstart specific identifiers, and create a file which is completely de-identified. Goodstart will then provide this de-identified file to BetterStart. This de-identified information could include information such as place and country of birth, if your child has a health care card, if your child is Aboriginal and/or Torres Strait Islander, languages spoken at home, if your child has any additional needs or is eligible for additional funding, attendance patterns and development progress outcomes as well as parent/guardian demographics.

Once added to the BEBOLD platform, the de-identified data from Goodstart will be linked to other deidentified data held on the platform. The data can be accessed, as deidentified group data, by researchers approved by the Human Research Ethics Committee for approved research.

3. What is the purpose of this research?

The project seeks to link information held by Goodstart about you and your child with other data held about you and your child on the BEBOLD platform, being de-identified administrative datasets from government agencies, hospitals, schools etc from pregnancy onwards including:

- parent/ guardian demographics (*eg country of birth, marital status, highest level of education achieved, etc*).
- health - *medical and health information collected in health services such as hospitals.*
- education and wellbeing – *early childhood care, education and wellbeing information.*
- social and welfare – *information collected about different types of services provided including housing, financial, child protection, community and family support and justice*

The purpose of 'joining up' Goodstart information with the BEBOLD platform is to assist research to achieve better outcomes in the health, wellbeing and development of children.

Only researchers approved by the Human Research Ethics Committee will have access to any data on the platform for approved research.

Importantly, approved researchers accessing linked data will never be told who individual children or parents are and only ever undertake research looking at outcomes for large groups of people.

4. Do you have to agree to take part in this research project?

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. Any decision you make regarding participation will not affect any service received from Goodstart.

5. What are the possible benefits of taking part?

There will be no immediate benefit to participants in this research. However, possible long-term benefits to the broader population may include better outcomes in the health, wellbeing and development of children.

Goodstart, BetterStart nor any of its research personnel will receive a personal financial benefit from your involvement in this research project (other than his or her ordinary wages).

6. How is the risk of my data being re-identified addressed?

The risk of any individual being identified in the data has been addressed through the data-linkage process, in accordance with the Office of the Australian Information Commissioner's De-Identification Decision-Making Framework, to protect the privacy of all individuals. All approved researchers who use de-identified data are also bound by ethical and confidentiality agreements that make sure outputs are never presented in a way where any individual can be re-identified.

7. What if I withdraw from this research project?

If you do consent to participate, you may withdraw at any time. If you decide to withdraw from the project, please notify the Goodstart Representative (see point 10). If you decide to withdraw from the project, Goodstart will not provide any additional information to the BEBOLD platform. You should be aware that data included in the project up until that time would remain a part of the research project as it would be impossible to delete historical information without re-identifying individuals.

8. How will your deidentified, linked information be stored?

The de-identified, linked dataset added to the BEBOLD platform will be stored on the University of Adelaide servers. It uses high security username/password access for accessing the files and only authorised research personnel in secure locked environments have access to the data.

SA NT DataLink is a specialised data linkage agency, subject to Australia's strict privacy laws and operates under strict data security protocols and implements high-level physical security measures. Their security protocols are in accordance with the Australian Government Protective Security Policy Framework, the Population Health Research Network Information Governance Framework, and the NHMRC Code for Responsible Conduct of Research. For further information, please see <https://www.santdatalink.org.au/security>. Once SA Datalink create linkage keys, any personal information received will be stored and maintained in a master linkage file, located within a secure and protected facility in their Data Link Unit.

9. Who has reviewed the research project?

An independent group of people called a Human Research Ethics Committee (HREC) reviews all research in Australia involving humans. The HREC of the SA Department of Health and Wellbeing (Ref HREC/13/SAH/106) have approved the ethical aspects of this research project.

This project will be carried out according to the National Statement on Ethical Conduct in Human Research (2007). This statement has been developed to protect the interests of people who agree to participate in human research studies.

10. Further information and who to contact

The person you may need to contact will depend on the nature of your query. If you want any further information concerning this project or if the participant has any problems, which may be related to involvement in the project, you can contact any of the following people:

Goodstart Representative:

<i>Name</i>	Leona Olsen
<i>Position</i>	National Manager Impact Measurement – Goodstart Early Learning
<i>Telephone</i>	0406 426 543
<i>Email</i>	lolsen@goodstart.org.au

BetterStart Representative:

<i>Name</i>	Dr Angela Gialamas
<i>Position</i>	Postdoctoral Researcher
<i>Telephone</i>	(08) 8313 0962
<i>Email</i>	angela.gialamas@adelaide.edu.au

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

Reviewing HRECs approving this research and HREC Executive Officers' details:

<i>Reviewing HREC name</i>	SA Department of Health and Wellbeing
<i>Telephone</i>	(08) 8226 8102
<i>Email</i>	Health.Humanresearchethicscommittee@sa.gov.au