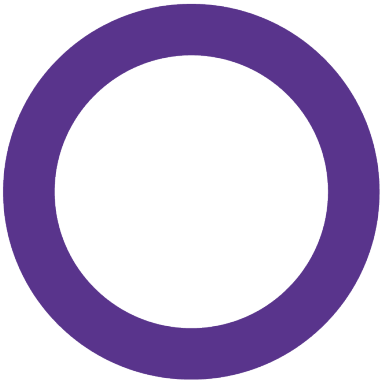

InterAction
for Health and
Human Rights

Decision-making by Australian hospital multidisciplinary teams regarding treatment of children with innate variations of sex characteristics, 2018-2023

An analysis of redacted information produced by Freedom of Information requests, prepared by Morgan Carpenter, PhD, on contract to Equality Australia for InterAction for Health and Human Rights.

Morgan Carpenter, PhD
2025

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2 InterAction and Dr Morgan Carpenter

This paper is written by Morgan Carpenter PhD, under contract to Equality Australia by InterAction for Health and Human Rights.

InterAction for Health and Human Rights is a new name, following the merger of Intersex Peer Support Australia (also termed the AIS Support Group Australia) into Intersex Human Rights Australia. InterAction is an intersex community-controlled charity. It promotes the health and human rights of people with innate variations of sex characteristics (also termed intersex variations or differences of sex development) through policy and advocacy work, and through delivery of psychosocial and peer support services, education and training.

Dr Carpenter is the Executive Director of InterAction for Health and Human Rights. A human rights advocate with lived experience of an innate variation of sex characteristics, he has 20 years of experience in intersex organising, including as a co-founder of Intersex Human Rights Australia, one of InterAction's two founding organisations, and the head of its Policy Program since 2013. In 2013 he designed the intersex flag around the concepts of bodily autonomy and bodily integrity, and made it freely available.

Dr Carpenter is also an Associate Professor and bioethicist at Sydney Health Ethics in the University of Sydney School of Public Health where he leads Interconnect Health Research, a Medical Research Future Fund project on the health and wellbeing of people with innate variations of sex characteristics. He is also a board member of the Australian Capital Territory's Variations in Sex Characteristics Restricted Medical Treatment Assessment Board.

In the intersex movement, his particular interest is to build community, and coherent, ethical and effective infrastructure — including norms, data models, regulation, services, and community-owned organisations. Bringing his expertise and lived experience to bear, he has been named as a significant contributor to 2023 legislative protections from harmful practices in medical settings in the Australian Capital Territory, and to a 2021 Australian Human Rights Commission report on the health and human rights of people born with variations of sex characteristics. He has written extensively on the issues directly addressed in this report and engages tirelessly on a domestic and international stage promoting the health, wellbeing and human rights of people with innate variations of sex characteristics.

The FOI materials were made available in May 2025; analysis was completed in August 2025, and edited in November 2025. Draft versions of this document were kindly reviewed by the InterAction board and Equality Australia team, and proof-read by Katie Gabriel.

3 This analysis and the Freedom of Information requests

Equality Australia initiated requests under Freedom of Information (FOI) legislation in most State and Territory jurisdictions, aiming to ascertain how hospitals treat children with innate variations of sex characteristics (also termed intersex variations or differences of sex development) in collaboration with InterAction. The FOI process provides a mechanism set out in legislation and regulation, protected by law, to promote transparency and accountability in the work of governmental bodies. It gives the public the legal right to access information held by governmental bodies. Governmental bodies can assess whether the information should be made available, and can withhold information, including personal identifiers.

The FOI requests led to the release of around 700 pages of documents, a significant volume of data, redacted at source to protect the privacy of individuals involved. Personal, familial and cultural information has been redacted at source to avoid identification.

The redacted materials provide an exceptional degree of transparency on the work of some clinical multidisciplinary teams (MDTs) working with the population. Most data has been obtained from NSW and Queensland. The Sydney Children's Hospital Network MDT (NSW MDT) has met since August 2012, established during a Senate inquiry into involuntary or coerced sterilisation.[1]

MDTs in South Australia and Western Australia are new, while the Australian Capital Territory and Northern Territory lack their own MDTs.

A Victorian MDT was "formalised" in January 2014.[2] It has since expanded to become a Victorian and Tasmanian MDT, with representation from the Royal Children's Hospital Melbourne, Monash Children's Hospital, Tasmanian Health Service, Victorian Clinical Genetics Service, Murdoch Children's Research Institute and Hudson Institute of Medical Research, This is the only well-established MDT which declined to release redacted case reports in line with the FOI requests. This is regrettable.

The materials provide extensive evidence of situations where multidisciplinary teams lack involvement of key stakeholders whose significance is recognised in clinical "consensus statements", and make decisions that – in some cases explicitly and deliberately – pre-empt the right of children to make their own decisions about their bodies.

[1] Komal A Vora et al, 'Multidisciplinary Team (MDT) Review of Management Decisions in Disorders/Differences of Sex Development (DSD): Experience of Two Paediatric Tertiary Hospital Networks' (at the Australasian Paediatric Endocrine Group Annual Scientific Meeting – APEG 2016, Alice Springs, NT: Alice Springs Convention Centre, 14 August 2016).
[2] Ibid.

Alternative existing clinical data have significant limitations so, where adequate redacted data has been made available as a result of the FOI requests, it is significant.

Evidence is scarce for many practices, claims of changed practices have been made in situations where practices of concern persist,[3] and many traits are uncommon causing recourse to literature and consultation with overseas institutions.

Different clinical centres have different understandings of which traits to include within research on "differences of sex development".[4] Commonalities can be seen across MDTs, likely reflecting their longer development and cross-border collaboration in Victoria and NSW. Different hospitals and teams have different practices.[5] Queensland appears to be an outlier, with a history of recourse to the courts.[6]

Adults who speak up today about medical interventions they received as children are often dismissed as having had "obsolete" interventions. [7] However, it is never possible to adequately study outcomes of surgical interventions on infants and children until those children become adults, by which time practices are likely to have changed further; this is illustrated in a narrative of continued scientific progress dating back to the 1980s.[8] Clinical research is largely the product of small cohort studies conducted by surgeons and other biomedical clinicians on outcomes in their patients, subject to confirmation bias and limitations in study design.

Engagement by people with innate variations of sex characteristics with clinical research is impacted by both adverse clinical experiences and a continuing history of clinical secrecy, motivated disclosure and non-disclosure.[9] Only a non-random subset of patients engage with clinical research, skewed against the inclusion of individuals who experience adverse outcomes, and omitting a population that did not receive adequate disclosure of diagnoses and other clinical histories. Disclosure by clinicians of diagnostic and clinical histories to individuals with innate variations of sex

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[3] Morgan Carpenter, 'Fixing Bodies and Shaping Narratives: Epistemic Injustice and the Responses of Medicine and Bioethics to Intersex Human Rights Demands' (2024) 19(1) *Clinical Ethics* 3 ('Fixing Bodies and Shaping Narratives').
[4] Emmanuèle C Délot and Eric Vilain, 'Towards Improved Genetic Diagnosis of Human Differences of Sex Development' [2021] (22) *Nature Reviews Genetics* 588.
[5] John Hutson et al, 'Intersexion: The Birth of Ambiguity' (at the Melbourne Medical Student Conference 2020, University of Melbourne, 23 June 2020) <https://interaction.org.au/resource/intersexion-mdscx-2020/>.
[6] Garry Warne, 'My Life of Engagement with Intersex Issues: The Getting of Wisdom' (at the AISSGA conference, Melbourne, Victoria, 24 August 2013).
[7] Hutson et al (n 5).
[8] Thom E Lobe et al, 'The Complications of Surgery for Intersex: Changing Patterns over Two Decades' (1987) 22(7) *Journal of Pediatric Surgery* 651 ('The Complications of Surgery for Intersex'); Carpenter, 'Fixing Bodies and Shaping Narratives' (n 3).
[9] Peter A Lee et al, 'Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care' (2016) 85(3) *Hormone Research in Paediatrics* 158 ('Global Disorders of Sex Development Update since 2006'); Carpenter, 'Fixing Bodies and Shaping Narratives' (n 3).

characteristics has historically not occurred, and disclosure remains variable,[10] or limited in ways that are motivated to produce particular treatment decisions.[11]

These limitations mean that the redacted FOI materials provide important documentation of current clinical processes and practices. Given the time period the FOI materials relate to (2018 to 2023), many of the children whose treatment is discussed in case reports are still undergoing treatment in Australian paediatric hospitals.

While the FOI data has been redacted at source, quotations and other uses of these data in this report also seek to protect the privacy of subjects and avoid the possibility of reidentification. The focus of this research is on the operation and decision-making of MDTs, and so minimal information is included on the specific characteristics of individuals being treated.

4 Innate variations of sex characteristics

People with innate variations of sex characteristics, or intersex traits, have any of a wide range of innate physical traits that differ from medical and social norms for female and male bodies. Responses to these perceptions of difference create experiences and risks of stigmatisation, discrimination, violence, and harmful medical practices intended to promote social and familial integration and conformity with gender norms and stereotypes.

Like all stigmatised populations, a range of different language is used to describe intersex traits, but many individuals with these traits lack access to words that can help them make sense of their bodies and their capabilities, and connect with peers.[12]

The term intersex has a medical origin and was adopted by the first self-organised groups of intersex people in the 1990s, including the now-defunct Intersex Society of North America. Up until 2006, the term intersex coexisted with pejorative traditional terms such as “hermaphrodite”, and the clinical term “pseudo-hermaphrodite”.

In 2005, an invite-only clinical meeting and subsequent “consensus statement on management of intersex disorders” introduced a new clinical umbrella term of “disorders of sex development”,[13] sometimes referred to by similar terms such as

[10] Office of the Privacy Commissioner, ‘Handling Health Information of Intersex Individuals’, *Office of the Privacy Commissioner* (2 March 2018) <https://www.privacy.org.nz/blog/handling-health-information-of-intersex-individuals/>.
[11] Carpenter, ‘Fixing Bodies and Shaping Narratives’ (n 3).
[12] Morgan Carpenter, ‘From Harmful Practices and Instrumentalisation, towards Legislative Protections and Community-Owned Healthcare Services: The Context and Goals of the Intersex Movement in Australia’ (2024) 13(4) *Social Sciences* 191.
[13] IA Hughes et al, ‘Consensus Statement on Management of Intersex Disorders’ (2006) 91 *Archives of Disease in Childhood* 554.

"disorders of sexual differentiation"[14] and "differences of sex development"[15] (all "DSD"). While these terms have been implemented within medicine, globally, they have never been accepted or adopted by community and patient organisations in Australia. Support for their use in national statistical standards reflects a pragmatic decision to mitigate against epistemic injustices.

Individuals also use specific diagnostic terminology, with more than 40 distinct entities. These can be grouped in multiple different ways. One method is as follows:

- Chromosomal variations: such as 47,XXY (Klinefelter syndrome), 45,X0 (Turner syndrome), mosaicism, mixed gonadal dysgenesis.
- Androgen production or action in people with XY chromosomes: androgen insensitivity ("AIS"); 5 alpha reductase 2 deficiency ("5α-RD2") and 17 beta hydroxysteroid dehydrogenase 3 deficiency ("17β-HSD3"); congenital adrenal hyperplasia due to 17-hydroxylase deficiency.
- Androgen production in people with XX chromosomes: many forms of congenital adrenal hyperplasia ("CAH"), maternal androgen excess, aromatase deficiency.
- Structural variations affecting gonad or genital development: micropenis, anorchia (no testes), ovotestes, hypospadias, cloacal and bladder exstrophies, vaginal agenesis (MURCS/MRKH), gonadal dysgenesis, congenital forms of hypogonadism.

Each trait is associated with its own physical characteristics and potential health needs, and typical age of diagnosis, treatment and typical sex registration. Where traits are evident at birth, factors known to influence sex registration include a range of subjective factors such as "surgical options" for feminising or masculinising surgery, and parental wishes, in addition to diagnosis.[16] Across each trait, experiences of stigmatisation, shame, medicalisation and harm are widespread.

Diagnostic terminology is undergoing rapid change, from terminology using eponyms and language based on terms using the old and often pejorative term "hermaphroditism", towards descriptive terms and terms arising from genetics research.

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[14] Medicare Benefits Schedule Review Taskforce, *Taskforce Report on Paediatric Surgery MBS Items* (2020) <https://www.health.gov.au/resources/publications/taskforce-final-report-paediatric-surgery-mbs-items>.

[15] Nicolas Kalfa et al, 'Adult Outcomes of Urinary, Sexual Functions and Fertility after Pediatric Management of Differences in Sex Development: Who Should Be Followed and How?' [2024] *Journal of Pediatric Urology* S1477513124000524 ('Adult Outcomes of Urinary, Sexual Functions and Fertility after Pediatric Management of Differences in Sex Development').

[16] S Faisal Ahmed and Salma R Ali, 'Disorders of Sex Development (DSD) in the Newborn' in John AH Wass, Wiebke Arlt and Robert K Semple (eds), *Oxford Textbook of Endocrinology and Diabetes 3e* (Oxford University Press, 3rd edition, 2022) 1169; Morgan Carpenter, 'Is It Ever OK to Reclassify Someone Out of Their Birth-Observed Sex Without Personal Consent? How Do We Manage Competing Methods of Classifying Sex?' (2024) 24(11) *The American Journal of Bioethics* 18 ('Is It Ever OK to Reclassify Someone Out of Their Birth-Observed Sex Without Personal Consent?').

The neutral and descriptive term "innate variations of sex characteristics" and the phrase "people born with variations of sex characteristics" are increasingly used in Australian policy contexts.[17] I use this term in this paper, along with the term "intersex variations", as synonyms.

5 Health needs of people with innate variations of sex characteristics

Individuals with innate variations of sex characteristics commonly experience a range of health issues and risks, including for mental health issues arising from experiences of trauma, stigmatisation, and shame, and including experiences arising in medical settings. Some traits can be associated with specific health issues, frequently including innate or iatrogenic infertility. Some traits need urgent treatment or may be fatal if not treated (such as salt wasting congenital adrenal hyperplasia or bladder exstrophy). Newborn bloodspot screening has been introduced nationally to facilitate identification of infants at risk of salt wasting.

