



Participant Information and Privacy Notice

This Participant Information and Privacy Notice provides information we must tell you about the Study according to Australian laws and ethics guidelines. For the purpose of this information sheet, 'your child' means Study Youth in The *Footprints in Time* Study.

The *Footprints in Time* Study

Footprints in Time is a voluntary survey that takes place every year. The Study takes 'pictures in time' to develop a 'story' about how children develop and grow. The Study collects information from the same children and their families about different people in their lives, year after year. It started in 2008 with over 1700 Aboriginal and/or Torres Strait Islander babies and children who were 6-18 months or 3 or 4 years old.

The Study is overseen by an Indigenous led Steering Committee. It is funded and managed by the Australian Government Department of Social Services (DSS).

The research acknowledges, respects, and reflects the diversity of Aboriginal and Torres Strait Islander cultures and communities.

Why do we need *Footprints in Time*?

The Study gives you a voice to help everyone learn how children and young people can grow up strong. Your voluntary support of the Study will help communities, governments and Aboriginal and Torres Strait Islander people make decisions about important resources and services for child development for many years to come.

It is about how YOU see:

Your own / your child's: health, learning and development, place in the family and community, culture and identity and significant events.

Your family: parent/carer health, work, education, social circumstances, housing and family issues.

Where you live/ your community: facilities, services, history, social and community issues.

Services: you may or may not be getting, for instance, education, health.

It is your choice to take part or not

It is up to you to decide whether you want to take part in the Study. You can leave the Study at any time, or decide to miss a year if you are too busy.

How does *Footprints in Time* work?

After learning about your rights and choices, if you are interested in participating and consent or assent to participate, you will be asked questions for about 25-30 minutes. Participation in the Study is entirely voluntary and you/your child can say 'no' to take part at any time. You do not get to see how others answer the questions as all responses are private.

Interviews will be conducted by Indigenous interviewers and can take place at your home, place of work, interviewer's accommodation or another place that you and your interviewer have agreed to

meet. Interviews are done using a mix of face-to-face, telephone and videoconference methods. At some points during the interview, computer-assisted interviewing methods are used to keep your answers private, even from the interviewers. This is because some questions can be very personal and the Study would like you to feel comfortable when answering them. As the interviewer does not see any of these responses, you/your child will have greater comfort in refusing questions. Some questions within the interview will have attached recordings. You/your child can choose to listen to the questions like this through headphones or you can read the questions in English without audio. The audio questions are recorded in English, Torres Strait Creole and Djambarrpuyngu by male and female Indigenous interpreters.

If you find any of the questions a bit personal, you can skip any question you do not want to answer, you can pause at any time and have a break, or you can end the interview at any time if you do not wish to continue. Your interviewer can provide contact details of support services for you to contact if you want them.

What's new in this year's surveys (Wave 17 Pilots)?

- **Linking Medicare data with The *Footprints in Time* Study**

We will ask consent from Study Youth to link their Study data with their data from the Medicare Benefits Schedule (MBS) and/or Pharmaceutical Benefits Scheme (PBS) and Australian Immunisation Register (AIR).

The reason we are asking Study Youth to link this data is to make this survey as short as possible. By doing this, we will have important information on Study Youth's health such as vaccination status, how they go to see doctors and what medicines they take. We can use this information to see how Study Youth are growing up strong.

We will ask Study Youth permission every year to link this data, and if they say yes this year, it does not mean they have to say yes next year. It is their choice to link this data and they can let us know if they change their mind by speaking with the interviewer, calling 1800 106 235 or by emailing LSIC@dss.gov.au.

The data and information from *Footprints in Time* **will not** be shared with MBS, PBS and AIR. This linking is one-way. The MBS, PBS and AIR data will be included with Study Youth's *Footprints* answers.

It is entirely up to you to give consent for Medicare linking, just like any other consent for the Study.

- **New questions for Study Youth and Primary Carer**

We will ask you about physical activity, food and gambling as new questions. We would like to know if these questions work for you. If you have any feedback, concerns or queries, please let your interviewer know.

Privacy and your/your child's personal and sensitive information:

Your personal information collected in the Study is protected by Australian law, including the *Privacy Act 1988* (Cth) (**Privacy Act**). This means that the information that you provide us with, cannot be linked to who you are as an individual, and you will not be able to be identified from the data.

Your/your child's personal information may only be collected by DSS, or a contracted service provider on behalf of DSS with your permission. However, all of these institutions are regulated in the ways they collect, use and disclose your/your child's personal information.

- 1. Parents and carers – Collection of your and/or your child's personal and sensitive information**

This Study will ask you questions that will require you to share your, or your child's personal information. Personal information includes information about you or your child's name, address, contact details, date of birth and Aboriginal and/or Torres Strait Islander status. Personal information

also includes sensitive information, is about you or your child's cultural or language background, racial or ethnic origin, health and any criminal record.

2. Study Youth – you, your parents or carers and your teacher's personal and sensitive information

Personal and sensitive information about you may be collected from yourself and your parents/guardians. If you or your parent provide permission, personal and sensitive information may also be collected about you from your English teacher, school principal, or Aboriginal and Torres Strait Islander Education Worker. This includes information about your school, behaviour, programs and activities.

3. Other members of households where an interview is conducted

If you live with someone who participates in a *Footprints in Time* interview, some personal and sensitive information may be collected about you, such as how you are related to the Study Youth, your age and Aboriginal and/or Torres Strait Islander status. This information enables us to better understand the household environment Study Youth are living in.

Your information is collected and managed in the same way as other Study participants. You may choose to have your personal information not included in the Study at any time.

