



Royal Children's Hospital Multidisciplinary Team information and participation Consent Form

Department of Endocrinology, urology & Gynaecology



To ensure you and your family receive quality care from the Royal Children's Hospital we provide a multi / interdisciplinary approach to caring for our patients who have a variation in their sex characteristics.

This team includes:

Endocrinology – Doctors that specialise in the endocrine system and hormones

Urology – Doctors (surgeons) that specialise in the urogenital tract and its function

Paediatric and Adolescent Gynaecology – Doctors (surgeons) that specialise in the urogenital tract & specifically female health

Genetics (Victorian Clinical Genetic Service) – Doctors that specialise in human genetics - inherited characteristics and the function of genes in the body

Complex Biochemistry – Perform diagnostic biochemistry assays to understand chemical processes within the human body

Anatomical Pathology - Doctors that examine human tissue's function and structure

Genetic Scientists (Victorian Clinical Genetic Service) – Scientists that perform diagnostic genetic testing for patients

Children's Ethics Centre – Bio-Ethicists that provide discussion reviewing ethical principles when making clinical decisions for patients

Reproductive Development group (Murdoch Children's Research Institute) – Scientists who have a focus on understanding sex determination (our reproductive systems)

Usually when you or a family member has a new diagnosis relating to a variation in their sex development our team will review the case in a multidisciplinary team meeting – where many new diagnoses and review cases are discussed to ensure our team reaches a consensus in care.

This multidisciplinary team meeting is a partnership between the clinical team at the Royal Children's Hospital and the clinical team at Monash Children's Hospital, as well as participation of other interstate and international expert clinicians. All members of this meeting have signed confidentiality and privacy agreements. You / your child will be de-identified (given a pseudonym) identifying information such as name, birth date, and home address will **not** be used in the multidisciplinary team meeting.

These monthly meetings include key members from a range of disciplines meeting to discuss individual care to ensure each patient/person has:

- Clinical review in relation to clinical guidelines and practice
- Care has been reviewed with all relevant disciplines
- Consideration for the long-term health and wellbeing of person
- Consideration of surgery or hormone interventions and the alternative options
- All members of the clinical team are working together
- All appropriate referrals are made
- Identify best clinical management team

These meetings also include education and presentations from various disciplines to ensure the team are up-to-date with current guidelines, diagnostic tools, and human rights considerations.

I consent for (name of patient).....
To have their case reviewed at this multidisciplinary team meeting

Name of parent/Guardian (or individual/patient).....

Signature.....

Date

More information about your/your child's care at the RCH.

Typically, individuals and families will not see all the members of the multidisciplinary team, instead only one or two different clinicians. There are sometimes options to see clinicians together (ie: your urologist and endocrinologist together in a clinic appointment) or to see them on the same day if you prefer.

If you live far from the hospital, there may be an option to have a 'Telehealth appointment' where you video call in to your specialist using your home computer or visit your local paediatrician and have a telehealth appointment together with your RCH specialist/s.

After a new diagnosis

It is likely there will be multiple appointments at the RCH for the first few months, this is to gather all relevant clinical information for the team to provide the best care, and secondly, so individuals and families are able to ask questions and receive support from the team. It is important that individuals are informed about their variation early in life and our specialist team can help with this.

You can speak with a member of the team if you would like to discuss these appointments or access some further support. Support like counselling, psychology or peer support can be really useful.

In the following years it is likely that you will see specific specialists once or twice a year to follow up health needs. All families have ongoing follow up care and access to information as things change over time. For some kids, appointments during adolescence may be more frequent. In late adolescence we will work with families to make the appropriate referrals to adult health services, kids can access our RCH transition team if they/ you would like support to transition into adult health services.