Some traits are associated with elevated cancer risks in gonads such as testes, ovotestes, or streak gonads. Gonadal cancer risks have an unhelpful history of exaggeration and intertwining with "psychosocial" rationales for treatment.[18] Psychosocial rationales are aimed at eliminating risks of stigmatisation through surgery and hormonal treatment, facilitating "social or familial integration", eliminating perceived risks of gender dysphoria if gonads are retained, and mitigating parental distress.[19] Some traits are associated with cardiovascular, skeletal, renal, neurodevelopmental, and other issues.

Diagnosis can occur prenatally, at birth, during childhood or adolescence, and later in life — for example, due to genetic diagnosis of an intersex trait in a foetus following diagnosis in a relative or prospective parent, genital appearance at birth, a failure to menstruate in an adolescent girl, atypical pubertal development, or infertility.

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[17] for example, Department of Health and Aged Care, *National Action Plan for the Health and Wellbeing of LGBTIQA+ People 2025-2035* (2024) <https://www.health.gov.au/resources/publications/national-action-plan-for-the-health-and-wellbeing-of-lgbtiqa-people-2025-2035?language=en>; Australia and New Zealand Society for Paediatric Endocrinology and Diabetes, *Response to World Athletics Re Sex Differentiation* (2025) <https://media.anzsped.org/2025/03/24155441/o_25_02-World-Athletics-response-re-Sex-differentiation.pdf>.

[18] Senate of Australia Community Affairs References Committee, *Involuntary or Coerced Sterilisation of Intersex People in Australia* (2013) <http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Involuntary_Sterilisation/Sec_Report/index>; Morgan Carpenter, *Ambivalent Attention and Indeterminate Outcomes: Constructing Intersex and DSD in Australian Data* (University of Huddersfield, May 2022) <http://www.intersexnew.co.uk/wp-content/uploads/2023/04/Morgan-Carpenter-MNC-publication-version-aihw-paper.pdf>.

[19] Morgan Carpenter, 'Protecting Intersex People from Harmful Practices in Medical Settings: A New Benchmark in the Australian Capital Territory' (2023) 29(2) *Australian Journal of Human Rights* 409 ('Protecting Intersex People from Harmful Practices in Medical Settings'); Carpenter, 'Fixing Bodies and Shaping Narratives' (n 3).

It remains the norm for children with innate variations who have a diagnosis to be subjected to surgical and/or hormonal interventions early in life. These interventions are intended to make these children's bodies appear or function in ways that are more typically in line with sex registered at birth. For example, Australia's paediatric endocrine group has described "surgical management" as indicated "for the purpose of appearance including reduction of an enlarged clitoris or repair or construction of a urinary outlet to the end of the penis", despite "particular concern" regarding post-surgical "sexual function and sensation".[20]

Many people with innate variations of sex characteristics have significant health issues arising from early elective and non-urgent medical treatment. This particularly includes experiences of trauma; pain; loss of sensation and sexual function from unnecessary early medical interventions; loss of fertility; incontinence; limited or absent disclosure of health information; and a lack of ability to make informed decisions about treatment, including lack of access to resourced peer support; and distress from infertility or limited fertility.[21]

"Normalising" surgeries and hormonal interventions are frequently grounded in gender stereotypes or psychosocial rationales for treatment. Clear demonstrations of underlying gender stereotypes can be found in clinical propositions that girls with intersex variations need surgery to "enhance" genital appearance, while boys need surgery to ensure a "functional" norm of standing to urinate.[22] These are more properly described as grounded in cultural norms. These interventions can deliberately pre-empt opportunities for individuals to make their own choices, and they assume individuals' future values and preferences.

Evidence supporting such interventions is low, based on clinician opinion. Most studies are subject to confirmation, ascertainment and other forms of bias, for example where surgeons study outcomes in their own patients, in line with their own values.[23]

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[20] Australasian Paediatric Endocrine Group et al, *Submission of the Australasian Paediatric Endocrine Group to the Senate Inquiry into the Involuntary or Coerced Sterilization of People with Disabilities in Australia: Regarding the Management of Children with Disorders of Sex Development* (Submission, 27 June 2013) <http://www.aph.gov.au/DocumentStore.ashx?id=aafe43f3-c6a2-4525-ad16-15e4210ee0ac&subId=16191>.

[21] Office of the High Commissioner for Human Rights, *Background Note on Human Rights Violations against Intersex People* (October 2019) <https://www.ohchr.org/en/documents/tools-and-resources/background-note-human-rights-violations-against-intersex-people>; Australian Human Rights Commission, *Ensuring Health and Bodily Integrity: Towards a Human Rights Approach for People Born with Variations in Sex Characteristics* (Australian Human Rights Commission, 2021) <https://humanrights.gov.au/intersex-report-2021> ('*Ensuring Health and Bodily Integrity*'); Carpenter, 'Fixing Bodies and Shaping Narratives' (n 3).

[22] Carpenter, 'Fixing Bodies and Shaping Narratives' (n 3); *Re: Carla (Medical procedure)* [2016] FamCA 7 7 ('*Re: Carla*'); Australasian Paediatric Endocrine Group et al (n 20).

[23] Arlene B Baratz and Ellen K Feder, 'Misrepresentation of Evidence Favoring Early Normalizing Surgery for Atypical Sex Anatomies' (2015) 44(7) *Archives of Sexual Behavior* 1761; Tim C van de Grift, 'A Textbook Example of Bias in Disorders/Differences of Sex Development (DSD) Outcome Research. A Commentary to: "Congenital Adrenal Hyperplasia: Does Repair after Two Years of Age Have a Worse Outcome?"' (2020) 16(5) *Journal of Pediatric Urology* 742 ('A Textbook Example of Bias in Disorders/Differences of Sex Development (DSD) Outcome Research. A Commentary To'); Carpenter, 'Fixing Bodies and Shaping Narratives' (n 3).

Comparative studies are lacking. Clinician and patient-reported outcomes are often significantly divergent.[24]

6 Responding to human rights violations in medical settings

The intersex movement was founded to challenge secrecy, stigma, and the harm caused by unnecessary medical interventions. In 1994, the then Intersex Society of North America called for the registration of infants with intersex traits as female or male, without elective or non-urgent surgeries, provision of professional, affirmative psychosocial support and peer support, and support for children to make their own decisions over time regarding elective interventions.[25] The same principles feature in a 2013 global community statement[26] and the Darlington Statement, a 2017 Australian – Aotearoa New Zealand community consensus statement. [27] In the light of continued inaction on ending harmful practices in medical settings, the Darlington Statement called for the criminalisation of deferrable medical interventions on children unable to consent – an approach which recognises that some interventions may be necessary for physical health, such as where there is strong evidence of gonadal cancer risks.[28]

The Senate Community Affairs References Committee and community, public health, and human rights institutions regard unnecessary non-urgent and early elective medical interventions as examples of discriminatory treatment, associated with the stigmatisation of bodies that are different; they do not mitigate risks of discrimination and stigmatisation.[29]

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[24] Kalfa et al (n 15); Tim C van de Grift et al, 'Masculinizing Surgery in Disorders/Differences of Sex Development: Clinician- and Participant-Evaluated Appearance and Function' (2022) 129(3) *BJU International* 394 ('Masculinizing Surgery in Disorders/Differences of Sex Development'); Hedvig Engberg, Lisa Örtqvist and Gundela Holmdahl, 'The Options for Delayed Surgery – Is There Evidence Available for Delayed Genitoplasty in Differences/Disorders of Sex Development?' [2025] *Best Practice & Research Clinical Endocrinology & Metabolism* 102024.

[25] Intersex Society of North America, 'Recommendations for Treatment' (1994) <http://www.isna.org/recommendations.html>; Alice Dreger, 'Twenty Years of Working toward Intersex Rights' in *Bioethics in Action* (Cambridge University Press, 2018) 55.

[26] Third international intersex forum, *Malta Declaration: Public Statement by the Third International Intersex Forum* (2 December 2013) <http://intersexday.org/en/third-international-intersex-forum/>.

[27] AIS Support Group Australia et al, *Darlington Statement* (March 2017) <https://darlington.org.au/statement>.

[28] Ibid.

[29] Senate of Australia Community Affairs References Committee (n 18); Australian Human Rights Commission (n 21); Public Health Association of Australia, *The Health of People with Diverse Genders, Sexualities, and Sex Characteristics Policy Position Statement* (2021) <https://www.phaa.net.au/documents/item/5352>.

There is no evidence that surgeries are capable of addressing risks of stigmatisation,[30] and psychosocial rationales have been rejected by institutions of psychosocial experts.[31]

A systematic review of clinical rationales for early surgeries conducted by staff of the World Health Organization published in 2024 stated:

> "Sex-normalising" interventions are conducted based largely on rationales that were not adequately supported by evidence, a desire from parents and surgeons to match genital cosmesis typically ascribed to male and female bodies, and a parental desire for intervention conduct. Legislating and medical regulatory bodies should advocate for ending the conduct of irreversible, elective, "sex-normalising" interventions conducted without the full, free and informed consent of the person concerned, to promote and protect the highest attainable standard of health for people with intersex variations."[32]

A 2024 global bioethics consensus statement similarly challenges non-voluntary procedures on children in what it identifies as an intersex exception to a consensus in Global North countries (such as Australia) that:

> "holds that clinicians may not perform any nonvoluntary genital cutting or surgery, from "cosmetic" labiaplasty to medicalized ritual "pricking" of the vulva, insofar as the procedure is not strictly necessary to protect the child's physical health." [33]

It states:

> "as a matter of justice, inclusivity, and gender equality in medical-ethical policy (we do not take a position as to criminal law), clinicians should not be permitted to perform any nonvoluntary genital cutting or surgery in prepubescent minors, irrespective of the latter's sex traits or gender assignment, unless urgently necessary to protect their physical health"[34]

A 2013 Senate committee report called for the effective regulation of such interventions:

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[30] Lee et al (n 9); Australian Human Rights Commission (n 21); Lih-Mei Liao, *Variations in Sex Development: Medicine, Culture and Psychological Practice* (Cambridge University Press, 1st edn, 2022) <https://www.cambridge.org/core/product/identifier/9781009000345/type/book> ('*Variations in Sex Development*').

[31] Australian Human Rights Commission (n 21); Australian Psychological Society, *Submission to the Australian Human Rights Commission Project Research into the Human Rights of People Born with Variations in Sex Characteristics in the Context of Medical Interventions* (September 2018).

[32] Luke Muschialli et al, 'Perspectives on Conducting "Sex-Normalising" Intersex Surgeries Conducted in Infancy: A Systematic Review' (2024) 4(8) *PLOS Global Public Health* e0003568 ('Perspectives on Conducting "Sex-Normalising" Intersex Surgeries Conducted in Infancy').

[33] The Brussels Collaboration on Bodily Integrity, 'Genital Modifications in Prepubescent Minors: When May Clinicians Ethically Proceed?' (2024) 25(7) *The American Journal of Bioethics* 53 ('Genital Modifications in Prepubescent Minors').

[34] Ibid.

> "The committee recommends that all medical treatment of intersex people take place under guidelines that ensure treatment is managed by multidisciplinary teams within a human rights framework. The guidelines should favour deferral of normalising treatment until the person can give fully informed consent, and seek to minimise surgical intervention on infants undertaken for primarily psychosocial reasons.
>
> "In light of the complex and contentious nature of the medical treatment of intersex people who are unable to make decisions for their own treatment, the committee recommends that oversight of these decisions is required."[35]

These recommendations were not enacted.

In 2017, the Australian Human Rights Commission established an inquiry into medical practices on people with innate variations of sex characteristics. Following a process supported by a reference group including community, legal, human rights, and clinical experts, it reported in 2021.[36] In considering rationales for contested medical interventions, the Commission found that psychiatric and psychological professional bodies rejected psychosocial rationales for medical interventions that are relied upon by biomedical clinicians:

> "Psychosocial rationales do not rise to the standard of medical necessity to avoid serious harm, given that less intrusive options exist that should be preferred, and that psychological and psychiatric experts do not believe that there is any robust scientific evidence to support the assertion that interventions in the circumstances are in the individual's best interests"[37]

In considering the case for binding legislation and regulation in place of non-binding clinical guidance, it found that:

> "there is a real risk that medical interventions, other than on grounds of medical necessity, may be undertaken in the future. This position is informed by the views of a range of clinicians that psychosocial factors are justifiable considerations for medical interventions, with such justifications given weight in leading international guidance documents. Therefore, overall cultural change would be unlikely in the absence of binding directions"[38]

The Commission report called for legislation and regulation to be "guided by a human rights framework based on the following principles":

- "Bodily integrity principle", recognising that all "people have the right to autonomy and bodily integrity".
- "Children's agency principle", recognising the evolving capacity of children to express their views and have their views taken into account as they get older.

[35] Senate of Australia Community Affairs References Committee (n 18).
[36] Australian Human Rights Commission (n 21).
[37] Ibid.
[38] Ibid.

- "Precautionary principle", where medical interventions should be deferred until a child can express their own views regarding treatment, "where safe to do so".
- "Medical necessity principle", recognising that some interventions on children are necessary if "required urgently to avoid serious harm to the child".
- "Independent oversight principle", where decisions about medical necessity are subject to "effective independent oversight" due to the impact and "risk of making a wrong decision" [39]

Following a formal commitment in 2019, the ACT government undertook a process of reform to clinical practices. This led to the introduction and passing of legislation to protect the rights of people with innate variations of sex characteristics in medical settings in 2023, alongside significant new investment in psychosocial support. The legislation provides for a criminal prohibition of certain interventions, and oversight for interventions on individuals with certain variations if they are unable to personally consent.[40] Provisions ensuring transparency and reporting of medical interventions, and the establishment of a Restricted Medical Treatment Assessment Board and Variations in Sex Characteristics Psychosocial Support Service,[41] are internationally significant.

