



POSITION STATEMENT OF THE AUSTRALASIAN PAEDIATRIC ENDOCRINE GROUP ON THE CLINICAL CARE OF CHILDREN WITH DSD

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Version 1.1

Executive summary:

- I. Atypical development of the chromosomal, gonadal or genital sex in an individual is termed a difference/disorder of sex development (DSD) according to the World Health Organisation, though the Australasian Paediatric Endocrine Group (APEG) recognises the terminology is contentious.
- II. APEG acknowledges that some past clinical interventions led to harm, and APEG is committed to working with all stakeholders to achieve optimal outcomes in future.
- III. APEG supports the development of clinical practice guidelines to underpin decision-making in the care of affected individuals. The clinical guidelines should include standards for informed consent and for person-centred decision-making.
- IV. APEG strongly recommends the establishment of a funded clinical registry to document management and outcomes in affected individuals. This is essential to inform evidence-based clinical care.
- V. APEG supports appropriately funded mandatory multidisciplinary team review of complex management decisions affecting children with DSD, underpinned by clinical practice guidelines.
- VI. APEG opposes legislative prohibition in the clinical care of affected children, due to the significant risk of unintended harm.

Background:

The Australasian Paediatric Endocrine Group (APEG) is the peak professional body representing paediatric endocrinology in Australasia and is committed to high standards of clinical care, advocacy, education, research and stakeholder relationships. Paediatric endocrinology is a field of medicine with primary involvement in the care of many children with atypical development of their chromosomal, gonadal or genital sex, though care is provided in concert with multiple other clinical specialty groups. Developmental variations in sex characteristics are termed differences/disorders of sex development (DSD) according to the World Health Organisation's International Classification of Disease, though APEG recognises other terms are often used, and some individuals with certain differences do not consider that they should be included under this umbrella.

Care of a child with DSD often involves complex considerations of potential implications for the child. These include monitoring for and minimising the risk of adverse health outcomes, including cancer and other health issues, preserving the potential for fertility, supporting urinary continence, promoting the capacity to have satisfying sexual relations, leaving options open for the future and respecting the parents' wishes and beliefs¹. APEG recognises these complex considerations and acknowledges that certainly some past clinical interventions have led to harm. Careful consideration is therefore required around all interventions, particularly where the child is developmentally unable to be involved in decision-making themselves. APEG is committed to working with stakeholders to achieve optimal outcomes in future.

Recommendations:

1. Development of national clinical practice guidelines and standards of care

APEG strongly recommends the funding and resourcing of national clinical practice guidelines and standards of care as a high priority to provide a framework within which best practice care can be provided.

The development of clinical practice guidelines should include review of best current medical evidence, and should incorporate a process of multidisciplinary decision-making, informed consent, assessment of the impact

of deferral of treatment and stakeholder consultation, including input from young people themselves. The guidelines should define which clinical interventions need to be referred for oversight, and which interventions should routinely occur, such as offer of referral to peer support groups.

Development of the guidelines should occur across disciplines and include surgeons, psychologists and ethicists, as well as with advocates and peak bodies. APEG recommends guideline development consistent with the rigorous Australian National Health and Medical Research Council (NHMRC) guideline development process, which includes requirement for stakeholder involvement and for regular updating.

2. Establishment of a national clinical registry

Evidence regarding the outcomes of intervention and deferment of intervention is often unavailable, or insufficient to support mandated pathways of care. Research in this area is essential, in order to provide informed care leading to the best outcomes. APEG strongly supports the funding of national longitudinal research registries, which with informed consent record the clinical outcomes of individuals with DSD across the lifespan, the results of which will inform future clinical practice guideline revisions.

3. Requirement for multidisciplinary oversight of complex decision-making

APEG supports a mandatory requirement for multidisciplinary team review of complex treatment decisions. This should be reserved for defined circumstances and underpinned by clinical practice guidelines. The requirement for funded clinical and non-clinical expertise on the multidisciplinary team is supported, and it should include representation from medical, surgical, mental health and bioethical disciplines and participants independent of the treating practitioners. It is APEG's view that governance of the multidisciplinary body or bodies must have a health focus. This is consistent with international best practice². Standardised requirements around reporting and documentation (including provision of printed material to children and guardians) are recommended.

APEG acknowledges that not all children in Australasia currently have access to multidisciplinary team review of care. Appropriate resourcing of such teams is required by governments in order to enable this need, including ensuring access for and liaison with local care providers in regional and rural settings. The resourcing should be sufficient so as not to cause harm associated with delays in decision making.

Legal oversight within the Family Court of Australia has previously been utilised, however this legal structure lacked the clinical expertise and timeliness required to provide independent review of management decisions. Perversely, past legal processes have increased the risk of serious harm, including development of gonadal cancer, due to treatment delay. Placing bureaucratic obstacles in front of clinical care for children has the potential to cause harm, due to the complex considerations which do not lend themselves to the rigidity of individual case law. APEG is opposed to the legislative prohibition of clinical care.

Conclusion:

APEG represents clinicians and researchers who all aim to maximise positive outcomes for children with DSD. We are continuously reviewing and advocating for evidence-based, best practice care and are committed to engaging with children and their families. We look forward to improving the processes for decision-making in clinical care and will continue to work together with partner stakeholders in order to achieve the best possible outcomes.

¹ Gillam, Hewitt, Warne. Ethical principles for the management of infants with disorders of sex development. *Horm Res Paediatr*. 2010

² Lee, Nordenstrom, Houk et al. Global disorders of sex development update since 2006: perceptions, approach and care. *Horm Res Paediatr* 2016

This document was developed by the APEG DSD Subcommittee and can be cited as:

J.Hewitt, J.Walker, M.O'Connell, E.Wiltshire, E.Sharwood, L.Graves, G.Price, C.Hanna, E.Tham, E.Pelosi, A.Sinclair, L.Conwell, H.Woodhead and P.Hofman on behalf of the Australasian Paediatric Endocrine Group (2021). Position statement of the Australasian Paediatric Endocrine Group on the clinical care of children with DSD. Sydney, Australia.