



**Australian  
Human Rights  
Commission**

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

### **PRIVACY**

People born with variations in sex characteristics can experience breaches of their privacy in the context of medical interventions.

Privacy includes both the protection of people's physical selves against unwanted invasive procedures, as well as protecting and providing access to an individual's own health information.

Some people born with variations in sex characteristics have been subject to unwanted medical photography and examinations or examinations in front of more people than necessary.

These behaviours can intrude on a patient's privacy and, particularly for children, these experiences can normalise these behaviours and create issues around boundaries and consent.

People born with variations in sex characteristics have also faced difficulties in accessing their complete medical records. In Australia, the *Privacy Act 1988* (Cth) and the Australian Privacy Principles regulate how health organisations collect and handle personal health information and how individuals can access information about them.

Access can be refused where it could threaten someone's life, health or safety, or impact on someone else's privacy. This means that access can be refused where a health provider has reasonable grounds to believe that providing access may cause that person significant distress or lead to self-harm or harm to another person. Further, medical records can be destroyed after a certain period of time and this can act as a barrier to individuals finding out about their medical histories later in life.

#### **Discussion questions:**

- How can medical practices best respect the privacy of people born with variations in sex characteristics?
- Have you faced any difficulties accessing your medical records?
- How can access to medical records and histories be improved?



## Australian Human Rights Commission

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](mailto: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](mailto: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](mailto:human.ethics@sydney.edu.au), citing reference 2018/338.