Craig Dempster



Via email: craig.dempster@waikato.ac.nz

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Tēnā koe Craig

Official Information Act Request - OIA 13734 Surgical Procedures

On 31 August 2021, under section 12 of the Official Information Act, you requested the following information from Whanganui District Health Board (WDHB):

I am currently involved in a research project at the University of Waikato and would like to request 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, (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).
- 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

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- 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?

Whanganui District Health Boards response:

 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.

If any, these would have been done at MidCentral.

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.

If any, these would have been done at MidCentral.

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.

For questions 3 - 8: These procedures are not done at WDHB; this does not mean that our population does not have access, but they are not done here.

- 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).
- 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)?

n/a - all referrals go to MidCentral DHB.

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?

n/a

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?

n/a

Should you have any further queries about the above information, please contact our OIA co-ordinator Anne Phoenix at anne.phoenix@wdhb.org.nz

Ngā mihi

Russell Simpson

Chief Executive