



**Australian
Human Rights
Commission**

Australian Human Rights Commission inquiry

People born with variations in sex characteristics and medical interventions

WRITTEN SUBMISSIONS PARTICIPANT INFORMATION STATEMENT

1 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 the 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.

2 Who is running the inquiry?

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

3 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 written submission component.

4 What will providing written submissions involve for me?

A consultation paper and a number of accompanying “snapshot” sheets have been published for the inquiry. These materials discuss some of the key human rights issues that have been identified in relation to this population in the context of medical interventions.

You may choose to provide a written submission to the inquiry, in response to the questions raised in the consultation paper or snapshots, or separately.

You do not have to answer any questions you do not want to or provide any information you feel uncomfortable with sharing.

There are no costs associated with participating in this research inquiry.

5 How much of my time will a written submission take?

There is no word limit on the length of a written submission and therefore the time it will take to prepare will vary.

6 Who can provide a response?

Anyone aged 18 or over.

7 Do I have to provide a written submission?

No, contributions are voluntary and you do not have to take part.

Once you have provided a written submission, you may request that the information you provided not be used in the inquiry up until the time the final report has been published.

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

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

9 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.

10 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 your written submission about you for the purposes of this research inquiry.

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 from written submissions will be de-identified. Written submissions on behalf of an organisation will also be de-identified unless the organisation has explicitly stated that information they have shared is able to be attributed to that organisation.

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.

11 Can I tell other people about the inquiry?

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

12 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.

13 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.

14 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.

15 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 the 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 the 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)

16 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).