

22 December 2021

§ 9(2)(a)

By email: § 9(2)(a)
Ref: H202117825

Tēnā koe § 9(2)(a)

Response to your request for official information

Thank you for your request under the Official Information Act 1982 (the Act) which was transferred from the Office of the Associate Minister of Health, Hon Ayesha Verrall, to the Ministry of Health (the Ministry) on 20 December 2021 for information relating to the use of puberty blockers in New Zealand. I will respond to each part of your request in turn:

- 1. Is any information routinely collected and collated nationally on the use of puberty blocking hormones for gender dysphoria in New Zealand?*
- 2. If yes, how many children and young people were prescribed GnRH analogues for gender dysphoria in the most recent time period?*

Data on the number of people aged seventeen years and under who have received a dispensing of any Gonadotropin-releasing hormone (GnRH) between 2017 and 2020 is attached to this letter as *Document 1*. The notes in the document provide clarification about the data available and provided on this topic.

- 3. Given that the drugs are prescribed for an unapproved indication, and hence innovative or experimental, is it subject to national monitoring? If yes, what monitoring is in place?*

When an approved medicine is prescribed for a different use or condition, patient age, dose or route, it is considered to be an off-label use. Section 25 of the Medicines Act 1981 allows for such off-label prescribing. There is no requirement for reporting of such prescribing.

- 4. What level of psychological assessment is given currently, nationally, to children and young people before prescription of puberty blockers?*

It is the responsibility of the treating clinician to consider the appropriateness of a particular treatment for a particular patient, and to ensure that the patient is informed of the risks and benefits associated with that treatment. Informed consent should be obtained by the clinician from the patient before the choice is made to prescribe the medicine. The Code of Health and Disability Services Consumers' Rights establishes the rights of patients to be fully informed, and to make an informed choice and give informed consent. The Code notes that every consumer must be presumed competent to make an informed choice and give informed consent, unless there are reasonable grounds for believing that the consumer is not competent.

5. What information is held on time trends in the referral of children and young people with gender dysphoria to specialist services nationally? Is information available on trends in age at referral, the number and proportions of natal girls, the number and proportion who developed gender dysphoria only with the onset of puberty, and the number and proportion with autism spectrum disorder?

The number of referrals for people aged 0 to 24 years, who had a primary diagnosis recorded as gender identity disorder in the Programme for the Integration of Mental Health Data (PRIMHD), for the period 1 January 2016 to 31 December 2020 is attached to this letter as *Document 2*. The notes in the document provide clarification about the data available and provided on this topic.

This data includes age-group and gender of the service user. The number of referrals with a primary diagnosis of gender identity disorder has been provided, not the number of people referred, as some people may have more than one referral during this period. Data is reported to PRIMHD by district health board and non-government organisation (NGO) service providers. Therefore, if an individual has sought treatment at a primary care level only (for example through their General Practitioner), they will not be included in the data provided.

Gender is not recorded at the time of referral which means data provided includes the gender currently recorded on the National Health Index (NHI). The Ministry is unable to advise whether this is representative of sex assigned at birth. The age-group details provided are determined at the start of referral. As such, the Ministry is unable to advise the number and proportion who developed gender dysphoria only with the onset of puberty. No service users diagnosed with gender identity disorder during the period have had a primary diagnosis of autistic spectrum disorder (ASD) recorded in PRIMHD or publicly funded hospital discharges in National Minimum Dataset (NMDS).

6. Why does Pharmac fund GnRH analogues (goserelin implants, or leuprorelin injections for children and adolescents who are unable to tolerate administration of goserelin) for this indication, despite it not being approved by Medsafe?

On 12 August 2021, this part of your request was transferred to Pharmac as the information requested was more closely aligned with the functions of that organisation. You will have received a response from Pharmac directly regarding this part of your request.

7. Is the Ministry of Health planning to review the use of puberty blocking hormones?

No. As noted above, the use of any medication or treatment is a matter for discussion between a treating clinician and their patient, ensuring that patients are fully informed of their options (including any benefits, risks and alternatives) to make an informed choice and give informed consent.

It is the responsibility of the treating clinician to consider the appropriateness of a particular treatment for a particular patient, and to ensure that the patient is informed of the risks and benefits associated with that treatment. Informed consent should be obtained by the clinician from the patient before the choice is made to prescribe the medicine.

I trust this information fulfils your request under the Act. Under section 28(3) of the Act you have the right to ask the Ombudsman to review any decisions made under this request. The Ombudsman may be contacted by email at: info@ombudsman.parliament.nz or by calling 0800 802 602.

