EVALUATION OF RECORDS OF MEDICAL INTERVENTIONS IN CHILDREN WITH DEVELOPMENTAL VARIATIONS OF SEX CHARACTERISTICS IN AUSTRALIA

TECHNICAL REVIEW FOR EQUALITY AUSTRALIA

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Abstract

This review critically examined medical and surgical interventions performed on Australian children with developmental variations of sex characteristics, drawing on multidisciplinary team (MDT) records obtained through Freedom of Information requests from major Australian hospitals in 2022-2024.

Of 1,444 records reviewed, 64 (4.4%) contained sufficient detail for clinical analysis, and of these, 17 (27%) were identified for assessment of evidence supporting the clinical indication for the proposed intervention by Equality Australia. An independent evaluation of these 17 deidentified records was conducted to assess the quality of evidence supporting the proposed interventions, applying the Grading of Recommendations, Assessment, Development and Evaluations (GRADE) framework.

Four records (23.5%) were found to cite supporting medical literature, and one (5.9%) provided medical evidence for all proposed interventions.

The reports reviewed were examined for proposed surgical intervention, proposed medical intervention, or both. The proposed surgical interventions fell into three categories: hypospadias repair, feminising genitoplasty (vaginoplasty and clitoroplasty) in congenital adrenal hyperplasia (CAH), and orchidopexy. There was one non-surgical intervention category: adjuvant testosterone treatment with hypospadias surgery.

The surgical intervention of orchidopexy was supported by a large body of medical evidence as well as consistent international consensus. In contrast, the evidence supporting hypospadias repair, feminising genitoplasty (vaginoplasty and clitoroplasty), and adjuvant testosterone therapy for hypospadias repair remained low grade and largely based on expert opinion rather than strong research data.

A supplementary review of published clinical management guidelines confirmed these findings, revealing a well-established, concordant evidence base for the surgical procedure of orchidopexy, however ongoing uncertainty and divergence in recommendations for genital reconstructive procedures and adjuvant hormone therapy.

Taken together, these findings outline the limitations of the documentation and evidentiary foundation surrounding clinical decision-making for children with variations of sex characteristics in Australia. They underscore the need for comprehensive data collection and research, rigorous documentation, and evidence-based, and patient-centred frameworks that reflect both current scientific knowledge and evolving ethical standards.

Introduction

Between 2022 and 2024, Equality Australia undertook a national review of medical interventions performed in children with developmental variations of sex characteristics, using Freedom of Information (FOI) legislation to obtain relevant records of "Disorders of Sex Development" multidisciplinary team determinations for proposed clinical interventions at Australian hospitals.

Equality Australia reviewed the obtained documents, assessing in each case the proposed intervention and the evidence provided in support of the determinations made by the multi-disciplinary teams.

An independent scientific body was commissioned to conduct an objective evaluation of selected cases identified by Equality Australia as lacking clear evidence-based justification.

Analysis focused on structured academic grading of the quality of the evidence provided, and reviewing the availability and relevance of applicable clinical consensus guidelines.

This assessment was strictly limited to evaluating the medical and scientific accuracy and quality of evidence for the reviewed indications. We did not offer commentary on legal, ethical, or human rights matters.

Materials and Methods

Equality Australia accessed medical records between 2022 and 2024 using FOI legislation for "Disorders of sex development" multidisciplinary team review of proposed clinical interventions in intersex children after 1 January 2018. Over the 2 years, 248 documents were received from major tertiary paediatric hospitals in Australia.

These documents contained records from 1444 individuals. Of these, 1130 (78.3%) records were insufficient for meaningful analysis, 225 (15.6%) were too heavily redacted to allow for meaningful analysis, 9 (0.6%) were duplicated for the same individual, and 64 (4.4%) unique records were identified as suitable for analysis.

Equality Australia analysed these 64 records and identified 17 (26.6%) for recommended further academic examination due to a determination of limited evidence supporting the proposed intervention.

The documents for the 17 deidentified proposed interventions were provided for analysis. Each document was reviewed and analysed to identify the proposed medical and/or surgical intervention, aetiological diagnosis and indication for intervention, and literature provided in support of the proposed interventions.