Biomedical organisations have opposed legislation. However, community, mental health and public health organisations have supported the reforms by the ACT government.[42] The State of Victoria has made similar commitments to reform,[43] and legislation is anticipated in late 2025.[44]

The National Action Plan for the Health and Wellbeing of LGBTIQA+ People 2025-2035, published in 2024, states that the federal government is "working towards" "Supporting LGBTIQA+ people to make their own decisions about their bodies".[45]

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[39] Ibid.
[40] Carpenter, 'Protecting Intersex People from Harmful Practices in Medical Settings' (n 19); ACT Health, 'Protecting the Rights of People with Variations in Sex Characteristics' (6 March 2024) <https://www.act.gov.au/health/providing-health-care-in-the-act/treatment-and-clinical-information/restricted-medical-treatments-for-people-with-variations-in-sex-characteristics>.
[41] Canberra Health Services, 'Variations in Sex Characteristics Psychosocial Service' (22 May 2024) <https://www.canberrahealthservices.act.gov.au/services-and-clinics/services/Variations-in-Sex-Characteristics-Psychosocial-Service>.
[42] 'Variations in Sex Characteristics (Restricted Medical Treatment) Bill 2022'Letter from Public Health Association of Australia, 7 July 2022 <https://www.phaa.net.au/documents/item/5646>; Public Health Association of Australia, '"An Important Step Forward": If Passed, a New ACT Bill Will Help Protect the Human Rights of Intersex Children', *Intouch Public Health* (28 April 2023) <https://intouchpublichealth.net.au/an-important-step-forward-if-passed-a-new-act-bill-will-help-protect-the-human-rights-of-intersex-children/> (*'"An Important Step Forward"'*); Chief Minister, Treasury and Economic Development Directorate, *Protecting the Rights of Intersex People in Medical Settings Listening Report on Submissions Received about Regulatory Options* (October 2021) <https://www.cmtedd.act.gov.au/__data/assets/pdf_file/0008/1905119/Intersex-Options-Paper-Listening-Report-October-2021.pdf> (*'Listening Report on Submissions Received about Regulatory Options*').
[43] Department of Health, *(I) Am Equal: Future Directions for Victoria's Intersex Community* (July 2021) <https://www2.health.vic.gov.au/about/publications/factsheets/i-am-equal>.
[44] Department of Health, 'Victoria's Intersex Protection System', *Engage Victoria* (18 June 2023) <https://engage.vic.gov.au/intersex-protection-system>.
[45] Department of Health and Aged Care (n 17).

6.1 Contemporaneous developments

The FOI requests relate to the period of 2018-2023. This period coincides with notable developments in Australian jurisdictions. Community organisations and clinical teams involved in decision-making in cases released under the FOI requests were active partners in these developments:

- As mentioned above, the Australian Human Rights Commission completed an inquiry on medical interventions on children born with variations of sex characteristics, reporting in October 2021.[46]
- In 2023, the Australian Capital Territory enacted Australian-first legislation protecting many children with innate variations of sex characteristics from non-urgent medical interventions without personal consent.[47]
- In 2021, Victoria made a similar commitment to adopt legislative protections and establish new services.[48]
- The NSW government developed and adopted a first LGBTIQ+ Health Strategy in early 2022, noting "a need to recognise and respond to practices of unnecessary and deferrable medical interventions, undertaken in infancy and childhood, to 'normalise' the appearance of intersex bodies".[49] No action has occurred at time of writing.
- The Queensland government funded InterLink as a pilot community-controlled psychosocial support service. However, it has at the same time framed 'variations of sex characteristics' in medical data models within a "gender identity project" in ways that exacerbate misconceptions and risk introducing errors into data entry.[50]

Most of the data in this analysis relates to New South Wales and Queensland, due to the scale and depth of the materials provided in response to the FOI requests. We have scarce other evidence on contemporaneous clinical practices in NSW, but more on Queensland.

6.2 Queensland reports on clinical practices and rationales

The Queensland Department of Communities stated in a 2012 report that:

> "Previously it was an accepted practice to assign the external genitalia of a child during their childhood, often through surgical intervention, to determine the sex of the child early in their life. Research and investigation now advises against any irreversible or long-term procedures being performed on intersex children, unless a condition poses a serious risk to their health."[51]

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[46] Australian Human Rights Commission (n 21).
[47] ACT Health (n 40).
[48] Department of Health (n 43).
[49] NSW Health, *NSW LGBTIQ+ Health Strategy 2022-2027* (2022) <https://www.health.nsw.gov.au/lgbtiq-health/Pages/default.aspx>.
[50] Townsville Hospital and Health Service, 'New Project Transforming Healthcare with Respect and Inclusion' (6 June 2025) *blah blah blah* 5 < https://issuu.com/townsvillehospitalandhealthservice/docs/blah_blah_blah_6_june>.
[51] Department of Communities, *Engaging Queenslanders: A Guide to Working with Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Communities* (No 2896–11 FEB12, January 2012).

Evidence from a range of sources shows that such interventions continue.

A 2016 Family Court case known as *Re: Carla (Medical procedure)* was adjudicated in Queensland. The case was taken before the Family Court of Australia to approve the gonadectomy of a 5-year-old child with XY chromosomes, testes, and the trait 17-beta hydroxysteroid dehydrogenase 3 deficiency (17β-HSD3).

The case documented the judge's view that a prior clitoral "recession" (a form of clitoral reduction) and labioplasty had "enhanced the appearance of her female genitalia."[52] The judge also noted the timing of these interventions:

> "In 2014, Carla [a pseudonym] underwent two operations. In March that year, Dr B, performed a 'clitoral' recession and labioplasty to feminise Carla's external appearance"[53]

These occurred 2 years after the Queensland Department of Communities asserted that irreversible surgical procedures are no longer "performed on intersex children, unless a condition poses a serious risk to their health".[54]

The judgment cites obsolete evidence on gonadal tumour risk levels associated with retaining gonads, yet dismissed the same source where it recommended "monitoring" of gonads rather than their removal.[55]

Carla's treatment plan follows international norms, as described in the World Health Organization's International Classification of Diseases 11 Foundation document,[56] which characterises gonadectomy as dependent on gender assignment, and not cancer risks:

> "If the diagnosis is made at birth, gender assignment must be discussed, depending on the expected results of masculinizing genitoplasty. If female assignment is selected, feminizing genitoplasty and gonadectomy must be performed. Prenatal diagnosis is available for the kindred of affected patients if the causal mutations have been characterized."[57]

The judge also dismissed the possibility of puberty suppression that might allow time for the child to determine and express her own preferences. The judgment states that:

> "doctors say Carla would, in the circumstances of the onset of male puberty, be at increased risk of developing mental health problems including, potentially, a variety of anxiety and depressive disorders and serious confusion about her gender identity. Carla's parents are, quite naturally, very worried that if the procedure is not undertaken and Carla goes through male

[52] *Re: Carla* (n 22).
[53] Ibid.
[54] Department of Communities (n 51).
[55] Hughes et al (n 13).
[56] World Health Organization, '46,XY Disorder of Sex Development Due to 17-Beta-Hydroxysteroid Dehydrogenase 3 Deficiency' in *ICD-11 Foundation* (2022) <https://icd.who.int/dev11/f/en#/http%3a%2f%2fid.who.int%2ficd%2fentity%2f887793448>.
[57] Ibid.

> puberty that she will suffer significant distress as Carla clearly identifies herself as female"

A 2016 clinical statement identifies "clinical distress" in people with this trait raised female; the statement also identifies peer support as a key component in healthcare, and this is absent in all Queensland cases involving children with innate variations of sex characteristics.[58] The discussion in the judgement appears to regard Carla's medical treatment as a way of managing or directing the development of her gender identity, by eliminating the child's natural physical developmental pathway, in the belief that the possibility of untreated virilisation at puberty might give rise to gender dysphoria or gender identity issues.

The rationale for the gonadectomy of this pre-school child was substantively comprised of gender stereotypes, observed by a treating doctor in her multidisciplinary team and recounted by the judge:

> "Her parents were able to describe a clear, consistent development of a female gender identity;
>
> "Her parents supplied photos and other evidence that demonstrated that Carla [a pseudonym] identifies as a female;
>
> "She spoke in an age appropriate manner, and described a range of interests/toys and colours, all of which were stereotypically female, for example, having pink curtains, a Barbie bedspread and campervan, necklaces, lip gloss and 'fairy stations';
>
> "She happily wore a floral skirt and shirt with glittery sandals and Minnie Mouse underwear and had her long blond hair tied in braids; and
>
> "Her parents told Dr S that Carla never tries to stand while urinating, never wants to be called by or referred to in the male pronoun, prefers female toys, clothes and activities over male toys, clothes and activities, all of which are typically seen in natal boys and natal girls who identify as boys."[59]

These rationales for irreversible medical interventions on a pre-school child are disturbing. This evidence describes parental descriptions, and culturally specific, socially constructed ideas of femininity associated here with a child too young to freely articulate a gender identity, as rationales for an irreversible medical intervention.

Given that the surgeries in this case were each predicated on the initial gender assignment, the timing of the gonadectomy was deliberate:

> "it will be less psychologically traumatic for Carla if it is performed before she is able to understand the nature of the procedure."[60]

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[58] Lee et al (n 9).
[59] *Re: Carla* (n 22).
[60] *Ibid 30.*

At the same time, the heteronormative nature of the gender stereotypes involved in clinical and judicial decision-making are evident in a comment that presumes a particular role in future heterosexual intercourse, which may require surgery that Carla will remember:

> "Carla may also require other surgery in the future to enable her vaginal cavity to have adequate capacity for sexual intercourse."[61]

A 2012 systematic review of gender dysphoria in people with innate variations of sex characteristics found that "reported rates of gender dysphoria range from [...] 39–64% for patients with 17β-HSD3".[62]

The case *Re Carla* likely contributed to establishment of the Australian Human Rights Commissions inquiry into medical interventions on children born with variations of sex characteristics, which reported in 2021.[63] Its recommendations have not been implemented in Queensland.

While the 2016 Family Court case occurred in the period preceding the time period for the Freedom of Information requests, the decisions evident in the case are consistent with those described in a 2019 report on children seen by a paediatric and adolescent gynaecology clinic in Queensland. This shows that all children with XY traits presenting to the gynaecology clinic with so-called "ambiguous genitalia" in the preceding decade were subjected to feminising surgeries, likely soon after diagnosis.[64] For example, "In [complete androgen insensitivity], bilateral gonadectomies were most often done at infancy'; all individuals with partial androgen insensitivity were also subjected to gonadectomies. Specific cases involving children presenting with "ambiguous genitalia at birth" include children with partial androgen insensitivity and mixed gonadal dysgenesis, and the following treatment plans:

> "Gonadectomy and feminizing genitoplasty 1 year age. Vaginal dilatation."
>
> "Gonadectomy and genitoplasy [sic] as infant. Pubertal induction and HRT. Vaginal Dilatation."
>
> "Gonadectomy and reconstructive surgery as infant. Pubertal induction and HRT. Vaginal dilatation."
>
> "Gonadectomy and surgical creation neovagina as child. Pubertal induction and HRT. Vaginal dilatators."
>
> "Gonadectomy and feminizing surgery age 2yo. Pubertal induction and HRT. Vaginal dilatation."[65]

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[61] Ibid 18.
[62] Paulo Sampaio Furtado et al, 'Gender Dysphoria Associated with Disorders of Sex Development' (2012) 9 *Nature Reviews Urology* 620.
[63] Australian Human Rights Commission (n 21).
[64] T Adikari et al, 'Presentations and Outcomes of Patients with Disorders of Sexual Development (DSD) in a Tertiary Paediatric and Adolescent Gynaecology (PAG) Service' (at the RANZCOG Annual Scientific Meeting 2019, Melbourne, 2019) <https://ranzcogasm.com.au/wp-content/uploads/2019/10/243.pdf>.
[65] Ibid.

In one case involving cloacal exstrophy in a child with XY chromosomes, the report noted:

> "Repair coacal [sic] exstrophy and gonadectomy as child. Vaginal Dilatation and HRT." [66]

Children with 5α reductase deficiency and 17β hydroxysteroid dehydrogenase deficiency were likely diagnosed later in childhood but with surgical interventions and induced puberties:

> "Gonadectomy and surgical creation neovagina in adolescence. Pubertal induction and HRT."
>
> "Bilateral orchidectomy and hernia repair aged 12. Pubertal induction and HRT. Vaginal dilatation. Vaginal dilators."[67]

The document did not disclose surgical interventions on children with congenital adrenal hyperplasia, no information was disclosed about psychosocial support, peer support, or consent and information disclosure, and the gynaecology clinic by definition does not treat children subjected to masculinising interventions.

The 2017 Family Court case of *Re: Kaitlin* was also adjudicated in Queensland, in relation to an adolescent born with a pituitary impairment who was unable to commence or undergo puberty without hormone treatment. "Kaitlin" [a pseudonym] was 16 years old and assessed as Gillick competent at the time of the case.

The judge reported that: "At about age 12 or 13 she was prescribed testosterone in order to commence puberty". [68] However, the judge also reported that Kaitlin "identified as female from a very early age. She has always resented being characterised as male".[69]

When Kaitlin became aware of the nature of her treatment, she became non-compliant. Her family sought court approval for oestrogen treatment under rules then in effect.

The judge in *Re: Kaitlin* did not question the testosterone treatment in a girl who always understood herself as female, nor improvements in patients' access to peer and psychosocial support that might be warranted, as these may have established her values and preferences before being prescribed a sex hormone. Instead, the judge commented that:

> "It would seem fanciful to suggest that court authorisation was required before Kaitlin could be prescribed testosterone by Dr W in 2014."[70]

Concerningly, this treats the prescription of male hormones as simply a historical artefact to be contrasted with an absurd alternative when, instead, the then child could

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[66] Ibid.
[67] Ibid.
[68] *Re: Kaitlin* [2017] FamCA 83 7 ('*Re: Kaitlin*').
[69] *Ibid*.
[70] *Ibid*.

have been supported to understand and express her own values and preferences for treatment.

6.3 Attitudes of NSW clinicians

Less information is available on practices in New South Wales in comparison to Queensland, but clinical attitudes are evident from peer-reviewed sources.

A 2016 paper by Mike O'Connor, an obstetrician and gynaecologist, stated in relation to the 2013 Senate committee inquiry that:

> "When a child's gender is ill-defined at birth, parents can express considerable anxiety and doubt about their child's future social acceptance. [...]
>
> "The problems of these children were explained to the Australian Senate Community Affairs References Committee in 2013 during its Inquiry into the Involuntary or Coerced Sterilisation of Intersex People. Unfortunately, the preliminary recommendations of that Committee did not include a consideration of the key paediatric specialist concerns [...]
>
> "The author agrees with a substantial body of paediatric opinion that it is impractical to defer all modifications of indeterminate genitalia until the child reaches an age of consent as proposed by the Australian Senate."[71]

The Committee did not call for the deferral of all surgical interventions, it called for the favouring of deferral, combined with establishment of a human rights framework and oversight.

