

Records of Concern:

Record #	Age	Proposed Surgery	Rationale for Surgery	MDT Recommendation	Outcome	Notes	File Reference
NSW - 1	<1	Hypospadias repair	Parents want early surgery, Pros + cons of early surgery discussed with parents	Redacted	Unclear	Surgery for [redacted] degree of undervirilisation 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. It was recommended this be discussed with the parents. On the other hand, there is urgency for orchidopexy	NSW DSD MDT Minutes of Meeting dated May 2018 (3)
NSW - 2	<1	Hypospadias repair, Orchidopexy	Repair hypospadias, Parents want early surgery, Pros + cons of early surgery discussed with parents	Discuss surgery options with parents, Recommend early surgery	Early surgery likely	Proceed with hypospadias at discretion of family / if family want to proceed with the surgery after discussion of potential risks	NSW DSD MDT Minutes of Meeting dated August 2018 (2)
NSW - 3	<1	Vaginoplasty	Child unlikely to remember surgery, Better healing, UTI prevention, Parents want early surgery	Recommend early surgery	Early surgery likely	CASE STUDY: Vaginoplasty for infant with CAH. Reasons included "avoiding stigmatisation of genital variation by restoring female anatomy, preventing parental anxiety"	NSW DSD MDT Minutes of Meeting dated November 2018 (1)
NSW - 4	1-3	Clitoroplasty	Parents want early surgery, Psychological risk of later surgery unknown, Cosmetic reasons, Pros + cons of early surgery discussed with parents	Discuss surgery options with parents, Discuss at future DSD meeting	Early surgery performed	CASE STUDY: Previously underwent vaginoplasty, treating clinicians best placed to decide if the clitoral surgery is "therapeutic". "If the family wish to pursue genital surgery the case should be re-discussed at a future DSD meeting." [page 3]	NSW DSD MDT Minutes of Meeting dated June 2020 (1)
NSW - 5	<1	Hypospadias repair	Parents want early surgery	Refer parents for psychological support, Hormone treatment	Unclear	CASE STUDY: Gender normalisation / gender preferences / "cosmetic" surgery. Unclear outcome - psych counselling for parents about gender, DHT for 12 months then consult with a surgeon.	NSW DSD MDT Minutes of Meeting dated October 2020 (1)
NSW - 6	<1	Hypospadias repair	Pros + cons of early surgery discussed with parents, Parents want early surgery	Refer parents for psychological support, Refer child for psychological counselling, Further testing	Early surgery likely	CASE STUDY: Surgery is deferrable - but if surgeons and parents in agreement to proceed with surgery with full informed consent, this would be supported by the group [page 3]	NSW DSD MDT Minutes of Meeting dated October 2020 (3)
NSW - 7	<1	Hypospadias repair, Orchidopexy	Repair hypospadias, Parents want early surgery, Early surgery consistent with guidelines, Pros + cons of early surgery discussed with parents	Further testing, Recommend early surgery, Hormone treatment	Early surgery likely	CASE STUDY: Male gender of rearing supported, further genetic testing for 5ARD, parental preference discussed as part of rationale for early surgery.	NSW DSD MDT Minutes of Meeting dated October 2021 (1)
NSW - 8	1-3	Hypospadias repair	Pros + cons of early surgery discussed with parents, Child unlikely to remember surgery, Parents want early surgery, Psychological risk of later surgery unknown, Early surgery consistent with guidelines	Recommend early surgery	Early surgery likely	CASE STUDY: Significant discussion about risks and benefits of hypospadias repair - supported parents decision to proceed with early surgery, but misgivings within MDT team.	NSW DSD MDT Minutes of Meeting dated February 2022 (2)
NSW - 9	<1	Hypospadias repair	Parents want early surgery		Early surgery likely		NSW Checklist referral for complex hypospadias to SCHN DSD group prior to surgery dated June 2022 (3)

NSW - 10	<1	Hypospadias repair	Parents want early surgery	Refer parents for psychological support, Other	Unclear	CASE STUDY PARENTS VIEWS: Heavily redacted, but "The parents have been counselled against proceeding with hypospadias repair by both their [redacted] and their [redacted] but remain keen to go ahead". Previous operations on both testes - right orchidopexy.z	NSW DSD MDT Minutes of Meeting dated October 2022 (6)
NSW - 11	3-6	Hypospadias repair	Parents want early surgery	Discuss at future DSD meeting	Unclear	CASE STUDY PARENTS VIEWS: Example of push for surgery coming from parents. "Both his parents are very sure they would like early surgery despite carefully outlining all the risks of [redacted]". "Pt did not allow [redacted] to examine his genitalia... Discussion around age of patient and tolerating hypospadias surgery. [redacted] and expressed that age 6 is outside the best age range for genital surgery of this kind."	NSW DSD MDT Minutes of Meeting dated October 2022 (8)
QLD - 1	<1	Hypospadias repair, Biopsy	Gender of rearing not at issue, Parents want early surgery, Preservation of function, Better healing, Improve function, Early surgery consistent with guidelines	Recommend early surgery, Refer parents for psychological support, Further testing	Early surgery likely	CASE STUDY: Early hypospadias repair surgery for infant male with 46,XY	QLD DSD for Multiprofessional Team Review Case Summary dated 13 December 2022(3), pages 10-16
QLD - 2	<1	Vaginoplasty	Non-functioning, Parents want early surgery, UTI prevention	Defer surgery decision to later date, Discuss surgery options with parents, Further testing	Early surgery likely	CASE STUDY: Strong parental distress noted around not having early surgery including vaginoplasty, and clinicians' notes on changes in surgery practices in Australia. Will need surgery prior to puberty given no separate vaginal opening. Two surgical consultants discussed timing of vaginoplasty and could take place in next 12 months for urogenital compromise given high risk of infection.	QLD DSD for Multiprofessional Team Review Case Summary dated 13 December 2022(4), pages 17-20
NSW - 12	<1	Hypospadias repair	Parents want early surgery, Redacted, Repair hypospadias, Pros + cons of early surgery discussed with parents	Recommend early surgery	Early surgery likely	CASE STUDY PARENTS VIEWS: Surgery recommended by group - parents' views persuasive	NSW DSD MDT Minutes of Meeting dated February 2023 (10)
NSW - 13	1-3	Orchidopexy, Other	Parents want early surgery	Recommend surgery with child's consent, Discuss at future DSD meeting	Surgery likely deferred	CASE STUDY: Parents want "normalising" surgery (cosmetic / appearance). Doctors agree with orchidopexy but not surgery for chordee - recommended deferred until after puberty.	NSW DSD MDT Minutes of Meeting dated February 2023 (11)
NSW - 14	1-3	Hypospadias repair	Parents want early surgery, Repair hypospadias, Psychological risk of later surgery unknown, Pros + cons of early surgery discussed with parents	Discuss surgery options with parents, Recommend early surgery	Early surgery likely	CASE STUDY DOCTORS DEFERRING: Doctors had concerns about surgery, but will operate if parents wish to proceed	NSW DSD MDT Minutes of Meeting dated April 2023 (13)
QLD - 3	3-6	Vaginoplasty, Clitoroplasty	Parents want early surgery		Unclear	CASE STUDY: Parent wanting "feminising surgery" before child starts school	QLD DSD for Multiprofessional Team Review Case Summary dated March 2023(3), pages 39-40
NSW - 15	6-10	Hypospadias repair, Other	Parents want early surgery	Other	Unclear	CASE STUDY DISAGREEMENT: Strong parental preference for surgery despite risks. Disagreement between DSD group about surgery	NSW DSD MDT Minutes of Meeting dated April 2023 (14)