Corporate Services



4 October 2021



Dear

YOUR OFFICIAL INFORMATION ACT (1982) REQUEST HBDHB REF: OIA2021104

I refer to your Official Information Act request dated 30 August 2021 where you requested information from Hawke's Bay District Health Board (HBDHB). Your questions and HBDHB's response is provided below:

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.

Discharge Financial year		TOTAL						
	0-4	5-9	10-14	15-19	TOTAL			
2017	3	1	0	0	4			
2018	3	1	0	0	4			
2019	2	0	0	0	2			
2020	4	0	1	0	5			
TOTAL	12	2	1	0	15			

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.

Nil

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 table 1 below.

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.

Nil

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?

Hawke's Bay District Health Board does not capture the individual diagnoses digitally, and to obtain this information would require a manual search and assessment of individual patient files. Therefore, this portion of your request is declined under Section 18(f) of the Official Information Act relating to substantial collation or research.

The DHB can, however, provide general data (table below) of surgical vaginal constructions, reconstructions, repairs, vulvectomy, as well as surgical work on perineum, vulva or clitoris across the age group and year periods you have requested.

Discharge Financial year	Age Group	Age Group											
	0-4	5-9	10-14	15-19	1								
	0	0	1	1	2								
2018	0	0	1	1	2								
2019	0	0	1	0	1								
2020	0	0	0	0	0								
TOTAL.	0	0	3	2	5								

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.

This information is included in the response to question five above.

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).

Please refer to the table below for the total number of gonadectomies performed over the time period and age ranges specificed.

Discharge Financial year -		TOTAL				
	0-4	5-9	10-14	15-19		
2017	0	0	0	2	2	
2018	2	0	1	2	5	
2019	1	0	0	3	4	
2020	1	0	1	2	4	
TOTAL	4	0	2	9	15	

The DHB is unable to digitally extract data from patient files regarding the reason for removing gonads. This would require a manual search and assessment of individual patient files. Therefore, this portion of your request is declined under Section 18(f) of the Official Information Act relating to substantial collation or research.

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).

This portion of your request is declined under Section 18(f) of the Official Information Act relating to substantial collation or research of individual patient files.

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)?

There is no specific protocol due to the small population size of Hawke's Bay DHB and the infrequency of these procedures being performed. Any new cases are addressed with tertiary hospital consultation.

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 per response above.

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?

These procedures are largely done by General Practitioners Special Interest (GPSI) professionals who specialise in gender affirming care. This group of medical professionals offer a wrap around service for gender affirming care including referring patients for support, counselling and providing all information for patients.

Generally, only the very complex cases or those with certain types of medical histories are referred to the hospital with the preliminary consultations, information and support having already been offered by GPSI.

The DHB provides generic information for gonadectomy in the Urology department, but this is not specific to AIS patients.

The DHB follows World Professional Association for Transgender Health (WPATH) standards of care for the health of transsexual, transgender, and gender nonconforming people and also obtain resources and form the basis of our local resources from this document.

Patients are also referred to www.agender.org.nz for further information and support.

I trust this information meets your needs. If you would like any further information or clarification please phone me. If you are not satisfied with this response you may contact the Office of the Ombudsman, phone 0800 802 602.

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

Yours sincerely

pp Rl-lentsche |

Chris Ash

Chief Operating Officer

cc: Ministry of Health via email: SectorOIAs@moh.govt.nz

oia@hbdhb.govt.nz

Table 1

		0-4		5-9			10-14			15-19				TOTAL						
Procedure Description	2017	2018	2019	2020	2017	2018	2019	2020	2017	2018	2019	2020	2017	2018	2019	2020	2017	2018	2019	2020
URETHROPLASTY - SINGLE STAGE PROCEDURE	0	0	1	0	1	0	0	0	0	0	0	0	0	0	0	0	1	0	1	0
MEATOTOMY AND HEMICIRCUMCISION FOR HYPOSPADIAS	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
PARTIAL AMPUTATION OF PENIS	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
CORRECTION OF CHORDEE OF PENIS	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
CORRECTION OF CHORDEE OF PENIS WITH MOBILISATION OF URETHRA	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0
FRAENULOPLASTY OF PENIS	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	1	0
Expl scrotal contents fix testis, uni	0	1	2	8	0	0	0	2	0	1	0	2	0	2	3	3	0	4	5	15
Expl scrotal contents fix testis, bil	0	1	0	1	0	1	2	0	2	2	2	7	1	0	3	4	3	4	7	12
GLANULOPLASTY FOR HYPOSPADIAS	0	1	0	1	1	0	0	0	0	0	0	0	0	0	0	0	1	1	0	1
DISTAL HYPOSPADIAS, SINGLE STAGE REPAIR	2	1	2	3	0	1	0	0	0	0	0	1	0	0	0	0	2	2	2	4
HYPOSPADIAS, STAGED REPAIR, FIRST STAGE	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	1	0	0
HYPOSPADIAS, REPAIR OF POSTOPERATIVE URETHRAL FISTULA	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
SUTURE OF LACERATION OF SCROTUM OR TUNICA VAGINALIS	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
OTHER REPAIR OF SCROTUM OR TUNICA VAGINALIS	0	0	0	0	0	_ 1	0	0	0	0	0	0	0	0	0	0	0	1_	0	0
	4	5	5	13	2	3	2	2	2	3	3	10	1	2	6	_7_	9	13	16	32