O'Connor went on to state that the establishment of "independent multidisciplinary advisory teams of paediatricians and paediatric surgeons is seen by physicians as a safeguard against the previous excesses of intersex surgery."[72] Those excesses are not specified, but the text conveys a sense of reassurance, while masculinising surgeries to address hypospadias were characterised as "necessary and uncontroversial surgery".[73] O'Connor concluded that a "ban on all DSD surgery" "may breach the human rights of the child"; "The voices of paediatric endocrinologists and paediatric surgeons need to be heeded."[74]

In 2020, NSW paediatric endocrinologists Komal Vora and Shubha Srinivasan authored a paper in the Australian Journal of General Practice. It identified "surgical options", i.e. options for feminising or masculinising surgery, as a factor in sex assignment in cases of doubt, and identified an absence of consensus in relation to key aspects of clinical care:

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[71] Mike O'Connor, 'The Treatment of Intersex and the Problem of Delay: The Australian Senate Inquiry into Intersex Surgery and Conflicting Human Rights for Children' (2016) 23(3) *Journal of Law and Medicine* 531.
[72] Ibid.
[73] Ibid.
[74] Ibid.

> "There is currently no consensus in relation to the need for, or optimal timing of, many surgical interventions"

The authors identify a range of factors including cosmetic appearance, in considering surgery:

> "Functionality, malignancy prevention and cosmetic appearance are all taken into account when considering surgical procedures."[75]

Functionality is not defined, and may refer to a cultural norm that males stand to urinate, as described in a 2013 clinician submission to the Senate.[76] The authors also suggest that lack of a "universal interpretation" of "medically necessary surgery" is a barrier to regulation, recognising "patient advocate requests for deferral of non-therapeutic surgery" but also commenting that:

> "Some patient groups advocate a complete moratorium on any genital/ gonadal surgery." [77]

This statement is attributed to European academics, not patient groups. In response to misrepresentations of community testimony and institutional positions, the Australian Human Rights Commission found it necessary in its 2021 report to comment:

> "Some stakeholders seemed to base their opposition to any legal sanctions on the premise that all medical interventions modifying sex characteristics would be prohibited, in all circumstances. However, neither the Commission nor any stakeholders have advocated such a blanket prohibition"[78]

These attitudes have been characterised as epistemic injustices in a 2023 paper by Morgan Carpenter.[79]

6.4 Existing data on numbers of procedures and individuals impacted

Existing data does not provide a clear analysis of numbers of procedures and individuals impacted by them.

- NSW and Victorian multidisciplinary teams (MDTs) reported in August 2016 on some aspects of decision-making in the period between August 2012 and May 2016.[80] "A total of 100 cases were discussed" but the data allow for limited conclusions to be drawn about outcomes, but the material identifies that clinical "dilemmas" are referred to the Sydney Children's Hospital MDT, while cases in Victoria relate to "those with a diagnostic dilemma as well as those requiring ethical discussion". Overall the teams identity the MDTs as for review of "challenging DSD cases" and, significantly despite consideration of only a

[75] Komal A Vora and Shubha Srinivasan, 'A Guide to Differences/Disorders of Sex Development/Intersex in Children and Adolescents' (2020) 49(7) *Australian Journal of General Practice* 417.
[76] Australasian Paediatric Endocrine Group et al (n 20).
[77] Vora and Srinivasan (n 75).
[78] Australian Human Rights Commission (n 21).
[79] Carpenter, 'Fixing Bodies and Shaping Narratives' (n 3).
[80] Vora et al (n 1).

clinically determined subset of cases, "an alternative to legal oversight of all decisions in DSD". [81]

- Published in 2017, I conducted an analysis of numbers of selected medical interventions associated with Medicare Benefits Schedule (MBS) item codes for the period 2002-3 to 2014-5.[82] The data include a range of codes relating to feminising and masculinising interventions. This established no clear trends in relation to numbers of interventions, except for rising numbers of vulvoplasties (surgeries to external female genitalia) and a peak in interventions in the period 2005-6, possibly associated with the development of a clinical consensus statement that could impact treatment. These data had a "poor fit" with contemporaneous media and clinical reports,[83] for example, media reports of "genital enhancement operations" and "10 to 15 genital reconstruction operations a year often on girls under the age of two" at the Royal Children's Hospital.[84] The use and reporting of MBS codes by public and private institutions is not mandatory.
- In a 2022 publication I reviewed the numbers of relevant procedures considered by a Medicare Benefits Schedule Review Taskforce in 2018, which is subject to the same limitations.[85]
- In 2019, a Queensland team reported on presentations and outcomes of patients seen by a paediatric and adolescent gynaecology clinic, detailed above.[86]

Referral to multidisciplinary teams (MDTs) is not mandatory, resulting in an underrepresentation of many more common traits in the case reports. In the absence of notable outcomes (such a child subjected to feminising surgeries in infancy but growing up to identify as male in adolescence), associated treatment plans are unlikely to be considered "dilemmas" warranting review by an MDT. Relevant traits likely to be under-represented include most cases of hypospadias, surgery for congenital adrenal hyperplasia, MRKH, congenital forms of hypogonadism, and hormonal treatment associated with 47,XXY and related sex chromosome variations. As indicated in small distinctions in referral practices between NSW and Victoria, referral practices between teams may also differ in subtle but important ways that are not adequately captured in the FOI data.

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[81] Ibid.
[82] Morgan Carpenter, 'The "Normalisation" of Intersex Bodies and "Othering" of Intersex Identities' in Jens Scherpe, Anatol Dutta and Tobias Helms (eds), *The Legal Status of Intersex Persons* (Intersentia, 2018) 445.
[83] Ibid.
[84] Andrew Bock, 'It Takes More than Two', *The Age* (online, 20 June 2013) <http://www.theage.com.au/national/it-takes-more-than-two-20130619-2oj8v.html>.
[85] Carpenter, 'Ambivalent Attention and Indeterminate Outcomes: Constructing Intersex and DSD in Australian Data' (n 18).
[86] Adikari et al (n 64).

7 The composition and role of multidisciplinary teams

Multidisciplinary Teams (MDTs) have been acknowledged as a core component of healthcare for infants, children and adolescents with innate variations of sex characteristics since 2006:

> "In 2006 the Chicago consensus statement on the management of people with variations of sex characteristics (VSC) acknowledged the importance of a multidisciplinary team (MDT) approach. The consensus update from 2016 reinforced the call for multidisciplinary collaborations between medical professionals, parents and support groups, and proposed guidelines to improve shared decision making and patient-centred care embedded in ethical principles of self-determination and child participation."[87]

Despite this, they have been recognised since 2006 as "neither a guarantor of nor a necessity of patient-centered care for DSDs".[88] UK DSD clinical psychologist and expert Lih-Mei Liao notes that:

> "a "biogenetic framing of DSD means that narratives of intersex are intrinsically pathology-centred" and the role of psychologists in multidisciplinary teams is devalued."[89]

The 2021 scoping review found that:

> "collaboration in MDTs is poor, that medical professionals dominate over other healthcare professionals, that psychosocial care is secondary to medical treatment and that ethical frameworks excluded the voices of people with VSC."[90]

In an Australian context where the Family Court has jurisdiction over "special medical procedures and Queensland institutions have availed of this oversight to the consternation of clinicians in other States,[91] MDTs have been framed by clinicians in NSW and Victoria as a "viable alternative to involvement of the Family Court in the management of DSD", evading legal oversight.[92]

However, their implementation contains many of the same flaws as those identified in European research. A biogenetic focus and devaluation of non-biomedical perspectives

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[87] Martin Gramc, Jürg Streuli and Eva de Clercq, 'Multidisciplinary Teams Caring for People with Variations of Sex Characteristics: A Scoping Review' (2021) 5(1) *BMJ Paediatrics Open* e001257.
[88] Consortium on the Management of Disorders of Sex Development et al, *Clinical Guidelines for the Management of Disorders of Sex Development in Childhood* (Accord Alliance, 2006).
[89] Carpenter, 'Fixing Bodies and Shaping Narratives' (n 3); citing Lih-Mei Liao, 'Western Management of Intersex and the Myth of Patient-Centred Care' in *Interdisciplinary and Global Perspectives on Intersex* (Springer International Publishing, 2022) 241.
[90] Gramc, Streuli and Clercq (n 87).
[91] Mike Thomsett and Garry Warne, 'History', *Australasian Paediatric Endocrine Group* (April 2021) <https://apeg.org.au/about-apeg/history/>; Warne (n 6).
[92] Vora et al (n 1).

are baked into the NSW Terms of Reference.[93] There is no evidence of collaboration, negligible engagement with diverse perspectives, and participation by psychologists and ethicists is considered optional.

While the Victorian and Tasmanian MDT did not release its Terms of Reference in response to an FOI request, it has been obtained through other means and it also indicates that participation by psychosocial and ethics professionals is not part of an MDT quorum; participation by these professionals is optional, not a requirement for an MDT meeting to proceed. The absence or marginalisation of psychosocial experts, peer support and community-controlled organisation representatives, and people with lived experience generally is contrary to recommendations from international clinical consensus statements.[94] In a 2023 paper on epistemic injustice, I state:

> "The epistemic authority afforded to surgeons and other biomedical clinicians impacts contributions to decision-making by other medical and allied health professionals"[95]

Redacted cases in NSW released under the FOI requests indicate a paradigm where psychosocial support is not considered to be a core component of healthcare. It treats psychosocial support as peripheral, only in the event of a crisis, or a need demonstrated to a biomedical professional. Surgery is not treated as any cause of psychological risk, while absence of surgery is considered to create psychological risks. This approach is illustrated in two case reports, one involving a contested male sex assignment and the other involving an adolescent with CAH whose mother deferred surgery for the individual to make her own decision.

Six case reports (5 NSW and 1 Queensland) contain explicit and welcome references to referral to community controlled psychosocial support or to peer support organisations.[96] Three involved referral to InterLink, one to AISSGA (now Intersex Peer Support Australia) and "other international support groups", while remaining cases related to unnamed support for a child with hypospadias and a child with cloacal exstrophy. The general absence of these referral pathways is troubling when cases indicate instances of significant distress and "oppositional medical reactions"[97] where individuals and families would benefit from contact with peers, in line with recommendations from international clinical consensus statements.[98]

MDTs in NSW, Victoria and Tasmania have inserted references to the term human rights into their terms of reference, suggesting that their purpose is to apply human rights

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[93] Sydney Children's Hospital Network, *SCHN Differences of Sex Development (DSD) Multidisciplinary Review Meeting Terms of Reference* (No SCHN23/5204, 2023).
[94] Hughes et al (n 13); Lee et al (n 9).
[95] Carpenter, 'Fixing Bodies and Shaping Narratives' (n 3).
[96] Cases are Sydney Children's Hospital Network, *Referral of a Child with a DSD for Multidisciplinary Team Review (Likely AIS)* (February 2019); Sydney Children's Hospital Network, *Referral of a Child with a DSD for Multidisciplinary Team Review (46XY)* (October 2022).
[97] Sydney Children's Hospital Network, *Referral of a Child with a DSD for Multidisciplinary Team Review (Gonadal Dysgenesis)* (October 2021).
[98] Hughes et al (n 13); Lee et al (n 9).

principles. However, they have done so without adding relevant professional expertise to their membership.

In general, the case reports indicate that there is infrequent debate about clinical practices. This appears to have been enlivened in 2022-3 subsequent to publication of an Australian Human Rights Commission report and in the context of legal reform in the ACT, but debate does not appear to have led to variation in MDT recommendations and clinical practice. Debate otherwise primarily focuses on exchanging diagnostic and test information in order to arrive at putatively objective decisions about treatment.

It is directly relevant to this that MDT membership is self-selected. To some extent this is comprehensible in an area of medicine with few practitioners, and an apprenticeship model: junior practitioners are selected by experienced practitioners and, if their careers progress, they become acculturated to institutional values and beliefs. However, the exclusion of mainstream human rights and ethics perspectives,[99] and alternative and diverse viewpoints contributes to groupthink and operation within an echo chamber for surgical and biomedical eminence.[100] This has pervasive effects. In a paper on epistemic injustice published in 2023, Morgan Carpenter writes:

> "Parents are typically dependent on a small number of clinical centres knowledgeable about intersex traits. Second opinions may be unavailable due to a scarcity of clinical specialists. This, combined with the perceived objectivity and prestige associated with recommendations by senior clinicians, particularly surgeons, limits parents' abilities to engage with alternative perspectives."[101]

In the case reports, parental views guide decision-making by MDTs, but parents clearly recapitulate the views expressed to them by clinicians. These two quotations, for example, relate to the same Queensland case:

> "Parents [redacted] as a 'normal girl' and pleased with their decision to [redacted] raise [redacted] as a girl.
>
> "Parents advised by Dr [redacted] that they should take time to talk to [redacted] about her karyotype during her adolescence; that it would not be advisable for [redacted] to find out herself googling her diagnosis etc. Suggested that an appropriate time might be when she is taught about chromosomes in biology/science in high school, though it is up to their discretion. They agreed with this. "[102]

There is a history of misrepresentation of community testimony.[103] An example is illustrated in the NSW MDT terms of reference which refers to unevidenced reports of "recent pressure from patient advocacy groups and some healthcare institutions to

[99] Muschialli et al (n 32); The Brussels Collaboration on Bodily Integrity (n 33).
[100] Carpenter, 'Fixing Bodies and Shaping Narratives' (n 3); Eric Lohman and Stephani Lohman, *Raising Rosie Our Story of Parenting an Intersex Child.* (Jessica Kingsley Publishers, 2018).
[101] Carpenter, 'Fixing Bodies and Shaping Narratives' (n 3).
[102] Endocrinology and Diabetes, Queensland Children's Hospital, *DSD for Multiprofessional Team Review* (13 December 2022).
[103] Carpenter, 'Fixing Bodies and Shaping Narratives' (n 3).

refer clinical management decisions to the Family Court".[104] The community consensus platform (the Darlington Statement) is critical of the role and decisions of the Family Court; the Australian Human Rights Commission proposes an alternative model for independent oversight, a form of which has been implemented in the ACT.[105]

8 The case reports

All FOI documents were reviewed. The FOI documents reinforce existing concerns regarding medical practice, as ascertained through national reports; dialogue with clinicians, parents and youth; clinical publications and ethical analysis. Given this breadth of evidence, there is nothing that is specifically new, but (even in their often heavily redacted state) the materials clearly indicate how medical practices are managed and how clinicians address perceived debate about treatment, and it does so in their own voices.

Three cases met community expectations regarding medical treatment and referral to peer and psychosocial support. Two cases were in NSW and involved children likely to have androgen insensitivity, although in neither case was diagnosis entirely certain. In both cases, gonadectomies were deferred until the persons concerned could personally express their values and preferences for treatment.