The body of evidence provided was analysed using the validated Grading of Recommendations, Assessment, Development and Evaluations (GRADE) system to evaluate the quality of evidence provided [1–3]. In accordance with the GRADE system, the provided literature was reviewed to assess for cited outcomes used to determine whether a certain decision should be made, then the evidence for each outcome is rated as high certainty, moderate certainty, low certainty, or very low certainty. The certainty is graded in a systematic manner based on the methodology and power of the studies, the specificity with which the evidence addresses the clinical intervention, and the degree to which the study and participants are exposed to bias.

In addition to the GRADE analysis, a search was conducted for all records - including where no medical evidence was provided in the documentation - to identify the presence of published consensus treatment guidelines endorsed by medical professional bodies to support the proposed interventions.

In the review of existing consensus clinical practice guidelines to inform practice regarding proposed interventions, an exhaustive search of all available medical evidence was not conducted, as undertaking such a task would be academically extensive and falls outside the scope of this technical review. Instead, a focused academic search was conducted to identify consensus management guidelines for the proposed interventions which have been endorsed by professional bodies.

Searches were performed on PubMed, Ovid MEDLINE, and Google Scholar to locate consensus guidelines which have been endorsed by, and reflected the positions of, professional learned medical bodies rather than the views or opinions of individual clinicians.

Results

GRADE Analysis

The 17 proposed interventions identified for review occurred in the period from 2018 to 2023.

All 17 (100%) included a recommendation for surgical intervention. The proposed surgical interventions fell within three categories: hypospadias repair (82.4%), feminising genitoplasty (vaginoplasty and clitoroplasty) (17.6%) and orchidopexy (proposed simultaneously in 17.6% with hypospadias repair). Adjuvant testosterone therapy was proposed in 36% of interventions where hypospadias repair surgery was proposed.

Functional rationales for surgical intervention included proposed improved wound healing with younger age, proposed prevention of urinary tract infections (UTI) and the need to create a separate vaginal opening to accommodate menstruation later in life. Multiple intervention proposals presented an aim to avoid a more traumatic experience for the child should surgery be deferred due to proposed reduced pain sensitivity at a younger age.

The rationale for the surgical intervention of hypospadias repair predominantly centred on the prevention of urinary tract infection and the perceived risk of psychological distress to both children and their parents in situations where genital appearance did not align with parental expectations or the designated sex of rearing. In instances where concern regarding recurrent UTI was cited, documentation did not specify whether there had been any UTIs experienced at the time of the review, or whether the proposed intervention was intended as a preventive measure.

In some instances cosmetic factors were cited as the primary justification for intervention, with cited justifications including aiming to align a child's genital appearance with normative standards, avoiding social stigmatisation and mitigation of parental anxiety.

Of the records reviewed, four (23.5%) included references to published literature to substantiate either all or part of the proposed interventions.

Multiple records proposing vaginoplasty in children with CAH referenced the 2018 Congenital Adrenal Hyperplasia (CAH) Guidelines, which offers an 'Ungraded Good Practice Statement' for the proposed intervention of feminising genitoplasty (vaginoplasty and clitoroplasty) [11]. In the context of medical guidelines, an ungraded good practice statement reflects the finding by the guideline authors that the current evidence available to support this statement is insufficient to provide any grading of evidence and are the least robust recommendation that medical guidelines can offer.

A proposal for clitoroplasty in childhood rather than delaying surgery until a later stage provided a series of cited literature that included 3 retrospective analyses, 1 literature review, 1 consensus statement, and 1 meta-analysis along with the 2018 CAH Guidelines [11–17]. The Grade analysis can be seen in **Table 1**.

Although a number of references were cited, following GRADE analysis it was found that many of the original studies either did not directly address the question being asked by the multidisciplinary team (MDT) reviewing the case, suffered from methodological quality issues such as significant attrition bias, low patient numbers, short duration of followup, lack of control or comparator groups, or suffered from other biases including lack of investigators independent from those who conducted the surgical intervention, and use of subjective scoring systems, that meant that the quality of evidence provided was still classified as very low on GRADE analysis.

