



Australian
Human Rights
Commission

Australian Human Rights Commission inquiry

People born with variations in sex characteristics and medical interventions

INTERVIEW PARTICIPANT INFORMATION STATEMENT

What is the inquiry about?

You are invited to take part in a research inquiry about **how best to protect the human rights of people born with variations in sex characteristics in the context of medical interventions.**

You have been invited to participate in the inquiry because you have identified yourself as someone born with a variation in sex characteristics, a parent or carer, a medical professional or other stakeholder who is involved or interested in the topic of the inquiry.

This Participant Information Statement tells you about the research inquiry. Knowing what is involved will help you decide if you want to take part in the research. Please read this sheet carefully and ask questions about anything that you don't understand or want to know more about.

Participation in this research inquiry is voluntary.

By giving your consent to take part in this inquiry you are telling us that you:

- ✓ Understand what you have read.
- ✓ Agree to take part in the research inquiry as outlined below.
- ✓ Agree to the use of your personal information as described.

You will be given a copy of this Participant Information Statement to keep.

Who is running the inquiry?

The inquiry is being carried out and funded by the Australian Human Rights Commission.

What is involved in the inquiry?

The inquiry involves a national consultation phase that will start in the second half of 2018. It will include group and individual interviews, and a call for written submissions.

You can choose to be involved in any, all, or none of these components. This participant information statement provides further information on the interview component.

What will the interview involve for me?

Individuals with lived experience and parents/carers will have the option of being interviewed individually or as part of a group. Medical professionals, government and other stakeholders will be interviewed in group interviews.

The questions in the interviews will be structured differently depending on the group of interviewees. If applicable, we may ask you questions about you or your child's personal information relating to your age and type of variation and your experiences in the context of medical interventions; questions relating to medical knowledge and practices around the management of variations; or questions relating to the legal or policy implications involved. You do not have to answer any questions you do not want to.

Group interviews will take approximately 45–60 minutes and individual interviews will take approximately 30 minutes. There are no costs associated with participating in this research inquiry.

Due to the personal and sensitive nature of the topic of this inquiry, participation in the interview may be distressing for some participants. You are free to leave the interview at any time.

How much of my time will the interview take?

Group interviews will take approximately 45–60 minutes and individual interviews will take approximately 30 minutes.

Who can take part in an interview?

Anyone aged 18 or over who expresses interest may be invited for an interview if they:

- were born with a variation in sex characteristics
- are a parent or carer of a person born with a variation in sex characteristics
- are a medical professional
- represent a service provider or advocacy body
- represent government departments.

Do I have to be in an interview? Can I withdraw from the interview once I've started?

Being in an interview is completely voluntary and you do not have to take part.

You are free to leave the interview at any time.

At any point during or after the interview, you may request that the information you provided not be used in the inquiry up until the time the final report has been published.

Are there any risks or costs associated with being in the interview?

Aside from giving up your time, we do not expect that there will be any risks or costs associated with taking part in this interview.

Are there any benefits associated with being in the inquiry?

We hope to use information we receive from this research inquiry to improve decision-making and processes regarding medical interventions involving people born with variations in sex characteristics.

What will happen to information about me that is collected during the inquiry?

By providing your consent, you are agreeing to us collecting personal information that you choose to provide in the interview about you for the purposes of this research inquiry.

An audio recording may be made with your consent for internal use to ensure the accuracy of our notes and assist with research analysis.

Your information will only be used for the purposes outlined in this Participant Information Statement, unless you consent otherwise. Your information will be stored securely and your identity/information will be kept strictly confidential, except as required by law. Inquiry findings may be published, but you will not be individually identifiable in these publications.

We will store information about you in an electronic format at the Australian Human Rights Commission. Information will be stored in accordance with the *Archives Act 1983* (Cth), the *Privacy Act 1988* (Cth) and the *Australian Human Rights Commission Act 1986* (Cth). This may mean that some unidentifiable personal information may be required to be stored in perpetuity.

Information collected during the interview will be de-identified. Study findings may be published, but you will not be individually identifiable in these publications. Organisations may be identifiable only where the organisation has given permission for the Commission to publish information attributable to that organisation.

Can I tell other people about the inquiry?

Yes, you are welcome to tell other people about the inquiry.

What if I would like further information about the inquiry?

If you would like to know more at any stage during the inquiry, please feel free to contact Stephanie Lum, Project Support Officer at the Australian Human Rights Commission on (02) 9284 9650 or Daniel Nguyen, Specialist SOGII Adviser at the Australian Human Rights Commission on (02) 9284 9657 or sogii@humanrights.gov.au.

Will I be told the results of the inquiry?

The Australian Human Rights Commission intends to publish a report on the results of this research inquiry. The consultation phase of the project will start in the second half of 2018. The Commission will publish a report, with recommendations for reform, after the consultation process is complete.

This report will be publicly and freely available via the Australian Human Rights Commission's website.

Disclosure of interests

One of the project officers is a member of Androgen Insensitivity Syndrome Support Group Australia and has taken a leave of absence from the board of Intersex Human Rights Australia.

One of the project officers is a de facto partner of a senior adviser to a government minister who may be involved in state/territory reform.

What if I have a complaint or any concerns about the inquiry?

Research involving humans in Australia is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this inquiry have been approved by the HREC of the University of Sydney (HREC Number: 2018/338). As part of this process, we have agreed to carry out the inquiry according to the *National Statement on Ethical Conduct in Human Research* (2007). This statement has been developed to protect people who agree to take part in research studies.

If you are concerned about the way this inquiry is being conducted or you wish to make a complaint to someone independent from the inquiry, please contact the university using the details outlined below. Please quote the inquiry title and protocol number.

The Manager, Ethics Administration, University of Sydney:

- **Telephone:** +61 2 8627 8176
- **Email:** human.ethics@sydney.edu.au
- **Fax:** +61 2 8627 8177 (Facsimile)

Where can I go for further support?

If you are feeling distressed or would like further support, you can contact Androgen Insensitivity Syndrome Support Group Australia (aissgaustralia@gmail.com), Lifeline (13 11 14) or QLife (1800 184 527).