

PROTECTING THE HUMAN RIGHTS OF PEOPLE BORN WITH VARIATIONS IN SEX CHARACTERISTICS

EVIDENCE OF OUTCOMES

The outcomes of surgical and non-surgical medical interventions are poorly evidenced in Australia and internationally.

There is little data about the number or type of medical interventions involving people born with variations in sex characteristics, the optimal timing of interventions, and the long-term physical and psychological impacts of undertaking interventions or not undertaking interventions.

A lack of data directly affects the ability of individuals to make informed decisions about their healthcare. It can mean that decisions may be made based on assumptions rather than evidence.

Discussion questions:

- What are the current Australian sources of data on:
 - the number and nature of medical interventions involving people born with variations in sex characteristics
 - long-term outcomes of medical interventions involving people born with variations in sex characteristics
 - long-term outcomes of people born with variations in sex characteristics not undertaking medical interventions?
- How adequate are the current Australian sources of data for each of these areas?
- What barriers exist to nationally consistent data collection?

This sheet forms part of the Australian Human Rights Commission's inquiry into how best to protect the rights of people born with variations in sex characteristics in the context of medical interventions. These sheets are designed to prompt thoughts and considerations for written submissions. Submissions do not need to be limited to the issues raised in this sheet.



Writing a submission? Please complete a Participant Consent Form and attach it to your submission. Submissions should be sent by email to sogii@humanrights.gov.au or by post to GPO Box 5218, Sydney NSW 2001.

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. Submissions on behalf of organisations may be identifiable only where the organisation has given permission for the Commission to publish information attributable to that organisation.

For further information about the project, please email sogii@humanrights.gov.au or phone 02 9284 9650 or 1300 369 711.

Consultation for this project has been approved by an external, independent Human Research Ethics Committee (HREC). Any queries or concerns about ethics may be directed to the University of Sydney Human Research Ethics Committee by email to human.ethics@sydney.edu.au, citing reference 2018/338.