The following table considers total number of individual cases seen in case reports. The range of case discussions per individual ranged from 1 to 3 during the FOI study period.

Jurisdiction	Total cases	Adverse findings	Positive findings	Insufficient data
NSW	75	43	41	6
Queensland	8	6	3	0
Total	83	49	44	6

Adverse findings include inappropriate rationales for surgery; predetermined outcomes based on sex registration; surgery occurring despite pro forma clinical acknowledgement of a need for "realistic outcomes", high complication rates and dissatisfaction; and loss of ethical debate and detail arising from a transition to checklist discussions of complex hypospadias cases.

Positive findings include the ability of an adolescent to participate in decision, referral for psychosocial support in situations of distress or clinical identification of need, lack of urgency in relation to non-essential interventions, deferral of surgery, and conduct of additional testing prior to decision-making. These do not necessarily indicate that children have been treated in line with community expectations and human rights norms.

[104] Sydney Children's Hospital Network, 'SCHN Differences of Sex Development (DSD) Multidisciplinary Review Meeting Terms of Reference' (n 93).
[105] AIS Support Group Australia et al (n 27).

These counts do not attend to broader structural issues with multidisciplinary teams, and cases are not routinely referred for psychosocial and peer support. Additionally, the case reports, minutes and MDT terms of reference take place in a silo with no direct acknowledgment of well documented contestation regarding early elective medical interventions by community, human rights institutions and ethicists.

Concerns in following sections can be grouped around the conduct of four types of procedure:

- Masculinising surgeries – including hypospadias surgeries, where customary practice is to commence interventions in the first year of life, but also other surgeries including some – such as chest reconstruction – that take place when individuals are able to consent.
- Feminising surgeries – such as vaginoplasties, clitoral reduction and other genital surgeries, also commencing in the first months of life.
- Gonadectomies – often justified by reference to gonadal tumour risks, but sex of rearing and psychosocial fears also play a significant role in decision-making.
- Treatment with sex hormones – occasionally occurring in the first months of life, but primarily occurring to induce puberty in children whose gonads are non-functional or whose gonads have been removed, and required throughout life.

In the following sections, I additionally raise concerns about genital photography.

8.1 No elective surgery is uncontested, but surgery still happens

The FOI materials also establish that all feminising and masculinising surgeries are contested within MDTs. There is no uncontested elective procedure. However, even while some surgeries are contested, this did not impact MDT recommendations supporting surgery in any case. With a single exception, the MDTs supported surgery in all cases.

The caveat is a single case where the MDT did not support parents' decision regarding sex assignment; in this case, it is plausible that surgeries were withheld due to clinician objection to sex assignment, while an alternative sex assignment could have produced a recommendation for surgery in line with that assignment.

Two instances of delay also occur due to diagnostic uncertainty, which was addressed in case reports through discussion about additional testing. No further reports on these were contained in the documents released through FOI requests.

8.2 Inappropriate rationales

Community, human rights and mainstream health institutions reject a range of rationales for medical intervention that are "inadequately supported by evidence" and "gendered and social rationales".[106] A systematic review of clinical rationales performed by staff of the World Health Organization identified:

[106] Muschialli et al (n 32).

> "Assessment of surgical rationale and outcomes has revealed that medical teams continue to conduct these interventions in the face of controversy due to desires to mitigate parental distress surrounding the perceived difficulties of raising a child with a congenital variation in sex characteristics, as well as a variety of under-researched or outdated beliefs that doing so mitigates suboptimal anatomical, cosmetic, physiological, and psychological outcomes for a child, or that surgical intervention is best practice"[107]

These rationales are evident in the case reports, including frequent reports of parental distress and desire for early surgery, often clearly informed by clinical advice and beliefs:

> "Parents very keen for feminising surgery to be performed in childhood rather than delaying until patient can participate in decision-making. They understand the rationale for delayed surgery, however are concerned about possible negative psychological consequences"[108]

> "parents presented as distressed at the possibility of deferring surgery beyond infancy"[109]

> "There has been significant parental distress at possibility of delaying surgery until their child is able to decide for themselves."[110]

> "Social implications, including maintaining privacy regarding her condition (eg others changing nappies)"[111]

> "The family also expressed worries about their child remembering pain associated with surgery."[112]

NSW obstetrician Mike O'Connor made a striking statement in a journal article on the 2013 Senate inquiry, that the unique physical characteristics of infants with congenital adrenal hyperplasia and XX sex chromosomes were not noticed by parents until clinicians identified them:

> "Parents are often unaware of their daughters' clitoromegaly until paediatricians point this out to them."[113]

Parental rationales frequently appear to be recapitulations of views expressed by clinicians:

[107] Ibid.
[108] Sydney Children's Hospital Network, *Referral of a Child with a DSD for Multidisciplinary Team Review (CAH)* (June 2020).
[109] Endocrinology and Diabetes, Queensland Children's Hospital (n 102).
[110] Ibid.
[111] Ibid.
[112] Ibid.
[113] O'Connor (n 71).

> "Early surgery "under 2 years of age" proposed "as the child is unlikely to remember the surgery. Surgery between 4-10 years of age has a risk of being a more traumatic experience for the child"[114]
>
> "psychological risk of not operating in early childhood is also unknown"[115]
>
> "avoiding stigmatisation of genital variation by restoring female anatomy, preventing parental anxiety"[116]

However, these positions are based on opinion and lack evidence. Clinical "consensus statements" identify that purported risks of stigmatisation and psychological risks of conducting and not conducting early surgery have not been established.[117]

Discussion about masculinising and feminising surgery typically frame issues as "early versus late surgery", rather than concern regarding the necessity of surgery.[118] For example:

> "should Repair be undertaken now or delayed until adult life"
>
> "Surgery for [redacted] degree of undervirilisation [masculinising surgery] is frequently associated with a poor cosmetic and/or functional outcome. An alternative approach would be to postpone surgery until he has gone through puberty"
>
> "Brief discussion from the endocrinology team regarding [feminising] surgery, noting this would not be done before three months of age, and included mention that there is currently some controversy in the community regarding the timing of genital surgy [sic]"
>
> "Parents very keen for feminising surgery to be performed in childhood rather than delaying until patient can participate in decision-making. They understand the rationale for delayed surgery, however are concerned about possible negative psychological consequences"
>
> "strong parental preference re timing"

Surgery appears to take place in each case. Discussion also frames early surgery is inherent to a process of sex assignment. This position on surgery as an inherent component in sex assignment is also evident in statements of national clinical colleges. For example, the Royal Australasian College of Surgeons Health Policy and Advocacy Committee stated the following in a submission to the ACT government on then-proposed legislation to regulate surgeries:

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[114] Sydney Children's Hospital Network, *Referral of a Child with a DSD for Multidisciplinary Team Review (Epispadias/Micropenis)* (February 2018).
[115] Ibid.
[116] Sydney Children's Hospital Network, *Referral of a Child with a DSD for Multidisciplinary Team Review (Potential CAH)* (November 2018).
[117] Lee et al (n 9).
[118] Carpenter, 'Fixing Bodies and Shaping Narratives' (n 3).

> "An independent body being able to veto the desire of the parents to assign a gender and allow a child to socially integrate based on "human rights" when they bear no responsibility for looking after the child is troubling"[119]

One example in NSW is of a case involving masculinising surgery where the MDT case report from 2020 notes the following statements implying that surgery is a post-requisite of sex assignment, and identifying "high" risks:

> "Normal phenotype"
>
> "'he is a boy and should be raise as a boy'. Clear understanding about possible not good response in the future"
>
> "[A surgeon] explained how hypospadias should be repaired. Also discussed a possible "cosmetic surgery" to improve aspect of the genitalia
>
> male gender of rearing and management plan"
>
> "[physical characteristics mean] surgery very difficult"
>
> "very high risk of complications"
>
> "The family and patient should have ongoing psychological follow up to support an open mind about gender identity and cosmetic/functional outcomes of surgery"

Intersex community-controlled organisations have always asserted that sex assignment is necessary but should not be followed by elective or other non-urgent surgical interventions until such time as the individual can personally consent.[120]

A December 2022 case discussed in Queensland noted varying views on timing of feminising surgery but identified views on human rights frameworks:

> "Clinicians hold concerns that some proposed Human Rights frameworks do not take into account the rights of the parents, or adequately incorporated best interests into considerations"[121]

The human rights system is clear that parental rights to electively modify the bodies of their children are fettered, and the best interests test cannot be used to "justify practices" that "conflict with the child's [...] right to bodily integrity".[122]

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[119] 'ACT Variations in Sex Characteristics (Restricted Medical Treatment) Bill 2022'Letter from Royal Australasian College of Surgeons Health Policy and Advocacy Committee, 17 July 2022 <https://www.surgeons.org/News/Advocacy/ACT--Variations-in-Sex-Characteristics-Restricted-Medical-Treatment-Bill-2022>.

[120] Intersex Society of North America (n 25); AIS Support Group Australia et al (n 27); Carpenter, 'Fixing Bodies and Shaping Narratives' (n 3).

[121] Endocrinology and Diabetes, Queensland Children's Hospital (n 102).

[122] Committee on the Rights of the Child, *General Comment 13: Article 19: The Right of the Child to Freedom from All Forms of Violence* (No CRC/C/GC/13, 17 February 2011) 54; Morgan Carpenter, 'Intersex Human Rights, Sexual Orientation, Gender Identity, Sex Characteristics and the Yogyakarta Principles plus 10' (2021) 23(4) *Culture, Health & Sexuality* 516.

8.3 Reliance on customary practice and international guidance

In 2021 the Australian Human Rights Commission called for legislative and binding directions:

> "there is a real risk that medical interventions, other than on grounds of medical necessity, may be undertaken in the future. This position is informed by the views of a range of clinicians that psychosocial factors are justifiable considerations for medical interventions, with such justifications given weight in leading international guidance documents. Therefore, overall cultural change would be unlikely in the absence of binding directions"[123]

This position is supported by reliance on inappropriate rationales, and also appeals to international guidance and customary practice, developed without a clear evidence base. NSW and Queensland case reports note:

> "the requested surgery was in keeping with current guidelines"
>
> "as consistent with current international guidelines"
>
> "commencing multi-stage repair in infancy is the current established process"[124]

This inertia arises partly out of a lack of systematised research, including scarcity of data and lack of standardised methods. Kalfa and others, for example, attempted a systematic review of outcomes but this was impractical:

> "This paper is neither a systematic review nor a metanalysis considering the paucity of data, the extreme heterogeneity of conditions and various treatments that have been performed. Moreover, no standardized protocol of long-term follow-up has been proposed yet to the best of our knowledge and this prevents from drawing definitive conclusion regarding a validated protocol of follow-up."[125]

This inertia is also the combination of continually changing surgical techniques and an inability to determine outcomes from surgery on infants until subjects become adults. A NSW case report notes:

> "no high level evidence reporting outcomes in patients who have surgery using current day surgical techniques versus no surgery"[126]

There is no evidence of this form of comparative research being published by clinicians. Current techniques can never be assessed until they become obsolete because of continual changes to surgical techniques. Nevertheless, research is limited due to a history of non-disclosure and motivated disclosure of diagnoses and medical histories to patients, and the impact of adverse outcomes on engagement with clinical research.

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[123] Australian Human Rights Commission (n 21).
[124] Endocrinology and Diabetes, Queensland Children's Hospital (n 102).
[125] Kalfa et al (n 15); Muschialli et al (n 32).
[126] Sydney Children's Hospital Network, 'Referral of a Child with a DSD for Multidisciplinary Team Review (CAH)' (n 108).

A 2016 clinical "consensus statement" identifies issues with study design and bias in participation that underly the issues identified above by Kalfa et al.:

> "The practice of withholding medical history details, along with the possibility of negative medical experiences, likely contributes to patients with DSDs frequently being 'lost to follow-up.'"[127]

Acknowledging the selectivity in participation by people who are not lost to follow-up for these reasons in Europe, Kalfa et al. state:

> "A large study involving 1040 people from the European multicenter dsd-life study concludes that many people with a range of DSD conditions appear to be dissatisfied with their sex lives, experience a range of sexual problems and are less sexually active than the general population. The results in women with CAH seemed to vary, but in general surgery had a negative effect on sexual function."[128]

8.4 Masculinising surgeries

Masculinising surgeries encompass a range of interventions across the lifespan, including interventions in infancy (hypospadias surgery, hormone treatment), puberty (hormone treatment) and post-puberty (follow-up surgeries, hormone treatment, mastectomies). When these are conflated, views on outcomes can skew outcomes by failing to differentiate between populations subjected to surgery without personal consent and populations that could participate in decision-making. Kalfa et al. suggest, for example:

> "The majority of participants were neutral to satisfied with the appearance and function in the long-term after masculinizing surgery."[129]

MDTs primarily attend to "ethical dilemmas" relating to individuals unable to consent, so post-pubertal interventions are largely absent and discussion primarily relates to genital masculinisation surgeries. Cases discussed by MDTs relate to a range of diagnoses including mosaicism with mixed gonadal dysgenesis, Turner syndrome with mosaicism, penoscrotal hypospadias, complex hypospadias, perineal hypospadias, mid-shaft hypospadias, perineal hypospadias with penoscrotal transposition, 5α reductase deficiency, and "sex reversal". In some cases, diagnostic uncertainty was recognised. Hypospadias was often accompanied by other forms of uncommon genital development, and occasionally accompanied by other physical variations.

