

Cancer Records / Risk of Malignancy:

Record #	Age	Proposed Surgery	Rationale for Surgery	MDT Recommendation	Outcome	Notes	File Reference
NSW	10-16	Gonadectomy	Risk of malignancy, Non-functioning, Likely infertile	Recommend surgery with child's consent, Other, Hormone treatment	Surgery likely deferred	<p>"The group was supportive of gonadectomy if that is how the patient and parent which [sic.] to proceed after full informed consent"</p> <p>//</p> <p>Gonads non-functioning and "significant malignant potential and [redacted] requires pubertal induction"</p> <p>//</p> <p>Update on information about management from Finald - recommend gonadectomy if fibrothecomas present, surveillance is with 6 monthly USS and 12 monthly inhibin B levels. [redacted] has commenced pubertal induction with oestrogen gel with good response. Unclear whether surgery performed or not.</p>	NSW DSD MDT Minutes of Meeting dated February 2018 (3), (Application dated 19 September 2023, Schedule Doc No 22). // NSW DSD MDT Minutes of Meeting dated May 2018 (2), (Application dated 19 September 2023, Schedule Doc No 23).
NSW	<1		Child unlikely to remember surgery, Psychological risk of later surgery unknown	Hormone treatment, Discuss surgery options with parents	Early surgery likely	The parents are happy to be guided by the treating doctors and have not expressed specific opinion on the timing of surgery. Unclear whether surgery performed, and what treating doctors actually recommended from notes.	NSW DSD MDT Minutes of Meeting dated May 2018 (4), (Application dated 19 September 2023, Schedule Doc No 23).
NSW	10-16	Gonadectomy	Risk of malignancy, Likely infertile	Recommend early surgery	Early surgery likely	Good suppression of gonadal access	NSW DSD MDT Minutes of Meeting dated November 2018 (2), (Application dated 19 September 2023, Schedule Doc No 25).
NSW	10-16	Laparoscopy, Orchidopexy	Preservation of function, Risk of malignancy	Defer surgery decision to later date, Recommend surgery with child's consent, Other, Further testing, Discuss surgery options with parents	Surgery likely deferred	Offer auto-transplantation, gonadectomy if he consents, and fertility preservation options prior to surgery // 2x docs May 2018 (5)? // Leave the testis in situ to give him the best chance of going through puberty at his own pace.	NSW DSD MDT Minutes of Meeting dated October 2020 (3), (Application dated 19 September 2023, Schedule Doc No 35). // NSW DSD MDT Minutes of Meeting dated May 2018 (5), (Application dated 19 September 2023, Schedule Doc No 23). // NSW DSD MDT Minutes of Meeting dated August 2018 (7), (Application dated 19 September 2023, Schedule Doc No 24).

NSW	<1	Orchidopexy, Gonadectomy	Preservation of function, Risk of malignancy	Defer surgery decision to later date, Recommend early surgery	Early surgery likely	Proposed for surgery re-considered around time of toilet training to gauge likelihood of achieving continence // Proceed with orchidopexy, defer decision regarding hypospadias surgery	NSW DSD MDT Minutes of Meeting dated August 2018 (3), (Application dated 19 September 2023, Schedule Doc No 24).
NSW	10-16			Refer child for assessment of capacity, Other, Discuss at future DSD meeting	Unclear	Psychological review, review by tertiary pain management team // Chronic pain management introduced	NSW DSD MDT Minutes of Meeting dated November 2018 (3), (Application dated 19 September 2023, Schedule Doc No 25).
NSW	<1	Hypospadias repair, Gonadectomy	Risk of malignancy, Repair hypospadias, Pros + cons of early surgery discussed with parents	Recommend early surgery	Early surgery likely	Bilateral gonadectomy to occur at time of nephrectomy, hypospadias surgery supported by group and timing to be decided between surgical team and family - severe penoscrotal hypospadias but no clear rationale for hypospadias repair in minutes	NSW DSD MDT Minutes of Meeting dated August 2018 (5), (Application dated 19 September 2023, Schedule Doc No 24).