Question	Should feminising genitoplasty (vaginoplasty and clitoroplasty) in children with CAH occur early in life or should it be delayed surgery until the child is older	
Outcomes	Cosmetic Outcomes	GRADE of evidence
	Patient satisfaction with genital appearance	Very low grade of evidence ⨁OOO
	Lowered parental anxiety with early surgery	Very low grade of evidence ⨁OOO
	Avoidance of psychological distress regarding genital appearance with early surgery	Very low grade of evidence ⨁OOO
	Functional Outcomes	GRADE of evidence
	Long-term risk of vaginal stenosis with early surgery	Very low grade of evidence ⨁OOO
	Ability to use tampons with early surgery	Very low grade of evidence ⨁OOO
	Long-term risk of sexual dysfunction with early surgery	Very low grade of evidence ⨁OOO
	Long-term risk of reduction in clitoral sensation with early surgery	Low grade of evidence ⨁⨁OO
	Risk to long-term fertility outcomes with early surgery	Very low grade of evidence ⨁OOO
	Increase UTI risk with delayed surgery	Very low grade of evidence ⨁OOO
	Risk of incontinence with early surgery	Very low grade of evidence ⨁OOO
	Risk of need for recurrent surgical intervention with early surgery	Very low grade of evidence ⨁OOO
	Risk of early surgical complications with early surgery	Very low grade of evidence ⨁OOO

	Risk to neurodevelopment with early surgical intervention	Very low grade of evidence ⨁◯◯◯
	Ease of surgery at an earlier age	Very low grade of evidence ⨁◯◯◯
Evidence	Creighton et al., 2001, *The Lancet* Creighton et al., 2004, Hormones - *International Journal of Endocrinology and Metabolism* Crouch et al 2008, *The Journal of Urology* Hughes et al., 2006, *BMJ – Archives of Disease in Childhood* Warne G et al., 2005, *Journal of Paediatric Endocrinology and Metabolism* Almasri et al., 2018, *Journal of Clinical Endocrinology and Metabolism* CAH Endocrine Society Clinical Practice Guideline, Speiser et al., 2018, *Journal of Clinical Endocrinology and Metabolism*	
Overall GRADE Classification	***Very low grade of evidence*** ⨁◯◯◯	

Table 1. The GRADE classification for evidence provided for a particular case.

Consensus guidelines for proposed interventions

The proposed interventions were categorised into the following major groups: hypospadias repair, adjuvant testosterone treatment for hypospadias repair, feminising genitoplasty (vaginoplasty and clitoroplasty) in children with congenital adrenal hyperplasia and orchidopexy.

With respect to surgical hypospadias repair, a single guideline which has been endorsed by a professional clinical body, The European Association for Urology was located, for which the 2010, 2018, and 2025 revisions were reviewed to assess the evolution of recommendations over time. The construction of these guidelines involved the utilisation of the GRADE system to classify their recommendations as either high (reflective of there being a robust body of evidence to support that recommendation) or low (reflecting the paucity of a strong body of evidence, equivocal balance of harm and benefit or uncertainty and variability between patient preference). There were strong recommendations to identify patients with disorders of sexual development (DSD) where relevant, counsel caregivers on the complications of surgery and ensure long-term follow up, however the only recommendation pertaining to intervention was that significant curvature of the penis should be corrected (over 30 degrees), and this was a classed as a low grade recommendation [18–20]. There was no distinct recommendation in the European Association for Urology guideline pertaining to hypospadias repair itself.

The search for consensus guidelines addressing feminising genitoplasty (vaginoplasty and clitoroplasty) identified two distinct documents, both endorsed by recognised professional clinical bodies. The 2006 Disorders of Sex Development consensus statement was endorsed by the European Society for Paediatric Endocrinology, however no formalised GRADE analysis of the evidence was performed to provide the recommendations. The 2018 European Society guidelines performed a GRADE analysis of the data provided in 29 observational studies regarding surgical outcomes in feminising genitoplasty (vaginoplasty and clitoroplasty) in congenital adrenal hyperplasia and noted that the evidence was of low quality and carried a high risk of bias, with most recommendations forming ungraded, good practice statements. The single exception in the 2018 European Society guidelines is a graded recommendation that if electing to proceed with surgery, urogenital mobilisation and neurovascular-sparing clitoroplasty for severe clitoromegaly are the surgeries of choice. [Very low grade evidence, ⨁◯◯◯] [11,17].

For orchidopexy, nine distinct clinical guidelines endorsed by professional clinical bodies were identified and included in the analysis. These were endorsed by several professional medical organisations, including the European Society of Endocrinology, the American Urological Association, the Canadian Urological Association and the British Association of Paediatric Surgeons. The cited guidelines all graded the evidence available for the recommendations made, and generally contained recommendations graded as medium to high certainty of evidence supporting their recommendation [18,21–27].