In relation to early masculinising surgeries, there is no high quality evidence of outcomes in Australian hospitals, aside from some follow-up research by surgeons at a Victorian hospital on their adolescent patients subjected to early surgeries for hypospadias; this suffers from multiple forms of bias, including in design of survey goals

[127] Lee et al (n 9); Carpenter, 'Fixing Bodies and Shaping Narratives' (n 3).
[128] Kalfa et al (n 15); Muschialli et al (n 32).
[129] Kalfa et al (n 15); Muschialli et al (n 32).

and conduct of research by the surgeons performing surgeries being researched (confirmation bias).[130]

In relation to people with a range of diagnoses who have been subjected to masculinising interventions, van de Grift and others[131] report on a large European study (large in the sense of numbers in the study, but not large in relation to the size of the European populations from which it is drawn). The authors differentiate outcomes based on type of surgical intervention, noting particularly in relation to hypospadias surgeries:

> "Physicians evaluated anatomical appearance at genital examination as poor in approximately 11% of patients. After hypospadias surgery, 38% of participants reported that they were (very) dissatisfied with anatomical appearance and 20% with function. Almost all who underwent this surgery for DSD had ambiguous genitalia at birth, indicating severe hypospadias, and underwent surgery at an early age."[132]

Long term outcomes following hypospadias surgery are not meaningfully ascertainable until adulthood, in particular due to physical growth and other changes in genital anatomy during puberty. Such growth has been associated directly to the development of urethral strictures (a narrowing of the urethra).[133]

Male assignment appears often to result in higher numbers of surgical interventions than female assignment. For example, in the case of children with 5α-reductase type 2 and 17β-hydroxysteroid dehydrogenase type 3, French research shows that infants with these traits undergo more interventions when assigned male than children with the same traits when assigned female.[134] In the European study, numbers of surgeries were extraordinarily high in many cases, with a mean average number of surgeries of 5.3:

> "Hypospadias reconstruction was performed in 84 males, with revisions in 60%, which is what would be expected based on the literature. The mean number of surgeries per person was 5.3, but ranged from one to 60 procedures [...] highest numbers among men who underwent surgery for hypospadias"[135]

European outcomes in terms of pain, physical sensation, appearance and impact on sexuality are poor:

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[130] Carpenter, 'From Harmful Practices and Instrumentalisation, towards Legislative Protections and Community-Owned Healthcare Services: The Context and Goals of the Intersex Movement in Australia' (n 12).
[131] van de Grift et al (n 24).
[132] Ibid.
[133] Guido Barbagli et al, 'Failed Hypospadias Repair Presenting in Adults' (2006) 49(5) *European Urology* 887; S Sansalone et al, 'A Natural History of Primary and Failed Hypospadias Repair in a Selected Series of 408 Patients' (2016) 15(8) *European Urology Supplements* 372.
[134] Estelle Bonnet et al, 'Changes in the Clinical Management of 5α-Reductase Type 2 and 17β-Hydroxysteroid Dehydrogenase Type 3 Deficiencies in France' (2023) 12(3) *Endocrine Connections* e220227.
[135] van de Grift et al (n 24).

> "One not so frequently described finding may be of interest, namely, the affected glans sensitivity after hypospadias surgery in seven of 74 participants; pain, in particular, was exclusively described in the group that underwent surgery. The finding that fewer than half of participants seemed to have normal sensitivity and one-third claimed a sensitivity as compared to the inner thigh could be a reason for dissatisfaction of function and sexual dysfunction."[136]

Dissatisfaction is high and views on timing of medical intervention likely reflect what Martha Nussbaum terms an "adaptive preference"[137]:

> "Dissatisfaction often remains high after hypospadias surgery, especially with regard to appearance and sexuality, and this was confirmed in the present study. Most patients have no insight into preoperative status as surgery was performed early in life, which also gives them no experience of being non-operated. [...]
>
> "There is a tendency to prefer the timing of surgery according to one's individual experience. "[138]

This variability depending on timing of actual interventions has been used by clinicians to support existing timings of surgeries, but these data equally support an alternative scenario: that questions of timing can be resolved in line with human rights norms and community expectations, thereby protecting personal autonomy and rights to consent.

In the absence of Australian research, European outcomes in comparable high-income jurisdictions with comparable healthcare systems should be taken as indicative.

One single instance was recorded in NSW in February and June 2022 of clinicians declining to perform masculinising hypospadias surgeries. This involved an instance where clinicians clearly disagreed with the male sex assignment chosen by the child's parents. This disagreement is evident in decisions to refer the parents for specialist psychological assessment, queries about "the family's certainty about male gender of rearing", interviews by multiple team members, and references to the "cost of over-riding parental preference".[139] This extended process could be regarded as a withholding of elective surgical interventions – otherwise considered essential by the MDT – as a means of incentivising a change in parental decision about sex of rearing.

References are made in NSW cases involving hypospadias to adverse outcomes, a need for "realistic expectations" and claims about a perceived need for early intervention to prevent traumatic memories and adverse psychosocial outcomes. However, these are

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[136] Ibid.
[137] Martha C Nussbaum, 'Adaptive Preferences and Women's Options' in *Women and Human Development: The Capabilities Approach* (Cambridge University Press, 2000) 111 <https://www.cambridge.org/core/books/women-and-human-development/adaptive-preferences-and-womens-options/BEC5953115039AA3B1234C81A287276B>.
[138] van de Grift et al (n 24).
[139] Sydney Children's Hospital Network, *Referral of a Child with a DSD for Multidisciplinary Team Review (46XY Ambiguous Genitalia)* (February 2022).

not appropriate rationales for treatment, and they do not meet community and human rights institutions' expectations.[140]

Teams display certainty that male assignment in children with atypical genitalia requires surgical intervention, even though this has always been disputed by intersex community-controlled organisations.[141] Case notes also display concern about outcomes even while surgery is approved, for example:

> "potential for poor outcomes regardless of timing"

Leading language of surgical "correction of hypospadias" is used even in a case where clinicians describe a "high likelihood that patient will be unsatisfied with genital appearance in the future".

In numerous cases, notably in relation to masculinising surgeries, bad or adverse functional and cosmetic outcomes are acknowledged using standardised disclaimers. One statement was repeated in multiple NSW reports, with only minor variation:

> "the usual caveats for severe proximal hypospadias such as multiple stage procedures, realistic expectations re cosmetic and functional outcome in adulthood and the need for ongoing psychological support to be offered/sought if required throughout childhood/adolescence and adulthood are to be discussed with the family and documented"

Surgery is nevertheless supported by MDTs in all of these cases and, on the basis of that support, likely proceeds. The lack of consequence for these ritualised disclaimers is an indication of a lack of neutrality and balance, and a systemic failure in the MDT model, expressed in the methods and language used to describe alternative treatment methods.

These issues are epitomised in an April 2019 case in NSW where the MDT supported multi-stage masculinising surgeries "for cosmetic and functional reasons" despite concerns about post-surgical "impaired function (sexual and/or urological) and cosmetic appearance of the genitalia". It should also be noted that function has been defined in a 2013 Australian clinical submission as referring to standing up to urinate,[142] so notions of functionality should not be taken to imply an inability to urinate without surgery. This case also provides strong evidence of a predetermined surgical outcome where the MDT report states that the infant "definitely needs a hypospadias repair, most likely a two stage repair".[143]

Multiple cases were brought before the NSW MDT on multiple occasions. In one case brought before the MDT on multiple occasions in 2018, the MDT noted that "corrective

[140] Muschialli et al (n 32); The Brussels Collaboration on Bodily Integrity (n 33).
[141] Intersex Society of North America (n 25); AIS Support Group Australia et al (n 27); Carpenter, 'Fixing Bodies and Shaping Narratives' (n 3).
[142] Australasian Paediatric Endocrine Group et al (n 20).
[143] Sydney Children's Hospital Network, *Referral of a Child with a DSD for Multidisciplinary Team Review (Penoscrotal Hypospadias)* (April 2019).

surgery is associated with a high rate of complications (approximately [redacted]%), and often, dissatisfaction with the outcome". Surgery was nevertheless supported.

In the case of a child whose case was brought to the MDT on multiple occasions in 2021 and 2022, the team held a "robust debate" "about the pros and cons of repair in perineal hypospadias because of the significant risk of complications of such surgery and uncertainty about [redacted] future gender identity". The team noted a "30-50% possibility that re-operation will be necessary" in adolescence or adulthood. Surgery was still seen as necessary based on sex assignment and gender identity. The case notes report that a team member "pointed out that hypospadias surgery is reversible".[144] This claim raises complex issues given the nature of the surgery, as it is certainly the case that physical sensation is not recoverable after hypospadias repair.

In discussion on this case in February 2022, urologists recognised the benefits of children participating in decision-making that begs important questions for decision-making across all cases involving proposals for hypospadias repairs:

> "The group discussed that there has been debate amongst surgeons in recent years about the pros and cons of repair of [redacted] in childhood because of the high complication rates; however also acknowledged that the potential for psychological harm of not repairing in childhood is unknown and may be significant[145]
>
> "The urologists were agreed that the optimal time for operation is prior to the age of 2yrs whereas boys operated on around the age of 4 yrs suffer more distress. Boys at older ages were said to cope better with the operation because it is more likely to be at their request. The urologists reported that they had yet to have the experience of parents deciding against hypospadias repair … They were not able to put a figure on the percentage of operations that are functionally successful in the long term allowing normal urination and sexual intercourse."[146]

This discussion clarifies that these are non-essential elective interventions. This material also offers conflicting views. The MDT concluded "we have no data on the risks of not proceeding with repair" perhaps dismissing as anecdotal the statement that older boys "were said to cope better with the operation because it is more likely to be at their request".[147] References to an "ongoing debate" appears to disregard the potential for children to make their own requests for surgery and "cope better".

The analysis in this report relies on a psychosocial hypothesis to justify continuing interventions, in a context where established outcomes are poor and deeply contested, and psychosocial rationales for early surgical intervention are rejected by psychiatric

[144] Sydney Children's Hospital Network, *Referral of a Child with a DSD for Multidisciplinary Team Review (Mosaic)* (February 2022).
[145] Ibid.
[146] Ibid.
[147] Ibid.

and psychological professionals in Australia.[148] It is an instance of what Dominic Wilkinson describes as a "self-negating prophecy" where "past predictions" "have led to interventions that" make it "impossible to know if the original prediction was correct".[149]

The MDT supported the parents' decision for surgery despite significant dissent, with some members feeling surgery should be deferred to allow the patient to participate in decision-making. Despite these statements about psychological harm, psychological support is not typically recommended from the outset in cases involving masculinising surgery, but only where significant distress appears to have already arisen.

It is notable that this case discussion took place in February 2022. This was likely the first meeting of the NSW MDT following publication of a major report in October 2021 by the Australian Human Rights Commission recommending broad changes to clinical practice, oversight and accountability.[150] Nevertheless, it indicates that team recommendations and clinical practice continued unchanged.

The NSW MDT discussion was also contemporaneous with debate on development of a pro-forma checklist for referrals of complex hypospadias, i.e. hypospadias accompanied by other factors such as undescended testes, microphallus or bifid scrotum.[151] The first pro-forma submissions were recorded as discussed in June 2022,[152] meaning that the debate on February 2022 may have been the last occasion for substantive discussion for and against elective early hypospadias surgeries. The cases documented in pro-forma checklists all propose early elective surgeries.

In addition to taking detailed discussion out of MDT review, the checklist includes a simple single checkbox where clinicians tick that the following statement is true:

> "consensus between parents and clinicians with male sex of rearing and that the proposed intervention/surgery supports the welfare and best interests of the child"[153]

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[148] Chief Minister, Treasury and Economic Development Directorate, *Draft Legislation To Protect The Rights Of People With Variations In Sex Characteristics In Medical Settings Listening Report on Submissions Received* (August 2022) <https://www.cmtedd.act.gov.au/policystrategic/the-office-of-lgbtiq-affairs/variations-in-sex-characteristics-bill/listening-report> ('*Listening Report on Submissions Received*'); Australian Human Rights Commission (n 21).

[149] Cindy Ho et al, 'Malignancy Risk in Turner Syndrome+Y, Early Gonadectomy, and the Ethics of Parental Choices' [2025] *Pediatrics* e2024067171; Dominic Wilkinson, 'The Self-Fulfilling Prophecy in Intensive Care' (2009) 30(6) *Theoretical Medicine and Bioethics* 401.

[150] Australian Human Rights Commission (n 21).

[151] Sydney Children's Hospital Network, *Checklist Referral for Complex Hypospadias (Peno-Scrotal Hypospadias or Any Hypospadias with Undescended Testis, Microphallus or Bifid Scrotum) to SCHN DSD Group Prior to Surgery* (2023).

[152] Sydney Children's Hospital Network, *Checklist Referral for Complex Hypospadias (Peno-Scrotal Hypospadias or Any Hypospadias with Undescended Testis, Microphallus or Bifid Scrotum) to SCHN DSD Group Prior to Surgery (1)* (June 2022).

[153] Sydney Children's Hospital Network, 'Checklist Referral for Complex Hypospadias (Peno-Scrotal Hypospadias or Any Hypospadias with Undescended Testis, Microphallus or Bifid Scrotum) to SCHN DSD Group Prior to Surgery' (n 151).

The adoption of this checklist and checkbox – even in cases of perineal hypospadias with added complexity[154] – has been accompanied by a significant loss of detail and absence of ethical debate. Indeed, it appears that any limited subsequent commentary on sex assignment, welfare and best interests invariably focuses on sex of rearing only.[155]

8.5 Feminising surgeries

Relatively scarce referrals relate to infant feminising surgeries, likely reflecting lower numbers of surgeries, but also reflecting a normalisation of such interventions on children with CAH, particularly those with high scores on the Prader scale (4-5), such that they are deemed not to require referral to an MDT. Cases involving referral include CAH (Prader 3), and CAH with male identity expressed in adolescence subsequent to early feminising surgery. Other diagnoses evident in case discussions for feminising surgery include uterine didelphys with urogenital sinus, 46XY gonadal dysgenesis, and 17β hydroxysteroid dehydrogenase 3 deficiency. Some cases indicate diagnostic uncertainty.

The case referrals that exist presume that infants "need" a vagina, contrary to recommendations by a 2013 Senate committee inquiry, community expectations and human rights norms.

Relevant clinical research in Australia typically involves studies of small cohorts carried out by their treating clinicians, and so subject to confirmation and ascertainment bias.[156] European research is more extensive, but there is a lack of systemic reviews. Kalfa and others attempted to conduct a systemic review, published in 2024, but they note that the scarcity of data and lack of standardised methods made such an approach impossible.[157] They also found, in relation to women with the trait CAH, that post-surgical outcomes had very adverse impacts on sexual and mental health. Almost all women in the study had been subjected to feminising surgeries as infants, as is also the norm in Australia:

> "In a recent study reporting the long-term results of a multicenter European registry study in women with CAH, the results cannot be interpreted as encouraging. One hundred and seventy-four 46, XX individuals were included. A gynecological examination was performed in 84 of whom 9.5% had a missing clitoris, 36.7% had a missing clitoral hood, 22.6% had abnormal large labia and 23.8% had small labia. In 30% of the total study population, sex life was described as poor on the basis of patient-reported

[154] Sydney Children's Hospital Network, *Checklist Referral for Complex Hypospadias (Peno-Scrotal Hypospadias or Any Hypospadias with Undescended Testis, Microphallus or Bifid Scrotum) to SCHN DSD Group Prior to Surgery (3)* (June 2022).
[155] See, for example, Sydney Children's Hospital Network, *Checklist Referral for Complex Hypospadias (Peno-Scrotal Hypospadias or Any Hypospadias with Undescended Testis, Microphallus or Bifid Scrotum) to SCHN DSD Group Prior to Surgery (5)* (August 2022).
[156] Carpenter, 'From Harmful Practices and Instrumentalisation, towards Legislative Protections and Community-Owned Healthcare Services: The Context and Goals of the Intersex Movement in Australia' (n 12).
[157] Kalfa et al (n 15).