NSW	<1	Laparoscopy		Defer surgery decision to later date, Recommend surgery with child's consent	Surgery likely deferred	DSD genetic panel negative. No need for laparoscopy now. Can offer in mid teenage years when patient can consent.	NSW DSD MDT Minutes of Meeting dated October 2019 (3), (Application dated 19 September 2023, Schedule Doc No 30).
NSW	<1	Biopsy, Orchidopexy, Hypospadias repair, Other	Risk of malignancy, Repair hypospadias, Gender of rearing not at issue, Pros + cons of early surgery discussed with parents, Parents want early surgery	Recommend early surgery, Refer child for psychological counselling	Early surgery likely	Orchidopexy and hypospadias repair approved - timing of hypospadias repair redacted// Streak gonad removed after last meeting. Further psychological support and counselling for parents before decisions about removal of vaginal pouch, uterine structure and fallopian tube remnant.	NSW DSD MDT Minutes of Meeting dated June 2019 (1), (Application dated 19 September 2023, Schedule Doc No 28). // NSW DSD MDT Minutes of Meeting dated August 2019 (2), (Application dated 19 September 2023, Schedule Doc No 29).
NSW	10-16	Laparoscopy	Risk of malignancy, Gender of rearing not at issue	Recommend surgery with child's consent, Refer child for assessment of capacity, Refer child for psychological counselling	Surgery likely deferred	Laparoscopy only	NSW DSD MDT Minutes of Meeting dated August 2019 (1), (Application dated 19 September 2023, Schedule Doc No 29).
NSW	6-10	Laparoscopy, Gonadectomy	Risk of malignancy	Defer surgery decision to later date, Recommend surgery with child's consent, Hormone treatment	Unclear	Support team and family decision to defer MRI, laparoscopy and/or gonadectomy/gonadepoxy until post puberty	NSW DSD MDT Minutes of Meeting dated October 2019 (1), (Application dated 19 September 2023, Schedule Doc No 30).

NSW	10-16	Gonadectomy	Risk of malignancy	Defer surgery decision to later date, Recommend surgery with child's consent	Unclear	No urgency to remove intra-abdominal testes, but long term methods of surveillance as poor	NSW DSD MDT Minutes of Meeting dated November 2019 (1), (Application dated 19 September 2023, Schedule Doc No 31).
NSW	1-3	Laparoscopy, Biopsy	Risk of malignancy	Other	Unclear	Repeat ultrasound prior to laparoscopy around whether surgical intervention appropriate	NSW DSD MDT Minutes of Meeting dated November 2019 (2), (Application dated 19 September 2023, Schedule Doc No 31).
NSW	10-16				Unclear	Continue monitoring for now	NSW DSD MDT Minutes of Meeting dated April 2021 (4), (Application dated 19 September 2023, Schedule Doc No 37).
NSW	10-16	Laparoscopy, Gonadectomy	Risk of malignancy, Non-functioning, Likely infertile	Hormone treatment, Recommend early surgery	Early surgery likely	CASE STUDY: Risk of malignancy justifies surgery before child can consent independently. "The interventions performed at the time included vaginoplasty, excision of [redacted] streak gonad (groin), biopsy of [redacted] gonad." [page 1]	NSW DSD MDT Minutes of Meeting dated June 2020 (2), (Application dated 19 September 2023, Schedule Doc No 33).
NSW	6-10	Gonadectomy	Risk of malignancy, Non-functioning	Recommend early surgery, Hormone treatment, Other	Early surgery likely	Risk of gonadoblastoma redacted	NSW DSD MDT Minutes of Meeting dated August 2020 (1), (Application dated 19 September 2023, Schedule Doc No 34).