Discussion

Of all the documents attained, 95.6% of these records were deemed unsuitable by Equality Australia for inclusion in analysis. Of those analysed by Equality Australia, 27% were classified as having unclear evidence based indication and were included in this evidence-based analysis.

A review of the proposed interventions contained within the subset of analysed records revealed that all included surgical interventions, with the proposed procedures in three principal categories: orchidopexy, hypospadias repair, and feminising genitoplasty (vaginoplasty and clitoroplasty). In 36% of the cases where hypospadias repair was proposed there was also a proposal for adjuvant medical (non-surgical) management, and all of these related to testosterone therapy.

In 5 records (29.4%), no rationale or indication for surgical or medical management was recorded, however the absence of documentation of indication for intervention is unlikely to indicate a lack of discussion regarding clinical reasoning.

In 4 records (23.5%) there existed citations of medical evidence to support the proposed intervention. However of these, half provided evidence to support decisions unrelated to the proposed surgical procedure, resulting in 11.8% of records analysed providing citations of medical evidence in orders to support the proposed surgical intervention. The remaining reports that were reviewed (76.5%) did not cite any evidence in support of any proposed interventions.

These findings highlight variability in documentation practices and underscore the need for improved standardisation in reporting clinical rationale and supporting evidence for clinical interventions in a population for which the grade of medical evidence for intervention is typically low. The limitation is likely multifactorial in origin.

First, there remains a notable paucity of robust empirical evidence delineating the optimal management strategies for children with developmental variations of sex characteristics. The decision to pursue many interventions in this population have been the subject of considerable ethical and clinical debate in recent years. Some authors have argued in favour of delaying deferrable surgery or hormone treatments until the child is sufficiently mature to participate meaningfully in decision-making processes. This position contrasts with the historically more prevalent approach of early surgical intervention, which sought to align genital appearance with the sex of rearing and thereby minimise perceived psychosocial distress for the child and family [12–14,28,29].

However, there are currently no high-quality comparative studies evaluating outcomes between early and delayed surgical intervention for hypospadias repair or feminising genitoplasty (vaginoplasty and clitoroplasty). As such, clinical practice continues to rely heavily on low-powered studies, anecdotal experience and clinician opinion. A recent 2025

review by Engberg et al. examined this issue in detail, emphasising the ongoing lack of rigorous trials and comparative outcome data to guide clinical decision-making in the management of children with virilised congenital adrenal hyperplasia (CAH) and hypospadias [30]. It is recognised that there are limited research data in the medical literature to support recommendations on whether some types of surgery should proceed and the timing for surgery.

The second explanation for these findings is due to likely limitations in documentation practices within MDT settings. It appears that meeting records likely omit citations of the literature that informed the MDT deliberations and, ultimately, proposed interventions. While the omission of explicit literature references is consistent with standard medical documentation practices - particularly in contexts where decisions align with established best practice - this approach may not be optimal in ethically complex and professionally evolving areas, including several categories of surgical or hormonal interventions for children with developmental variations of sex characteristics. In such contexts, documentation of the evidentiary basis for the proposed intervention would ensure auditable accountability in patient care and facilitate informed future decision-making.

Clinical guidelines review

The supplementary review of international clinical guidelines was undertaken to address a limitation identified during the primary analysis: in the majority of records reviewed, MDT documentation did not include citations of medical literature or evidence supporting the proposed interventions. Consequently, it was not possible to determine whether the proposed interventions were consistent with contemporary professional standards or based on recognised consensus statements which have been endorsed by professional bodies.

To address this limitation, a targeted review of international, peer-endorsed clinical guidelines was performed to independently assess whether current evidence-based recommendations exist to support the interventions proposed within the reviewed records.

This approach allowed the evaluators to identify areas where robust, standardised guidance is available, as well as areas characterised by uncertainty, inconsistency, or absence of consensus within the medical community, providing insight into whether the deficiencies observed in the case documentation reflected incomplete record-keeping or a more fundamental lack of evidence and consensus within the field.

Across the interventions reviewed, three principal surgical categories were identified: hypospadias repair, feminising genitoplasty (vaginoplasty and clitoroplasty) and orchidopexy, and one medical category was identified: adjuvant androgen therapy in the peri-operative period for hypospadias repair.