> outcomes, which contrasts with the positive assessment of outcomes by 97% of clinicians and which emphasizes the need to obtain the patients' perspective [...]
>
> "The current analysis of long-term outcomes did not take into account any additional procedures needed later in life after infant surgery. However, we know that up to 50% of patients after pediatric vaginoplasty require additional procedures later in life to allow coitus."[158]

While claims of change to clinical practice over time may suggest that outcomes have improved over time, such claims date back to the 1980s; they are accompanied by claims of scientific progress and lack supporting evidence.[159] In the absence of comparable independent research on anatomical and sexual health outcomes in Australia, this European research provides an indication of likely outcomes as obtained in comparable high income countries with comparable healthcare systems.

Claims of change to clinical practices also produce uncertainty about actual clinical practices under discussion in MDTs. The terminology relating to early feminising surgeries often lacks precision and can encompass a range of possible practices.

Reference is made in scarce MDT cases to an absence of need for clitoral reduction or "recession" – both of which surgical approaches modify appearance – but this does not appear to be associated with delay to vaginal surgeries. For example, an August 2018 in NSW case involved a child proposed to undergo a vaginoplasty with debate about timing. The discussion noted that "Early surgery can be associated with the development of strictures with the subsequent need for revision in adolescence" [160] and also made the claim that current surgical techniques may decrease this risk. In this case the MDT determined that "clitoral reduction/recession was not to be recommended". Vaginal surgery was supported, with a general presumption that questions about this surgery were solely matters of timing.

In a case involving a child with CAH discussed in November 2018, vaginoplasty was proposed "in the first year of life". The parents were advised that "a further procedure may be needed after puberty e.g. repeat vaginoplasty or dilatations" and the team noted that "There is no objective evidence at this time as to whether early, late or no surgery best preserves overall [quality of life] or sexual function". Rationales discussed included the unevidenced claim of "avoiding stigmatisation of genital variation by restoring [sic] female anatomy, preventing parental anxiety". Surgery was supported by the MDT "as per international guidelines as long as the pros and cons of early versus late surgery were clearly discussed with the family".[161]

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[158] Ibid.

[159] Lobe et al (n 8); Carpenter, 'Fixing Bodies and Shaping Narratives' (n 3).

[160] Strictures here refer to a narrowing of the vagina, a frequent complication arising from early vaginal surgery

[161] Sydney Children's Hospital Network, 'Referral of a Child with a DSD for Multidisciplinary Team Review (Potential CAH)' (n 116).

MDTs also refer in some cases to reports of clitoral resection or clitorectomies being a "previous" practice, no longer performed. Case reports from NSW indicate that clitoral surgeries are generally avoided in cases discussed by the NSW MDT, while vaginoplasties continue. However, the MDT may discuss only a subset of cases and this cannot be generalised to other centres and jurisdictions. The end dates of reportedly discontinued practices are not established for any hospital in Australia; this is concerning in a context where evidence of continuing practices has come to light subsequent to claims of it ending.[162] Children may still be seen by hospital services having undergone such procedures. Individuals subjected to these practices have not received apology or redress.

A suggestion by some surgeons is that current clitoral surgery interventions such as "clitoral recession" merely "hide" a large clitoris and are less invasive. These are sometimes framed as "nerve-sparing" surgeries, but there is no evidence to support assertions that these do in fact spare nerves and sensation.[163] It is plausible that these suggestions are merely the current narrative in a long history of claims of scientific progress; it is not possible to report adult outcomes until such time as practices will have evolved further.

The MDT reports demonstrate that early feminising surgeries lack clinical consensus regarding necessity, in addition to being the subject of community and human rights opposition. The Queensland MDT reported in December 2022:

> "The group discussed that there is variation in practice around Australia, with some centres avoiding all early surgeries in CAH; at the recent paediatric endocrinology annual scientific meeting an esteemed senior colleague presented on a lifetime overview of CAH and commented that early surgery would no longer be performed."[164]

Our ability to interpret this material is limited: it is not clear what exactly is meant by early, nor what alternative is recommended as a result of the lifetime review. However, while it is not possible to establish from the FOI data which centres avoid early genital surgeries in CAH due to adverse outcomes, the confirmation that some centres avoid such interventions indicates that it is possible for all centres to do the same.

Case reports also include comments by a MDT member suggesting that worse outcomes are attributable to surgical limitations associated with assessment as Prader 4-5:

> "[redacted] stated that prefers to not do early surgery as this may make a second revision surgery more difficult due to scar tissue. [redacted] wondered if this was due to selection bias as the Prader 4 & 5 cases are more

[162] Carpenter, 'Fixing Bodies and Shaping Narratives' (n 3).
[163] Casey Orozco-Poore and Alex S Keuroghlian, 'Neurological Considerations for "Nerve-Sparing" Cosmetic Genital Surgeries Performed on Children with XX Chromosomes Diagnosed with 21-Hydroxylase Congenital Adrenal Hyperplasia and Clitoromegaly' [2023] *LGBT Health*.
[164] Endocrinology and Diabetes, Queensland Children's Hospital (n 102).

> difficult to correct at any age and will be the ones that represent after transition [to adult care] with complications such as introital stenosis"

No evidence is documented, and no conclusions were drawn.

NSW case reports contain a small number of cases, all involving children assessed as "Prader 3" (in one case, borderline 3-4) where surgery was agreed. No cases were presented of children with physical characteristics assessed as lower or higher on the scale. This may indicate that selected "edge cases" have been presented to the MDT for consideration.

In Queensland, multiple cases involving children subjected to feminising surgeries were the subject of MDT discussions. In one case from December 2022, the focus of discussion was on post-gonadectomy hormone replacement. The case history notes a gonadectomy, a hernia repair, inaccurately reports contemporaneous rationales for the gonadectomy, and also notes a "Clitoral recession", i.e. feminising genital surgery.

An additional Queensland case discussed an adolescent with congenital adrenal hyperplasia. The child who was raised female with "Surgical management in infancy" (not disclosed in any further detail) had "stated wish to continue as female at initial appointments" and "Initially expressed frustration with the lack of breast development" and "lack of puberty" leading to pubertal hormone interventions, appears to have been the subject of MDT discussion because the adolescent now reported a "Strong male identity" and "a desire for gender-affirming genital surgery". The team noted that "cultural safety and patient and family comfort with disclosing gender identity may be impeding interactions and clinical care in some instances".[165] In light of the newly identified context, psychosocial support was now proposed, and treatment changed. The adolescent was not referred to the Queensland gender clinic.

A single NSW case was reported of a 16-year old choosing genital surgery, following deferral of elective interventions by her parents (the only such instance observed in the case reports), shows an instance where psychological support is recommended, as a checkbox measure to test her competence but also to assess any psychological risks associated with any further surgical delay:

> "If surgery is deferred, psychological support would still be required to support [redacted] with any body image and psychosexual concerns she may have [...]
>
> "plan for support if delaying surgery until 18 years old poses any risks to her psychological wellbeing"[166]

The discussion provides an indication of the scarcity of deferral and clinical attitudes regarding delay. The approach to psychosocial support expressed here appears to be

[165] Ibid.
[166] Sydney Children's Hospital Network, *Referral of a Child with a DSD for Multidisciplinary Team Review (CAH)* (February 2023).

associated with the established but unevidenced idea that surgical delay causes psychological harm.

One NSW case involving cloacal exstrophy (with sex chromosomes not disclosed) involved 2 case discussions during the FOI period due to concerns about outcomes from surgical interventions. Some surgical interventions for infants with this trait are urgent and unambiguously essential for physical health and wellbeing. Other interventions may relate to social norms, with no clarity about this in clinical discussions. The case also raised difficult issues regarding hormonal treatment and "likely technical difficulties due to adhesions from the many previous surgeries".[167]

Overall, the extent to which cases involving feminising surgery are referred to MDTs is unclear and concerning, due to views amongst many clinicians that early intervention is routine and not a "dilemma", for at least a subset of children with atypical genital characteristics.

8.6 Gonadectomies

Many cases consider risks of gonadal tumours (cancers) in decision-making about gonadectomies (removal of ovaries, testes and streak gonads and ovotestes). Victorian[168] MDT minutes in 2018, for example, refer to

> "Current practice is for removal of gonadectomy for individuals who have XY DSD malignancy risk."[169]

In the case reports, gonadectomies were discussed in cases relating to children with androgen insensitivity, hypogonadism possibly due to testicular atrophy, mosaic chromosomes, 46XY gonadal dysgenesis (registered female), Turner syndrome, and chimerism.

However, decision-making is not straightforwardly scientific and based on malignancy risk. At the time of writing by the Victorian MDT, risk levels were already known to have been exaggerated in the XY trait complete androgen insensitivity,[170] and associated only with female assignment in XY traits 5α reductase deficiency and 17β hydroxysteroid dehydrogenase deficiency;[171] they are now established to have been exaggerated in XY trait partial androgen insensitivity.[172]

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[167] Sydney Children's Hospital Network, *Referral of a Child with a DSD for Multidisciplinary Team Review (Cloacal Exstrophy)* (February 2020).
[168] The minutes do not refer to Tasmania and the time period may predate extension to Tasmania.
[169] Royal Children's Hospital Melbourne, *Multidisciplinary Team - Redacted Minutes - Freedom of Information Request* (2018).
[170] Senate of Australia Community Affairs References Committee (n 18); Erica M Weidler et al, 'A Management Protocol for Gonad Preservation in Patients with Androgen Insensitivity Syndrome' (2019) 32(6) *Journal of Pediatric and Adolescent Gynecology* 605.
[171] Morgan Carpenter, 'Intersex Variations, Human Rights, and the International Classification of Diseases' (2018) 20(2) *Health and Human Rights* 205.
[172] Michele A O'Connell et al, 'Establishing a Molecular Genetic Diagnosis in Children with Differences of Sex Development: A Clinical Approach' (2023) 96(2) *Hormone Research in Paediatrics* 1 ('Establishing a Molecular Genetic Diagnosis in Children with Differences of Sex Development'); Ho et al (n 149).

Risk levels are not always reported accurately in case notes. In a December 2022 case in Queensland, the team report an inaccurate reliance on already obsolete data justifying the gonadectomy in an incorrect statement that "at that time, literature describing 'intermediate' risk of gonadal germ cell malignancy".[173] The obsolete source of literature describing 'intermediate' risk called for monitoring of gonads, not their removal.[174]

Additional factors such as sex of rearing, perceived risk of stigmatisation and gender dysphoria contribute to decision making, as well as what Dominic Wilkinson terms a "self-negating prophesy" where Earp, Kraus and Carpenter identify that "data remain scarce and provide an inadequate basis for accurate risk assessment [as] the very prevalence of early gonadectomies [...] contributes to this scarcity of data".[175]

In 2013, the Senate Community Affairs Committee criticised an interpolation into this decision-making on gonadectomies (removal of gonads) of extraneous factors such as sex assignment, and management of perceived future gender identity, stating that this "may undermine confidence in the neutrality of those advocating for surgical interventions".[176]

Cases documented in the FOI data discuss gonadectomies to eliminate a perceived risk of pubertal changes that differ from sex of rearing. In gender diverse children, the use of puberty suppressants can provide time for adolescents to freely express their values, wishes and preferences, and the use of gonadectomies takes away this option. The risk of development of features contrary to sex of rearing is described in case reports as risk of "virilisation" in children assigned female to be managed through surgery, for example:

> "risk of virilisation at puberty associated with this condition"
>
> "Essentially phenotypically female until puberty and now virilising [parent and individual] report wanting to remain as a female"
>
> Questions for MDT: "degree of virilisation and timing of 'essential' surgery"
>
> "underwent gonadectomy in [redacted] Presented at age [redacted], with virilisation, having been raised as a female"[177]

Children assigned male may be identified as "undervirilised".

Assessment of gender identity prior to decision-making about surgery in adolescents is notably different to decision-making on feminising and masculinising surgeries in infants where the suggestion that children "need" surgery to grow up psychosocially "normal", in line with assigned sex. This frames surgery as a kind of conversion practice,

[173] Endocrinology and Diabetes, Queensland Children's Hospital (n 102).
[174] Hughes et al (n 13).
[175] Ho et al (n 149).
[176] Senate of Australia Community Affairs References Committee (n 18); Ho et al (n 149).
[177] Sydney Children's Hospital Network, *Referral of a Child with a DSD for Multidisciplinary Team Review (XY GD)* (April 2023).

instilling a sense of identity and normality; these are ideas based on clinician opinion and lack evidence.

8.7 Hormone treatment

Traits of children whose cases were discussed in relation to hormone treatment include Turner syndrome and variants, 17β hydroxysteroid dehydrogenase deficiency, 46,XY gonadal dysgenesis, and mosaic sex chromosomes. Discussions in NSW and Victoria in relation to hormone treatment predominantly focus on treatment with growth hormones, not sex hormones.

Sex hormone treatment is necessary in all children who have experienced bilateral gonadectomies, and in other children whose bodies do not produce sex hormones in sufficient quantities. Hormone treatment can be used to induce puberty, and is required for life in people whose bodies do not produce enough sex hormones. Decisions about hormone treatment do not only have a connection to personal experiences of gender, sexuality and identity; decisions about hormones also consider and influence factors such as future height, and have consequences for other decisions affecting sexual and reproductive health. Treatment decisions relating to children with other traits, including sex chromosome variations and hypogonadism, may not be brought to MDTs, even where early neonatal testosterone treatment is proposed as part of a standard treatment plan.

Growth hormones were discussed in the cases of children with Turner syndrome, mosaic chromosomes, gonadal dysgenesis and complex hypospadias. In some cases, gonadectomy (causing a later need for sex hormones) was regarded as a prerequisite for growth hormone treatment in order to mitigate risks of malignancy. Risks were not clearly established in the case reports, and one 2020 NSW case report stated there is "no proof that growth hormone treatment would accelerate a malignancy process".

