

11th October 2021

s9(2)(a)
[Redacted]

Dear s9(2)(a)
[Redacted]

Official Information Act Request for – Surgical Procedures

I write in response to your Official Information Act request received by us 31st August 2021, you requested the following information:

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,

- a. in how many instances was the diagnosis confirmed using molecular genetic techniques, and
 - b. 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).
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:
 - a. the opportunity to retain gonads,
 - b. 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)?
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?
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?

Counties Manukau Health Response:

For context Counties Manukau Health (CM Health) employs over 8,500 staff and provides health and support services to people living in the Counties Manukau region (approx. 601,490 people). We see over 118,000 people in our Emergency Department each year, and over 2,000 visitors come through Middlemore Hospital daily.

Our services are delivered via hospital, outpatient, ambulatory and community-based models of care. We provide regional and supra-regional specialist services i.e. for orthopaedics, plastics, burns and spinal services. There are also several specialist services provided including tertiary surgical services, medical services, mental health and addiction services.

In response to questions one to eight of your request, this is not data that is routinely collected by CM Health and would involve considerable time to manually search through individual patient files. This is because these operations can fall under a number of different codes in our coding system. Within each code there may be cases that are not directly related to what you have requested which is the reason a manual search would be required.

Due to the sensitivity of this information, frontline clinical staff would need to review individual clinical files and it would not be appropriate to use a contractor to review the records. This would take the frontline staff away from their clinical work and prejudice our ability to provide core clinical services. We have considered whether charging or extending the timeframe for responding to this aspect of your request would assist us in managing this work and have concluded it would not. We have, therefore, determined to decline this element of your request under Section 18(f) of the Official Information Act due to substantial collation and research.

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:**
- a. **the opportunity to retain gonads,**
 - b. **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)?**

We do not have protocol driven care delivery for this patient group, each case is considered individually, 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.

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 would be managed on a case by case basis. Resources or support services include:

- <http://www.ianz.org.nz/>
- <https://www.nhs.uk/conditions/androgen-insensitivity-syndrome/treatment/>

I trust this information answers your request. 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 may be published on the Counties Manukau Health website. If you consider there are good reasons why this response should not be made publicly available, we will be happy to consider this.

Yours sincerely



Fepulea'i Margie Apa
Chief Executive Officer
Counties Manukau Health