Hypospadias Repair

Hypospadias refers to an abnormality of the phallus of a male individual in which the urethral opening is displaced inferiorly from its usual position at the tip of the meatus. It is classified by the position of the urethral opening, ranging from distal (on the glans) to proximal hypospadias. This is commonly associated with a hypoplastic foreskin and abnormal curvature of the penis. Surgical repair of hypospadias has been reported as early as 1838 by Liston et al. Despite over 180 years of surgical experience in a large volume of patients, there remains a paucity of data and robust professionally endorsed guidelines to inform clinical practice [31,32].

A systematic review of surgical intervention for hypospadias by Castagnetti and El-Ghoneimi reviewed the 20 years of literature preceding their 2010 review and highlighted a lack of clear guidelines to support the indication for surgery and ideal surgical approach [33]. Fenner also calls for a clear set of diagnostic and management criteria in a thorough review, highlighting poor methodology and subjectivity in the analysis of surgical outcomes within existing literature [34]. Our review of international consensus guidelines endorsed by professional bodies found only the European Academy of Urology guideline to include recommendations for indications and timing of surgery in this population. The evolving recommendations from this guideline over time are shown in **Table 2** [18–20,35]. The timing of surgery across the years as recommended from this guideline has been consistently between 6 and 18 months, citing an outcome study from a single surgeon in India who operated on both children and adults, and reported higher complication rates in adults in the 1.5 years post-surgical intervention as rationale for the support for early surgery [36]. A consensus document on coding for billing purposes in hypospadias repair was led by Ewalt; however, this guideline does not provide recommendations on timing and indications for intervention [37]. Wood and Wilcox reviewed the current surgical practices and outcomes in 2023 and acknowledged that whilst there are many examples of good surgical practice, the data we have is often incomplete due to high rates of attrition and explores the shift in thinking with regards to indications for surgery [38]. This is reflected in the most recent European guidelines, with a move towards reserving surgical intervention for purely functional deficits, rather than cosmetic purposes as was previously the norm.

Some of the provided records in which hypospadias repair was recommended also suggested pre-operative dihydrotestosterone therapy. There is an absence of consensus statements on its use, and a 2022 review by Taghavi and Hewitt et al. summarised that studies investigating pre-operative hormonal treatment are non-uniform due to variation in the methods the therapy is implemented in clinical practice, and larger powered, well-designed studies are necessary to provide robust recommendations for or against its use in adjunct to hypospadias surgery [39].

Guidelines for Hypospadias Repair

Recommendations	Tekgul et al. 2010 (European Academy of Urology)	Radmayr et al. 2018 (European Academy of Urology)	Radmayr et al. 2025 (European Academy of Urology)	Baskin et al. 2025 (UpToDate)
Peer-Reviewed	Yes	Yes	Yes	Yes
Indications	Ventrally deflected urinary stream, meatal stenosis, curved penis, abnormally located meatus, cleft glans, rotated penis with abnormal cutaneous raphe, preputial hood, penoscrotal transposition or split scrotum	Ventrally deflected urinary stream, meatal stenosis, curved penis, abnormally located meatus, cleft glans, rotated penis with abnormal cutaneous raphe, preputial hood, penoscrotal transposition or split scrotum	Proximally located meatus, ventrally deflected urinary stream, meatal stenosis curved penis, preputial hood or penoscrotal transposition	Ventrally deflected urinary stream, curved penis, inability to urinate from a standing position, fertility issues due to sperm deposition difficulties or concern for developmental issues based on the appearance of the hypospadias
Timing	6-18 months, however earlier repair between 4 and 6 months has been reported	6-18 (24) months. Notes complication rates 2.5x higher in adults.	6-18 months. Notes complication rates 2.5x higher in adults.	6-12 months
Pre-operative hormonal treatment	Can be helpful in patients with a small penis or for repeat surgery	Patients with a proximal hypospadias, small appearing penis, reduced glans circumference or reduced urethral plate	Limited to children with proximal hypospadias, small appearing penis, reduced glans circumference or narrow urethral plate. Concerns about negative impact of DHT therapy – cease 1-2 months prior to surgery.	Limited to children with a microphallus (2SD below mean length for age).
Consent	Suggests thorough pre-operative counselling for the parents. Notes a risk for re-do operations and higher rates of dissatisfaction with penile size	Suggests thorough pre-operative counselling for the parents. Notes a risk for re-do operations for fistulae, strictures, recurrent curvature, diverticular repair and meatal relocation. Higher rates of dissatisfaction with penile cosmetic outcomes	Suggests thorough pre-operative counselling for the parents. Notes a risk for re-do operations for fistulae, strictures, recurrent curvature, diverticular repair and meatal relocation. Higher rates of dissatisfaction with penile cosmetic outcomes. Reduced paternity rates.	Routine surgical complications, fistulation, strictures, diverticular formation, urinary extravasation, UTI risk and poor cosmetic outcome. Risk of reintervention.
Experience	Knowledge of a variety of surgical techniques, wound care and post-operative wound care			Not mentioned