Often adolescents are able to participate in decision-making, or make their views, values and preferences known; sex hormone treatments commence at an age where children are usually able to participate in decision-making.[178] However, multiple reports indicate that adolescents lack accurate or sufficiently complete information about their bodies, and so their contribution to decision-making cannot be said to be fully informed. The psychosocial development of individuals is significantly impacted by parental and clinical expectations, and this may be intended to promote compliance with long term treatment plans.

A December 2022 report from Queensland[179] describes decision-making in a case of an adolescent whose case was previously brought before the Family Court. The case history notes a gonadectomy, a hernia repair, and early feminising genital surgery. The young person is unlikely to know that her gonads were testes, and did not know her sex chromosome complement, which is XY.

[178] P Alderson, 'Children's Consent and the Zone of Parental Discretion' (2017) 12(2) *Clinical Ethics* 55.
[179] Endocrinology and Diabetes, Queensland Children's Hospital (n 102).

Discussion of the case indicates that, even though a psychiatrist was involved in treatment, the young person did not have knowledge of her diagnosis, and was aware only that she could not have children due to being told "that she had her gonads removed as an infant and that she does not have a uterus".

The case illustrates a lack of age-appropriate disclosure of key information that may impact her views. The young person was not provided age-appropriate information prior to decisions being made about puberty induction with oestrogen, an irreversible treatment. Her views were formed within a bubble with only partial information that can appear motivated to produce compliance with the proposed treatment.

The child's parents are presented as having strong views, but they also have views that are clearly described in case reports as being heavily informed by clinical perspectives:

> "Parents [redacted] as a 'normal girl' and pleased with their decision to [redacted] raise [redacted] as a girl. [Redacted] has told parents she is [redacted] keen to commence oestrogen, she wants to grow breasts and be 'like other girls'. [...]
>
> "Parents advised by Dr [redacted] that they should take time to talk to [redacted] about her karyotype during her adolescence; that it would not be advisable for [redacted] to find out herself googling her diagnosis etc. Suggested that an appropriate time might be when she is taught about chromosomes in biology/science in high school, though it is up to their discretion. They agreed with this."[180]

The case notes also report the clinical view of her desires:

> "can clearly articulate her desire for medication [...] in alignment with her peers of female sex"[181]

Disclosure of her karyotype following school discussion on XX and XY chromosomes carries the potential to cause distress and anxiety. Disclosure of her diagnosis will radically change her worldview.

The child was assessed as having "Average cognitive ability for her age", but without having capacity to consent to treatment.[182] The case report includes a statement that indicates low expectations and seeks to minimise concerns about non-disclosure prior to commencing puberty induction, with irreversible consequences, by suggesting that comprehension will remain limited even as an adult:

> "It was noted that some of the concepts around the diagnosis including XY karyotype may still be difficult to understand even at the age of 18 when she is legally allowed to provide consent"[183]

[180] Ibid.
[181] Ibid.
[182] Ibid.
[183] Ibid.

This statement is paternalistic and decisions leading to partial disclosure prior to pubertal induction also fail to adequately recognise the evolving capacity of the child to be heard and to participate in decision-making over time.

The young person in this case should be entitled to more information about her body before making decisions about hormone treatment. Should the data on her identity remain valid, she will need more information during adolescence in relation to her sexual and reproductive health. For example, the case report placed inverted commas around the word vagina, and noted a vaginal cavity length of 2cm; this means that any future heterosexual intercourse will need to be preceded by dilation, or possibly surgery. Dilation is a repetitive and discomforting mechanical task that will require her active participation, considerable time, effort and patience.

Community and human rights institutions articulate that raising a child in a particular sex or gender does not require surgical intervention. However, these case notes identify a further concern, where an alternative vision of family connection with community and peers – from early years into adulthood – has been denied. Peer and community connection seeks to make it normal to live well with a body that is different.

8.8 Genital photography

Genital and other photography of infants and children with innate variations of sex characteristics has a history of causing harm, particularly when subjects have seen themselves and their body parts in medical records or journal articles.[184]

The case reports indicate that medical photography remains routine, and part of the documentation provided to MDT members. Medical photography is named as a field in the NSW complex hypospadias checklist, with the ability for form fillers to add a simple yes, no or add comments:

> "Pre-op clinical photography offered to parents and if consented to, photographs are filed in medical records as per local data storage policy."[185]

In these cases, sometimes medical photography on infant genitals is noted as having been performed by parents[186] and a genetic counsellor.[187] Text on reviewed completed NSW hypospadias referral checklists includes the following statements:

> "Photos have been taken"

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[184] Sarah Creighton et al, 'Medical Photography: Ethics, Consent and the Intersex Patient' (2002) 89 *BJU International* 67.
[185] Sydney Children's Hospital Network, *Checklist Referral for Complex Hypospadias (Peno-Scrotal Hypospadias or Any Hypospadias with Undescended Testis, Microphallus or Bifid Scrotum) to SCHN DSD Group Prior to Surgery (10 Prox Peno)* (June 2023).
[186] Sydney Children's Hospital Network, 'Checklist Referral for Complex Hypospadias (Peno-Scrotal Hypospadias or Any Hypospadias with Undescended Testis, Microphallus or Bifid Scrotum) to SCHN DSD Group Prior to Surgery (3)' (n 154).
[187] Sydney Children's Hospital Network, *Checklist Referral for Complex Hypospadias (Peno-Scrotal Hypospadias or Any Hypospadias with Undescended Testis, Microphallus or Bifid Scrotum) to SCHN DSD Group Prior to Surgery (8)* (April 2023).

"Done by genetic counsellor"

"Done on [redacted] ...on powerchart"

"Intra-operative photographs to be taken"

"Parents have taken photographs and gave consent to send to DMR and share with MDT"

"Parents have taken photographs and gave consent to send to DMR"

"Will organise on day of surgery"

The approach to photography on the hypospadias checklist indicates that photography is likely to be routine, but no mention of photography occurs in the FOI materials in relation to other referrals or case discussions.

The individuals whose photographs are taken may find these in their medical records decades later, raising questions about their bodies pre-surgery. In some cases, individuals have reported finding copies of their photographs in clinical journals, without their prior knowledge or personal consent. Older children have also been photographed during clinical examinations, recalling these as part of their experience of healthcare.[188]

These taking, use, reuse and storage of these photographs raise ethical and human rights concerns detailed in literature since at least 2002, but not addressed in MDT case reports.

9 Conclusions

The redacted FOI materials provide highly significant evidence of practices affecting children who, in many cases, are still being treated in Australian paediatric hospitals. In a context where adult outcomes are frequently dismissed as related to "obsolete" practices, lack of transparency, together with unevidenced claims of change to clinical practices, contribute to a lack of action to address the demands of community organisations and human rights institutions. Claims of change to clinical practice occur despite a lack of data on when discontinued practices ended, a lack of data on new practices, and new data demonstrating evidence of continuing practices of concern. Analysis of surgeries by Medicare Benefits Schedule code, and analysis of decisions by multidisciplinary teams are only able to provide partial, incomplete information on practices.

[188] Cheryl Chase, 'Hermaphrodites With Attitude: Mapping the Emergence of Intersex Political Activism' (1998) 4(2) *GLQ: A Journal of Lesbian and Gay Studies* 189; Ellen K Feder, 'Feminist Theory and Intersex Activism: Thinking between and Beyond' [2021] *Philosophy Compass* <https://onlinelibrary.wiley.com/doi/10.1111/phc3.12764> ('Feminist Theory and Intersex Activism'); Hedvig Engberg et al, 'The Experience of Women Living with Congenital Adrenal Hyperplasia: Impact of the Condition and the Care Given' (2016) 85(1) *Clinical Endocrinology* 21 ('The Experience of Women Living with Congenital Adrenal Hyperplasia').

The redacted FOI materials provide cause for serious concern regarding current clinical practices in Australian hospitals. Institutions in New South Wales and Queensland are to be commended for releasing adequate redacted documents, in line with the provisions of legislation and regulation. If the FOI requests had not been made, these concerns with current practice could not have come to light. It is deeply concerning that the Victorian and Tasmanian MDT, and teams in other jurisdictions, did not release comparable documentation. Community demands have long included calls for transparency regarding medical practices, to ensure accountability, and this is a feature of calls for legislative reform.[189] Lack of transparency on practices in other jurisdictions does not only limit the findings of this research, it should provide a serious cause for concern regarding clinical practices in those jurisdictions.

In considering the available case reports, 6 cases clearly involved referral to community-controlled psychosocial support or peer support groups. 3 cases unambiguously met community expectations regarding medical treatment and referral to peer and psychosocial support.

The following table considers total number of individual cases seen in case reports. The range of case discussions per individual ranged from 1 to 3 during the FOI study period.

Jurisdiction	**Total cases**	**Adverse findings**	**Positive findings**	**Insufficient data**
NSW	75	43	41	6
Queensland	8	6	3	0
Total	83	49	44	6

Adverse findings include inappropriate rationales for surgery; predetermined outcomes based on sex registration; surgery occurring despite pro forma clinical acknowledgement of a need for “realistic outcomes”, high complication rates and dissatisfaction; and loss of detail arising from a transition to checklist discussions of complex hypospadias cases.

Positive findings include the ability of an adolescent to participate in decision, referral for psychosocial support in situations of distress or clinical identification of need, lack of urgency in relation to non-essential interventions, deferral of surgery, and conduct of additional testing prior to decision-making. These do not necessarily indicate that children have been treated in line with community expectations and human rights norms.

The table counts do not attend to broader structural issues with multidisciplinary teams, and cases are not routinely referred for psychosocial and peer support. Additionally, the case reports, minutes and MDT terms of reference take place in a silo with no direct acknowledgment of well documented contestation regarding early elective medical interventions by community, human rights institutions and ethicists.

[189] Carpenter, ‘Protecting Intersex People from Harmful Practices in Medical Settings’ (n 19).

Without what the Australian Human Rights Commission calls the "binding directions" provided by legislation and regulation, it is difficult to envisage improvements to clinical practices, in line with community expectations and human rights norms.

9.1 Structural issues

Multidisciplinary teams (MDTs) have been framed as an alternative to court oversight, even while they only see a small subset of cases, such as those where clinicians identify a dilemma of some kind. Structural issues are evident within MDTs. They are not able to provide the kind of scrutiny that would meet community expectations and human rights norms.

Claims are made about human rights and ethical engagement by teams that do not include, or only optionally include, professionals with relevant expertise. As has been established by previous analysis, psychosocial, ethical and community perspectives are systematically marginalised and excluded. Debate about ethics in relation to surgical interventions does not lead to variation in decisions regarding treatment: this debate does not appear to ever lead to decisions against surgery in any case.

In the case of hypospadias surgeries, the timing of a debate establishing "high complication rates" and an inability of surgeons to "put a figure on the percentage of operations that are functionally successful in the long term allowing normal urination and sexual intercourse" occurred at the first meeting of an MDT following publication of a 2021 report criticising current practice by the Australian Human Rights Commission. The urologists in the meeting also "reported that they had yet to have the experience of parents deciding against hypospadias repair".[190] The same moment saw the adoption of a pro-forma checkbox that appears to have taken substantive ethical debate out of the purview of the multidisciplinary team.

Decision-making can wrongly frame concerns by community organisations and human rights institutions, for example, by framing debate as about timing of surgery rather than necessity and personal consent, or through lack of understanding about the role and limits of parental authority. Decisions are frequently made on the basis of clinical opinion or consensus, even where these provide inappropriate or inadequate justifications for non-urgent and other elective interventions without personal consent.

9.2 Feminising and masculinising surgeries

Surgical intervention appears to be seen as a routine and inherent consequence of diagnosis and sex registration. Even while debate about feminising and masculinising surgeries and their outcomes occurred in MDTs, this does not appear to have influenced decisions that children undergo them.

Parent views play a strong role in discussions about timing of surgery, and parents are clearly also guided by the views put to them – particularly views put by surgeons. Parental distress and parental wishes, and claims of hypothetical and unevidenced

[190] Sydney Children's Hospital Network, 'Referral of a Child with a DSD for Multidisciplinary Team Review (Mosaic)' (n 144).

psychosocial risks of not proceeding with surgery, appear to influence universal decisions in favour of unnecessary early elective interventions, with lifelong irreversible impacts, despite community and human rights opposition, established data on high complication rates, and lack of data on successful surgical outcomes.

Delay to surgery occurred in notably few instances, including an instance where parents chose not to undergo early surgery, causing a decision in favour of exploratory psychosocial support when an individual later requested it, and an instance where parental choice of sex registration did not align with the preferences of an MDT. Two instances o delay also occurred due to diagnostic uncertainty, which was addressed through discussion about additional testing, and without further documentation in the redacted FOI documents.

Debate documented in MDT records nevertheless demonstrates that it is possible for centres to cease unnecessary and elective interventions until such time as individuals undergoing these surgeries can express their own values and preferences for treatment.

9.3 Hormone treatment

Children are commencing hormone treatment without adequate knowledge about their bodies, diagnoses, prognoses, and their potentialities. Children unduly lack access to psychosocial and peer support to help generate this understanding. This creates risks, as seen in a 2017 Family Court case, where an individual commences treatment that did not align with their established values and preferences.

In one case, the future ability of a child with “average cognitive ability” to understand her body was dismissed in justification of a decision to commence hormone treatment prior to her being able to personally consent.

9.4 Psychosocial and peer support

Psychosocial support has a crucial role to play in communicating information about bodies, diagnoses and future possibilities, and can also play a key role in helping individuals to determine and express their own values and preferences for treatment.

Despite recommendations in clinical consensus statements recognising the role and importance of psychosocial support and peer support, these services and functions are largely absent from discussions, which correlates with the observations of community organisations that referrals from clinical centres are lacking. Teams hold presumptions that psychosocial support is primarily useful for management of crises or gender identity concerns.

The absence of psychosocial and peer support reflects the dominance of surgical and other biomedical perspectives. This absence also denies possible alternative models of care that centre access to peers and community, to enable children and their families to grow up well with bodies that are a little different.

In the context of this lack of referral and take-up of psychosocial and peer support, many parents clearly exhibit distress and demand early intervention – even when

exposed to information about high risks of complications. At the same time, the materials also show clinicians guiding parental decisions, including in relation to disclosure to their children and, in one surprising instance, withholding masculinising surgery in a case where clinicians opposed the parental choice of sex registration.