How your/your child's personal information may be used and disclosed

The personal information you provide will be used by DSS and its contracted service providers for the purpose of:

- statistical use, such as looking at and reporting on how Aboriginal and Torres Strait Islander children and youth are learning and growing; and
- if necessary, and if you and/or your child have agreed, accessing your/your child's Commonwealth, State or Territory agency records (e.g. Centrelink) to get new contact details, including a new address or phone number.

All personal information collected by the Study will be kept private (confidential) and will only be disclosed where:

- the disclosure is authorised or required by Australian law, such as where there is a risk of harm to yourself or others; or
- you give permission.

Who sees my raw personal data?

DSS' employees, and the DSS contracted data capture provider will be able to see your/your child's data. Strict procedures are followed to ensure that only authorised people have access to your/your child's data and that all *Footprints in Time* employees and the DSS contracted data capture providers staff comply with the Privacy Act.

Who sees my personal and sensitive data?

Your/your child's personal and sensitive information will be removed from your/your child's responses before it is shared with anyone else. This means the data is confidentialised and researchers and policy makers will not know your/your child's name, address, or other identifying information. Researchers and policy makers will look at your/your child's responses and put the information into data sets that may be published in reports.

The confidentialised data you/your child provides may be shared with:

- DSS' contracted service providers, such as organisations contracted by DSS to look at and write reports on the data;
- other government agencies and entities; and
- researchers, such as students and academics at universities.

Your privacy is very important to DSS and its contracted service providers. The data that DSS, or its contracted service providers gives to the above third parties **does not** include your personal and sensitive information.

Researchers must apply to access the data. Their application must be approved by DSS and strict procedures are followed to ensure that only authorised people have access to the data.

DSS regularly releases reports with *Footprints in Time* data collected from the Study in the prior years. If you tell us you don't want to include your responses or responses concerning you in *Footprints in Time* data, we will remove it from future data releases.

Transfer of data overseas

From time to time, DSS provides confidentialised data about the *Footprints in Time* Study to researchers located overseas. All authorised users of *Footprints in Time* data, located in Australia or overseas, have to abide by strict data use and confidentiality conditions. No one will know who you are or which answers you gave.

Intellectual property

Under Australian law, DSS owns the intellectual property of survey information, including your/your child's responses to the Study. This means your/your child's responses can only be accessed and used with the approval of DSS. DSS can take action against any person or organisation who accesses, uses or shares your/your child's responses in a way that has not been approved by DSS. This helps to make sure that your/your child's responses and privacy rights are protected.

Doing research the right way

You have rights under Australian law we want you to know about. There are guidelines for Aboriginal and Torres Strait Islander researchⁱ by which the Australian Institute of Aboriginal and Torres Strait Islander Studies (**AIATSIS**) Ethics Committee and other Human Research Ethics Committees operate.

Ethical clearance has been obtained for *Footprints in Time* from the AIATSIS, Human Research Ethics Committee.

Benefits and gifts

This Study is about Aboriginal and/or Torres Strait Islander children and their future. You will not receive any direct benefits from taking part. However, to thank you for the time you spend on the survey, we offer you the following remuneration.

- In Wave 17 (pilot surveys in 2023 and main surveys in 2024), remuneration is provided up to the following values: \$60 per Primary Carers
- \$40 per Other Carers
- \$90 per Study Youth
- \$60 per family for completion of administrative forms

This totals \$250 for a family with 2 main carers and a Study Youth if all forms and surveys are completed. You can choose between Coles, Woolworths, IGA, IBIS, Foodland, EB Games, Local Store Credit, or E-gift cards. You also have the choice of a *Footprints in Time* towel or t-shirt. The \$60 family remuneration for completion of administrative forms goes to the Study Youth living independently or aged 18 or over, or to Primary Carer where Study Youth is aged under 18 and living under their care. This remuneration is provided using the same range of gift cards and other options. The gift cards cannot be used to purchase alcohol and tobacco products or any forms of gambling.

Consequences of not providing information

There will be no fines or punishment if you do not wish to provide any personal or sensitive information to DSS or its contracted service providers. You are under no obligation to participate in the Study and participation is voluntary. You can decide not to take part in the Study at any time, even if you have been taking part for many years.

Results and reports

Lots of reports and promotional information are produced as the Study progresses. We regularly send out information packs to participants of *Footprints in Time* which include updates on the Study's progress across Australia and in your community. If you wish to access any DSS reports about the Study, they are available on our website at www.dss.gov.au/lxic. We are also happy to provide them to you if you get in touch with us using the contact details below.

Details of publications and reports by other approved researchers using *Footprints in Time* data are available at: <http://flosse.dss.gov.au>

Further information and contact details

You are welcome to share any suggestions or concerns. We value your feedback! Visit the *Footprints in Time* website at: www.dss.gov.au/lxic or ring **1800 106 235** or email us at lxic@dss.gov.au.

Concerns?

If you have any concerns or complaints you can contact the Executive Officer, Human Research Ethics Committee of the AIATSIS by email: Ethics@aiatsis.gov.au.

If you would like to access or seek correction of the information we have collected, you can contact the *Footprints in Time* team directly by email: LSIC@dss.gov.au or contact the DSS Feedback and Complaints team at complaints@dss.gov.au. DSS' privacy policy also contains details of how you can make a complaint to DSS about a breach of your privacy rights and how DSS will handle such a complaint. DSS' Privacy Policy is available on the DSS' website at www.dss.gov.au/privacy-policy. [You can also request a copy from DSS by email at DSSfeedback@dss.gov.au.](mailto:DSSfeedback@dss.gov.au)

Remember!

You can contact the *Footprints in Time* team by email at LSIC@dss.gov.au or on **1800 106 235**.

ⁱ The Ethical conduct in research with Aboriginal and Torres Strait Islander peoples and communities: guidelines for researchers and stakeholders (2018) issued by the National Health and Medical Research Council of Australia, is the main document under which these guidelines are issued