Table 2. A table outlining the recommendations from various international consensus guidelines on the indications and perioperative management of hypospadias.

Feminising Genitoplasty (vaginoplasty and clitoroplasty) in congenital adrenal hyperplasia

In children with congenital adrenal hyperplasia (CAH) and a 46,XX karyotype, an accumulation of steroid precursors due to a deficiency in a particular enzyme can lead to shunting of the steroid precursors towards the excess production of androgens, and in turn, the virilisation of the child's genitals towards a male phenotype. The first recorded reports of feminising genitoplasty in children with virilised genitalia due to CAH arose in the 1970s, however, despite over 50 years of experience, there remains a paucity of robust and unbiased outcome studies utilising methodology suitable for the formation of graded consensus guidelines [40,41].

For feminising genitoplasty (vaginoplasty and clitoroplasty), a review of professionally endorsed clinical practice guidelines revealed an evolution in clinical guidance over the past two decades, seen in **Table 3** [11,17,42,43]. Early consensus statements, such as the 2006 Chicago Consensus, tended to endorse early surgical intervention, often justified by psychosocial considerations. However, more recent guidelines - including the 2018 Endocrine Society Clinical Practice Guideline and the more recent but professionally unendorsed 2023 UpToDate review - have shifted towards a more cautious and individualised approach, acknowledging the lack of long-term outcome data and advocating for shared decision-making that includes consideration of delaying or forgoing surgery, and most recently, specifically advising against early clitoroplasty. Notably, the European Association of Urology's current guideline omits any recommendation for feminising genitoplasty at all, reflecting either the absence of high-quality data or a broader trend towards non-directive clinical practice in this area.

Guidelines for Feminising Genitoplasty (vaginoplasty and clitoroplasty) in CAH

Recommendations	Hughes et al. 2006 (Chicago consensus)	Speiser et al. 2010 (Endocrine Society)	Houk et al. 2013 (UpToDate)	Speiser et al. 2018 (Endocrine Society	Houk et al. 2023 (UpToDate)
Peer-Reviewed	Yes	Yes	Yes	Yes	Yes
Severity	Prader 3+			Recommends surgery only in low urogenital confluence	Recommends surgery only in cases of severe virilisation
Timing	Early, but late option eg. Delay vaginoplasty	Debatable early or late, clitoroplasty may be separated from vaginoplasty	Delay clitoroplasty at least for Prader 3	Consider delaying or forgoing surgery if minimally virilised, discuss early surgery if severely virilised	Endorses neither early nor late approach, but if proceeding with early approach, to delay clitoroplasty at least

Consent	Consequences throughout life	Long-term prognosis for sexual and reproductive function, offer deferring of surgery	Long-term prognosis for sexual and reproductive function, offer deferring of surgery	All information on timing, risks, benefits and complications. Counsel that delaying or forgoing surgery are options	Long-term sexual function, gender identity, surgical complications, counsel on risks of high and low confluence, with and without clitoroplasty and on delaying surgery
Experience	Specialist DSD surgeon/high-volume centre				

Table 3. A table outlining the recommendations from various international consensus guidelines on the indications and perioperative management of feminising genitoplasty (vaginoplasty and clitoroplasty) in children with CAH.

Orchidopexy

Orchidopexy refers to the surgical procedure by which testes that do not sit within the scrotum (cryptorchidism) are surgically retrieved and fixed within the scrotum to ensure they do not return to a position within the inguinal canal or within the abdomen. This intervention is designed to reduce the risk of malignancy and preserve fertility, as gonads that are not sited within the scrotum are at increased risk of malignancy and reduced fertility. Reports of attempted surgical intervention arose as early as the early 1800s, with the report of the first successful orchidopexy reported in 1877 [44]. Utilisation of this procedure in clinical practice has generated a robust body of evidence that now informs several international consensus guidelines.

