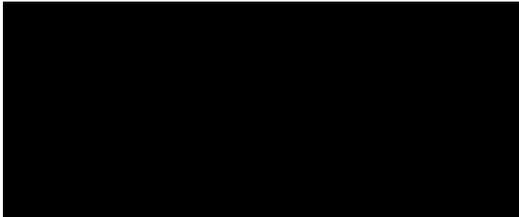


13 September 2021

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Re: Official Information Act request – Surgical procedures

I refer to your Official Information Act (OIA) request of 30 August 2021, in which you noted that you are currently involved in a research project at the University of Waikato, and then provided an extended and detailed list of data you would like for that project.

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.
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.
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.
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.
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?
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.
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).

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).

Response to 1- 8

As well as providing these services to its own population, Auckland DHB also provides these services to patients in the Waitematā DHB district. The following response is on behalf of both Auckland and Waitematā DHBs.

The Service Director, Urology, advised that this is not data that is routinely collected and thus it would involve considerable time to manually collate. Specifically, a manual search would be required within patient records, a task not normally undertaken without prior ethics approval.

His detailed comments: *The manual research would be required because, as an example, Urology would do a handful of hypospadias operations which could be coded under a number of different codes: urethroplasty, glans resurfacing, 2 stage urethral repair etc. Within each code there will be many cases that are not related to hypospadias, hence the manual search to confirm the diagnosis. Gonadectomies has a number of indications in urology; infection, cancer, torsion, gender affirmation, congenital. I don't think the researcher is wanting most of that information.*

It seems they want it in relation to androgen insensitivity and finding the ones done for that indication would likely need a manual search through patients notes who had gonadectomy. The part about other penile procedures would definitely need manual searching. Most of the cases they want will fall under paediatric surgery as they look after patients up to the age of 15.

Then there will be the 15-19yo age group which will be either under urology or gynaecology. It's possible some may have had surgery with plastics.

In conclusion, this is a very complex request. Auckland DHB has determined to decline pursuant to s18(f) – the information cannot be made available without substantial research.

We have responded to questions 9 – 11 as per below.

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?**

We do not have protocol driven care delivery for this patient group, each case is considered on its own merits, and all decisions are made by parents in collaboration with a multidisciplinary advisory group and based on international best practice. Wherever possible, current practice is to biopsy gonads for risk assessment purposes before considering gonadectomy. A second laparoscopy will then be considered to remove the remnant if the malignancy risk is high.

(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)?

Nil. Tissues have either been returned to patients or destroyed as per their instructions.

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?

As above, this occurs on a case by case basis and we do not collect the data requested.

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?

As above this is on a case by case basis. Most families are referred to either the Consult Liaison service at Starship, or to a local service for regional patients. Families are offered the contact details for ITANZ (<http://www.ianz.org.nz/>) or other support organisations. Resources include <https://www.nhs.uk/conditions/androgen-insensitivity-syndrome/treatment/>

You are entitled to seek a review of the response by the Ombudsman under section 28(3) of the Official Information Act. 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 Auckland DHB website.

Yours faithfully



Ailsa Claire, OBE
Chief Executive of Te Toka Tumai (Auckland District Health Board)