NSW	1-3	Gonadectomy	Risk of malignancy	Recommend early surgery	Early surgery likely	High risk of gonadoblastoma - presence of 'follicles' in recent ultrasound could be early gonadoblastoma	NSW DSD MDT Minutes of Meeting dated October 2020 (2), (Application dated 19 September 2023, Schedule Doc No 35).
NSW	<1	Redacted	Redacted	Redacted	Unclear	Heavily redacted ["The question asked of the forum was what the group felt was the best management of the gonads and any comment on management of the hypospadias and mullerian structure" [page 8]	NSW DSD MDT Minutes of Meeting dated August 2021 (2), (Application dated 19 September 2023, Schedule Doc No 39).
NSW	<1	Gonadectomy, Laparoscopy	Risk of malignancy	Refer parents for psychological support, Discuss at future DSD meeting, Other	Unclear	Decision around surgery to be deferred until parents have engaged with psychological services and risk of gonadoblastoma outweighs benefits of retaining future fertility	NSW DSD MDT Minutes of Meeting dated February 2021 (4), (Application dated 19 September 2023, Schedule Doc No 36).
NSW	10-16	Gonadectomy	Risk of malignancy	Surgery not recommended, Other, Hormone treatment	Surgery not recommended	Recommended no surgery (high risk), long term testosterone replacement therapy instead.	NSW DSD MDT Minutes of Meeting dated June 2021 (1), (Application dated 19 September 2023, Schedule Doc No 38).

NSW	10-16	Gonadectomy	Risk of malignancy	Refer child for assessment of capacity, Recommend surgery with child's consent, Further testing, Other	Surgery likely deferred	Further tests, recommended gonadectomy, psychological assessment around competency to consent, seek legal advice if concerns remain around consent //CASE STUDY CHILD CAPACITY: 15 y o girl with "known oppositional medical reactions" - referral for assessment of competency to consent, mother keen for surgery, legal oversight will be sought for gonadectomy given "significant malignancy risk"	NSW DSD MDT Minutes of Meeting dated October 2021 (2), (Application dated 19 September 2023, Schedule Doc No 40).
NSW	<1	Orchidopexy, Gonadectomy	Risk of malignancy, Non-functioning	Discuss surgery options with parents, Other	Unclear	Counselling regarding surgery, Genetic counselling as above // Delay any surgical intervention until DSD panel is back to clarify risk of gonadal malignancy to inform surgical decisions // CASE STUDY PARENTS POSITIVE: Parents preference to keep gonads in place and happy for orchidopexy. Decision to present options to parents to choose. Concerns around greater malignancy risk with gene. Genetic counselling for parents. // Waiting for DSD panel result to clarify risk of gonadal malignancy to inform surgical decisions. Gonadal sex unclear until gonadal biopsy done, parents certain about male gender of rearing but expressed they are open to child expressing a difference in gender identity as grows up	NSW DSD MDT Minutes of Meeting dated June 2022 (1), (Application dated 19 May 2023, Schedule Doc No 20). // NSW DSD MDT Minutes of Meeting dated February 2022 (1), (Application dated 19 September 2023, Schedule Doc No 41).
NSW	10-16	Laparoscopy, Biopsy, Gonadectomy	Risk of malignancy	Defer surgery decision to later date, Recommend surgery with child's consent	Surgery deferred	Delay laparoscopy / biopsy / gonadectomy until she's able to give fully informed consent // CASE STUDY CHANGING EVIDENCE: Decision to defer surgery until 15 y o can consent. Discussion of current literature showing malignancy risk lower than previously thought for this diagnosis (but diagnosis redacted)	NSW DSD MDT Minutes of Meeting dated April 2022 (1), (Application dated 19 September 2023, Schedule Doc No 42).