Numerous peer-reviewed consensus statements, including those from the American Urological Association, European Society of Endocrinology, Nordic Consensus, and Canadian Urological Association, uniformly recommend surgical correction between 6 and 12 months of age. The changes over time in guideline recommendations for undescended testes are summarised in **Table 4**, in which the primary area of change over time has been around pre-surgical treatment with hormonal therapy. Recommendations have moved from 'a surgical approach is preferred' in the 2008 European Society of Endocrinology's guideline through to a clear recommendation against adjuvant hormone treatment in the 2025 European Academy of Urology's guideline with respect to achieving testicular descent, however there is a growing support for consideration of gonadotropin therapy to support long-term fertility in these patients [18,21–27,45,46]. These guidelines are grounded in moderate- to high-certainty evidence and display strong agreement regarding timing, surgical approach, and preoperative management, including consistent recommendations against hormonal therapy for testicular descent.

Taken together, the review of consensus management guidelines highlights a disparity between the depth and quality of evidence supporting orchidopexy and the limited certainty of data available for hypospadias repair or feminising genitoplasty (vaginoplasty and clitoroplasty). Whilst the management of undescended testes is guided by multiple high-quality, evidence-based and concordant international recommendations, the surgical management of virilised genitalia in CAH and hypospadias remains characterised by variability, low-quality evidence, and evolving ethical and clinical considerations.

Guidelines for Management of Undescended Testes

Recommendations	Ritzen et al. 2007 (Nordic Consensus)	Ritzen et al. 2008 (European Society of Endocrinology)	Gapany et al. 2008 (Institute of Social and Preventative Medicine)	Kolon et al. 2014 (American Urological Association)	Al-Hamali et al. 2015 (British Association of Paediatric Surgeons)	Ludikowski et al. 2016 (Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften (AWMF))	Braga et al. 2017 (Canadian Urological Association-Paediatric Urologists of Canada)	Kolon et al. 2025 (American Urological Association)	Radmayr et al. 2025 (European Academy of Urology)	Cooper et al. 2025 (UpToDate)
Peer-Reviewed	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes
Indications	Any testis remaining in the suprascrotal position after exhausting the cremasteric reflex, or non-palpable testes	Any unilateral or bilateral cryptorchidism, unless in a child with DSD, in which case defer to the DSD team	Any unilateral or bilateral cryptorchidism, unless in a child with DSD, in which case defer to the DSD team	Any undescended testis at 6m of age, congenital or acquired – however if bilateral cryptorchidism with non-palpable testes, needs review by DSD team prior	Any child with non-scrotal tests at 6 months of age	Any child with non-scrotal tests at 6 months of age	Cryptorchidism or retractile testis beyond 6 months of age	Any undescended testis at 6m of age, congenital or acquired – however if bilateral cryptorchidism with non-palpable testes, needs review by DSD team prior	In any case where both testes are not palpable in the scrotum or cannot be milked into the scrotum at 6 months age correcting for prematurity.	Bilaterally non-palpable testes beyond 6m, congenital unilateral non-palpable testis, congenital palpable undescended testes, re-ascended testes or difficulty discerning between undescended, retractile or ectopic testes
Timing	Between 6 and 12 months.	Between 6 and 12 months of age if undescended, annual follow up if retractile	Between 6 and 12 months.	Between 6 and 18 months of age if undescended, annual follow up if retractile to	6 to 18 months of age	Between 6 and 12 months.	Between 6 and 18 months. Re-examine every 6-12 months for re-ascent.	Between 6 and 18 months of age if undescended, annual follow up if retractile to	6-12 months ideally, definitely before 18 months	4-12 months (definitely before 24 months)

