



20 September 2021

[REDACTED]

Dear [REDACTED]

### Official Information Act Request

You have asked for information about procedures related to variation in sex characteristics.

- *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.*
- *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.*
- *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.*
- *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.*
- *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?*
- *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.*
- *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).*
- *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).*

- *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)?*
- *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?*
- *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?*

Northland DHB does not perform the procedures listed above and therefore we do not hold the data you have requested.

Northland DHB supports the open disclosure of information to assist public understanding of how we deliver our services. This includes proactive publication of anonymised Official Information Act responses on our website from 10 working days after they have been provided to you. Personal or identifying information will be redacted from any response published online. If you consider there are good reasons why this response should not be publicly available we will consider your views.

If you have any queries regarding Northland DHB's response to your information request please contact me.

Yours sincerely



**Dr Nick Chamberlain**  
**Chief Executive**