NSW	10-16	Laparoscopy, Biopsy, Gonadectomy	Risk of malignancy	Defer surgery decision to later date, Refer child for psychological counselling, Recommend surgery with child's consent, Further testing	Surgery deferred	No medical urgency for unilateral or bilateral gonadectomy, ongoing counselling for child on pros and cons of each choice // CASE STUDY CHILD CONSENT: Group supportive of child's decision around gonadectomy. MRI pelvis identified cyst on one gonad	NSW DSD MDT Minutes of Meeting dated April 2022 (2), (Application dated 19 September 2023, Schedule Doc No 42).
NSW	10-16	Gonadectomy	Risk of malignancy	Recommend surgery with child's consent, Hormone treatment	Surgery deferred	Bilateral gonadectomy to proceed as soon as possible. Pubertal induction with oestrogen to commence after gonadectomy. // Child consents to surgery to reduce malignancy risk. Referred by general paediatrician with delayed puberty, parents and child's agree to gonad removal and wish to commence pubertal induction ASAP	NSW DSD MDT Minutes of Meeting dated June 2022 (2), (Application dated 19 May 2023, Schedule Doc No 20).

NSW	6-10	Laparoscopy, Gonadectomy	Risk of malignancy	Refer parents for psychological support, Refer child for psychological counselling, Defer surgery decision to later date, Other	Surgery deferred	Ongoing psychological and peer support, seek advice regarding genetic risk, monitor puberty, consider referral for puberty preservation, consider gonadectomy post-puberty when child can be involved in discussion // Monitor puberty clinically, specific genetic risk for cancer? (difficult to tell from redactions), consider referral for fertility preservation. Mention of parental anxiety about ... risks	NSW DSD MDT Minutes of Meeting dated October 2022 (5), (Application dated 19 May 2023, Schedule Doc No 22).
NSW	1-3	Hypospadias repair			Early surgery likely	Checklist completed	NSW Checklist referral for complex hypospadias to SCHN DSD group prior to surgery dated April 2023 (10), (Application dated 19 May 2023, Schedule Doc No 19).
NSW	10-16	Gonadectomy	Risk of malignancy, Likely infertile	Other, Discuss surgery options with parents	Unclear	Risk of gonadoblastoma cannot be quantified. Recommended 6 monthly gonad scans, but patient should have gonadectomy before GH is restarted.	NSW DSD MDT Minutes of Meeting dated June 2023 (18), (Application dated 19 May 2023, Schedule Doc No 25).
QLD	10-16	Biopsy, Gonadectomy	Risk of malignancy, Parents want early surgery	Defer surgery decision to later date, Further testing, Refer parents for psychological support, Other	Unclear	// Consider biopsy with plan to proceed to gonadectomy should malignant features be identified, literature review on fertility preservation and recommended timing of prophylactic gonadectomy in CAIS, referral to QCH Psychology team / CASE STUDY PARENTAL ANXIETY: Clinicians recommending biopsy and only gonadectomy if cysts confirmed malignant. Parents want surgery ASAP - concerned about malignancy risk given ultrasounds confirmed cysts.	QLD DSD for Multiprofessional Team Review Case Summary dated March 2023(1), (Application dated 13 June 2023, Case Summaries - 2023 pages 1-3)
QLD	6-10	Laparoscopy, Biopsy	Risk of malignancy	Recommend early surgery, Refer parents for psychological support, Refer child for psychological counselling	Unclear	Right streak gonad previously removed through elective surgery due to parental concerns related to malignancy recent. Recent ultrasound show tissue in location of right intr-abdominal gonad previously thought to be completely removed. Surgical investigation.	QLD DSD for Multiprofessional Team Review Case Summary undated 2023, (Application dated 13 June 2023, Case Summaries - 2023 pages 4-9)
QLD	10-16	Laparoscopy, Biopsy, Gonadectomy	Risk of malignancy	Hormone treatment, Recommend surgery with child's consent	Unclear	Proposed treatment included - recommendations and discussion redacted	QLD Referral of a child with a DSD for Multiprofessional team review Minutes of Meeting undated 2023(1), (Application dated 13 June 2023, Meetings 2023 pages 1-2 (pages 3-8 redacted))