				assess for secondary ascent				assess for secondary ascent		
DHT/hCG Therapy	In general, not recommended	Surgical approach preferred to hormonal therapy	If the testis lies distal to the superficial inguinal pouch, hCG or LH-RH analogues may be tried.	Not recommended	Not addressed	Recommended only for retractile testes, suggest GnRH and hCG	Not recommended	Not recommended	Not recommended for assisting testicular descent, GnRH analogues for boys with bilaterally undescended testes to preserve fertility potential	Not recommended
Consent	Routine surgical complications, testicular atrophy, recurrent cryptorchidism, fertility outcomes, failure of hormonal therapy	Routine surgical complications	Routine surgical complications, long term fertility and malignancy risk. Should discuss psychosexual wellbeing outcomes too.	Routine surgical complications. Counsel on testicular malignancy risk and long-term fertility outcomes	Patient information should be given to parents or carers prior to surgery	Routine complications, testicular atrophy, re-operation, discuss malignancy and fertility risk	Not mentioned. Risks regarding malignancy and fertility addressed in guideline.	Routine surgical complications. Counsel on testicular malignancy risk and long-term fertility outcomes	Counsel on risks including general surgical risk, testicular atrophy, testicular re-ascent and vas deferens injury. Counsel on long-term fertility and malignancy outcomes.	Routine surgical complications, inguinal hernia, torsion, testicular trauma, subfertility and malignancy risk.
Experience	Paediatric surgeon or urologist and a paediatric anaesthetist, all with special interest and experience	It should be done at a centre that specialises in paediatric surgery or urology by personnel trained in both surgery and	It should be performed by specialised paediatric teams	By a surgical specialist	Consultant general paediatric surgeon or urologist with appropriate experience and skills	Not mentioned	Not mentioned	By a surgical specialist	Not mentioned	Not mentioned

		anaesthesia for infants								

Table 4. A table outlining the recommendations from various international consensus guidelines on the indications and perioperative management of undescended testes.

Conclusion

Of the 64 records reviewed by Equality Australia and deemed adequate for evaluation, a subset of 17 were identified for further evidence-based analysis. An objective appraisal of these records was conducted, analysing diagnostic data, the interventions proposed, the rationale for proposed interventions, and the supporting evidence cited.

Four records (23.5%) referenced medical literature to support the proposed intervention. Of these, two records cited evidence unrelated to the proposed surgical intervention; one referenced a guideline that offered an Ungraded Good Practice Statement rather than a graded recommendation; and the fourth provided multiple studies that, when evaluated using the GRADE framework, were classified as representing very low-quality evidence.

This analysis highlights the substantial deficit in both the availability of robust empirical data to guide clinical decision-making in this domain and limitations of documentation practices within MDT records. The absence of references or documentation of clinical rationale is likely due to deliberations not being comprehensively recorded rather than absence of clinical reasoning. Nonetheless, incomplete documentation impedes transparency and the capacity for subsequent review or clinical audit.

The supplementary review of international consensus guidelines revealed a progressive shift in professional recommendations over time. For hypospadias repair, guidelines remain limited in number and scope, with continued reliance on low grade evidence and absence of professional consensus on optimal timing or preoperative management. For feminising genitoplasty (vaginoplasty and clitoroplasty) in CAH, contemporary guidelines reflect increasing uncertainty over time regarding the timing and indication for intervention, with a discernible movement towards deferring or forgoing early surgery in favour of patient participation in decision-making. In contrast, the management of undescended testes is supported by multiple high-quality, peer-reviewed international guidelines with consistent recommendations across professional bodies, reflecting a mature evidence base and alignment in clinical practice standards.

Of note, our grading of the medical evidence provided in the analysed records was consistent with the grading found in the international consensus guidelines. It must also be noted that where there is limited evidence to support clinical decision making, this does not immediately correlate to any indication that clinical interventions should or should not proceed, at an early or late stage, but rather that there exist areas of medical practice in the field of variations of sex characteristics with limited evidence-based guidance to support clinical decisions either way.

Taken together, these findings reveal limitations in the current evidence base underpinning several surgical and medical interventions for children with developmental variations of sex characteristics. The analysis also highlights an imbalance in the strength and availability of evidence across different intervention types - with robust, consensus-driven data supporting

some procedures, yet a paucity of high-quality evidence for others, despite nearly a century of clinical practice.

This underscores the need for improved clinical research, clinical guidance, and the development of documentation standards for several clinical interventions in children with variations of sex characteristics. Comprehensive and standardised data collection and research analysis, strengthened documentation of MDT deliberations and the support of transparent, evidence-based, and patient-centred clinical decision-making frameworks are essential to ensure that future care is informed by the best available science and aligned with contemporary professional standards.

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