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4 November 2021

9(2)(a)



RE Official Information Act request CDHB 10695

I refer to your email dated 28 August 2021 requesting the following information under the Official Information Act from Canterbury DHB for the purposes of conducting a research project at the University of Waikato. Specifically:

1. **How many surgical procedures have been carried out each year in relation to hypospadias (“hypospadias repair”) in the last 4 years (2016-2017, 2017-2018, 2018 – 2019, 2019-2020)? Please give specific numbers for each of the following age groups 0-4, 5-9, 10-14, 15-19 years.**

Please refer to **Appendix 1 Table one** for “hypospadias repair” data.

2. **How many surgical procedures have been carried out to repair post-operative urethral fistula in the last 4 years (2016-2017, 2017-2018, 2018-2019,2019-2020)? Please give specific numbers for each of the following age groups 0-4, 5-9, 10-14, 15-19 years.**

The re-operation rate after hypospadias repair at our hospital is 10% (18 out of 180 consecutive hypospadias patients reviewed as part of our audit), of which most were hypospadias fistulas – it also included wound breakdown, stenosis of urethral meatus, and correction of residual chordee. We do not have accurate or easily accessible data on this, but most fistula repairs are carried out about 9 months after the original surgery

3. **What other procedures have been carried out in relation to anomalies of male genitalia including, but not limited to, procedures intended to alter the shape or curvature of the penis, or to reposition the urethra in the last 4 years (2016-2017, 2017-2018, 2018-2019,2019-2020)? Please give specific numbers for each procedure carried out on people within the following age groups 0-4, 5-9, 10-14, 15-19.**

Please refer to **Appendix 1 Table two** for information regarding ‘correction of chordee’.

Note: One child had a complex congenital condition, epispadias repair combined operation with a Starship Hospital paediatric urologist – this was to correct a complex deformity, not a gender-altering procedure.

4. **How many surgical procedures have been carried out in relation to reducing or adjusting clitoral size or appearance in the last 4 years (2016-2017, 2017-2018, 2018-2019,2019-2020)? Please identify the diagnoses and give specific numbers for each of the following age groups 0-4, 5-9, 10-14, 15-19.**

There have been no surgical procedures carried out in relation to reducing or adjusting clitoral size or appearance in the last four years.

- 5. How many surgical vaginal construction (or reconstruction) procedures were undertaken in the last 4 years (2016-2017, 2017-2018, 2018-2019,2019-2020)? Please identify the diagnoses and give specific numbers for each of the following age groups 0-4, 5-9, 10-14, 15-19?**

About once every three years, we perform repair of a cloacal abnormality: in some of these patients the procedure involves ensuring the vagina reaches the perineum (without the surgery the vagina ends blindly or connects abnormally to the urethra and rectum). This is usually done in the first year of life.

- 6. What other procedures have been carried out (including, but not limited to, vaginal dilation, labiaplasty, vulvoplasty, and surgery to modify the urogenital sinus) in relation to anomalies of female genitalia in the last 4 years (2016-2017, 2017-2018, 2018-2019,2019-2020)? Please give specific numbers for each procedure carried out on people within the following age groups 0-4, 5-9, 10-14, 15-19.**

Occasionally, following repair of cloaca (see Q 5 above) vaginal dilatation may be required in the post-operative period. We perform no labioplasties, vulvoplasties, or surgery to modify the urogenital sinus, except as per Q 5 above where the procedure involves correction of a structural abnormality of development where we are, in effect, enabling normal function (although these children tend to have ongoing problems with control of the bowel).

- 7. How many gonadectomies have been performed in the last 4 years? Please identify the diagnoses and the reason for removing the gonads. Please give answers broken down by age groups (0-4, 5-9, 10-14, 15-19 years) and year in which interventions took place (2016-2017, 2017-2018, 2018-2019,2019-2020).**

In none of the year groups or age groups are there any more than sporadic cases. However, I can outline when gonadectomies might be considered:

- a. in a boy in whom the testis has twisted and died (become gangrenous) – we may remove the dead testis.
 - b. For cancer of the gonad, where international best practice dictates that the gonad should be removed.
 - c. Where the ovary has twisted because of an ovarian cyst and it has become gangrenous, although if possible we always try to preserve ovarian tissue.
 - d. where a testis has “disappeared”, and on surgical exploration an atrophic remnant of it is identified – this non-functioning tissue is removed for histological examination to confirm the diagnosis. Often, however, the tissue is just cartilage or scar tissue, and even though we know it had once been a testis there is not remaining testicular tissue within the specimen.
 - e. rarely, and we could not identify a particular example in the time period requested, where a gonad is removed because of its malignant potential as part of the best practice management, and following multidisciplinary discussion locally and with Starship Hospital, as part of treatment for a complex DSD (Disorder of Sexual Differentiation).
- 8. If gonads have been removed from people aged under 18 years in the last 4 years, (i) in how many instances was the diagnosis confirmed using molecular genetic techniques, and (ii) over what period of time were the gonads monitored or observed using MRI prior to gonadectomy? Please give answers broken down by age groups (0-4, 5-9, 10-14, 15-19 years) and year in which interventions took place (2016-2017, 2017-2018, 2018-2019,2019-2020).**

We are unable to find any examples to support a response for this question. We are therefore declining pursuant to section 18(g) of the Official Information Act i.e. we do not hold this information.

- 9. What is the current protocol followed (in this region or hospital) in relation to the retention or removal of the gonads of people with Androgen Insensitivity Syndrome? At what ages is there consideration of: (i) the opportunity to retain gonads, (ii) the removal of gonads? (In how many instances) have removed gonads or tissue been retained for future research purposes in the last 4 years (2016-2017, 2017-2018, 2018-2019,2019-2020)?**

Our patients are managed in collaboration and close consultation between the paediatric endocrinologists, paediatric surgeons/urologists both in Christchurch and in Auckland. Where necessary we also involve our Australian colleagues.

10. Does the protocol (mentioned in the question above) include explicit discussion of the pros and cons of gonadectomy with people diagnosed with AIS? At what age(s) does such discussion happen, according to the protocol? Who has this discussion with the young people/families concerned (e.g., surgeon, psychologist, peer support person)? At what stage, and over what duration, is a psychologist involved?

We would never even consider gonadectomy without careful discussion of all the pros and cons with the family and have them meet and discuss it with the experts in this field. These types of decisions are not made lightly, and plenty of time is taken to consider their merits.

11. To whom are young people and families referred for support and information prior to gonadectomy? Please may we see a copy of the resources shared with families and individuals under these circumstances?

Consideration of options and implications for surgical treatment and associated clinical support resources that may be required prior to gonadectomy are discussed face-to-face with young people and families by their respective, age-appropriate treating specialist surgeon; be this a paediatric surgeon, paediatric endocrinologist, general surgeon, gynaecologist, urologist, or other clinical expertise.

It is such an infrequent occurrence that counselling is individualised to suit the child and families. This is done on an individual case by case patient basis in accordance with the particular unique circumstances pertaining to each referral, as part of gaining informed consent.

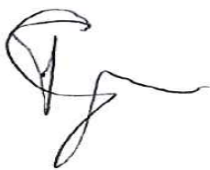
Any child with a DSD (disorder of sexual differentiation) is also discussed with a national clinical panel (made up of approximately 10 Paediatric Endocrinologists and Paediatric Surgeons) to ensure the recommendation for gonadectomy has been made by the consensus group with full clinical consideration.

I trust that this satisfies your interest in this matter.

You may, under section 28(3) of the Official Information Act, seek a review of our decision to withhold information by the Ombudsman. Information about how to make a complaint is available at www.ombudsman.parliament.nz; or Freephone 0800 802 602.

Please note that this response, or an edited version of this response, may be published on the Canterbury DHB website after your receipt of this response.

Yours sincerely



Tracey Maisey
Executive Director
Planning, Funding & Decision Support

Question 1 Table one: Repair of hypospadias

	2016/2017				2017/2018				2018/2019				2019/2020			
	Age band				Age bands				Age bands				Age bands			
Discharges	0-4	5-9	10-14	15-19	0-4	5-9	10-14	15-19	0-4	5-9	10-14	15-19	0-4	5-9	10-14	15-19
Repair of hypospadias	14	0	0	<5	17	0	0	<5	12	<5	<5	<5	22	0	<5	0

Question 3 Table two Correction of chordee of penis

	2016/2017				2017/2018				2018/2019				2019/2020			
	Age band				Age bands				Age bands				Age bands			
Discharges	0-4	5-9	10-14	15-19	0-4	5-9	10-14	15-19	0-4	5-9	10-14	15-19	0-4	5-9	10-14	15-19
Correction of chordee of penis	0	0	<5	<5	5	<5	0	<5	0	0	0	<5	10	<5	<5	0

Note: We are declining to provide information where numbers are smaller than 5 pursuant to section 9(2)(a) of the Official Information Act i.e. to protect individual privacy.