Please note that this response, with your personal details removed, may be published on the Ministry of Health website: www.health.govt.nz

Nāku noa, nā



Anne Stewart
Group Manager
Office of the Chief Clinical Officers

A count of people 17 and under who received a publicly funded dispensing of selected pharmaceuticals, by age 2017-2020. Selected pharmaceutical defined as those in Level 3 Therapeutic group "GnRH Analogues"

	Age Group				
	Total	00-04	05-09	10-14	14-17
2017					
Goserelin - Implant 3.6 mg, syringe	9	0	0	2	7
Goserelin - Implant 10.8 mg, syringe	26	0	0	7	19
Leuprorelin - Inj 3.75 mg prefilled dual chamber syringe	45	1	12	20	14
Leuprorelin - Inj 11.25 mg prefilled dual chamber syringe	309	4	80	128	127
Leuprorelin - Inj 22.5 mg syringe with diluent	1	0	0	0	1
2017 Total	364	5	88	149	156
2018					
Goserelin - Implant 3.6 mg, syringe	7	0	0	0	7
Goserelin - Implant 10.8 mg, syringe	27	0	2	6	20
Leuprorelin - Inj 3.75 mg prefilled dual chamber syringe	38	0	8	12	18
Leuprorelin - Inj 11.25 mg prefilled dual chamber syringe	344	5	79	166	138
2018 Total	399	5	87	180	173
2019					
Goserelin - Implant 3.6 mg, syringe	18	0	0	3	15
Goserelin - Implant 10.8 mg, syringe	39	0	1	13	27
Leuprorelin - Inj 3.75 mg prefilled dual chamber syringe	41	0	12	21	13
Leuprorelin - Inj 11.25 mg prefilled dual chamber syringe	419	4	91	197	157
2019 Total	491	4	103	223	199
2020					
Goserelin - Implant 3.6 mg, syringe	20	0	0	5	16
Goserelin - Implant 10.8 mg, syringe	41	0	2	10	29
Leuprorelin - Inj 3.75 mg prefilled dual chamber syringe	32	0	10	14	12
Leuprorelin - Inj 11.25 mg prefilled dual chamber syringe	496	6	116	256	181
2020 Total	568	6	125	276	229

Notes:

People may appear in multiple cells if, for example, they had a birthday between dispensings or received dispensings from multiple DHBs in the same year. Because of this, individual cells should not be summed, as people can appear in more than one cell and will be counted in each row and column they appear; this will result in double-counting. The totals presented here (i.e., the highlighted and bolded figures) are calculated without double-counting. They may not be equal to the total of the row, column or table.

Administrative and bulk dispensing data has been excluded. Dispensings without an NHI have also been excluded.

The Pharmaceutical Collection only counts publicly funded, community dispensed pharmaceuticals; It does not count hospital dispensings, drugs not funded by PHARMAC, or prescriptions that were never dispensed. Some medications can be dispensed via practitioner supply order; for example, a family planning clinic may be dispensed a large volume of contraceptives which they then dispense to clients. Dispensings of this type have very poor NHI reporting and it is often not possible to tell who is ultimately receiving the medication. These are excluded from the data.

The Pharmaceutical Collection does not record any data about the reason for a dispensing - it only captures information about the dispensing event. Hence while the pharmaceuticals in this extract can be used for gender dysphoria they can also be used for a number of other purposes, including inhibiting early on-set puberty. The Pharmaceutical Collection is a live dataset, whilst the Pharmaceutical Data Web Tool is a static extract. Comparing the two extracts may result in different figures.

Referrals of 0-24 year olds to mental health and addiction services, where primary diagnosis was classified as gender identify disorder, 2016-2020

Source: Ministry of Health, Programme for the Integration of Mental Health Data (PRIMHD)

Extracted: 16 August 2021

Notes:

Referral start date between 1 January 2016 - 31 December 2020

Calendar year relates to the referral start date period

A service user with more than one referral in a calendar year, will be counted more than once

Diagnosis type = 'A' - primary diagnosis

Team type not in '24' - Integrated Primary Access and Choice team, or '26' - Intellectual disability

Age determined at referral start date.

Gender is current on the NHI at time of data extraction

PRIMHD is the Ministry of Health national mental health and addiction information collection of service activity and outcomes data for health consumers. It does not contain information at a primary care level.

Some organisations have breaks in reporting and/or incomplete data in PRIMHD for some time periods.

PRIMHD is a living data collection, which continues to be revised and updated as data reporting processes are improved. For this reason, previously published data may be liable to amendments.

GENDER	AGE_GROUP	Calendar year				
		2016	2017	2018	2019	2020
Female	5 to 9	0	1	0	0	2
Female	10 to 14	3	5	1	10	9
Female	15 to 19	8	9	9	15	15
Female	20 to 24	7	4	4	2	3
Male	5 to 9	2	1	2	1	1
Male	10 to 14	2	3	1	19	7
Male	15 to 19	8	19	11	15	25
Male	20 to 24	1	2	3	3	2
Other	15 to 19	2	0	0	2	2
Other	20 to 24	0	0	0	0	1
Unknown	5 to 9	0	0	0	0	1
Unknown	10 to 14	0	1	0	1	0
Unknown	15 to 19	0	5	0	1	1
Unknown	20 to 24	0	0	1	0	0
Grand Total		33	50	32	69	69