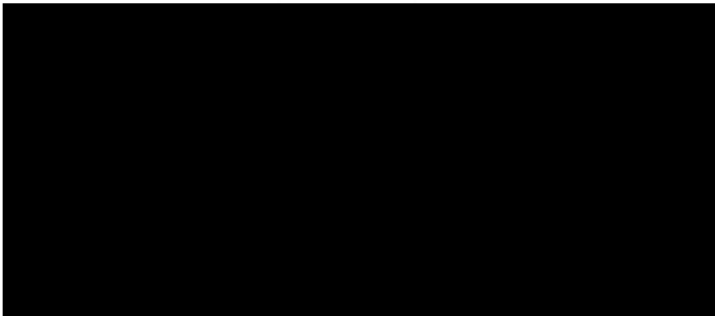


20 JUN 2019



Response to your request for official information

Thank you for your request for information under the Official Information Act 1982 (the Act) on 23 May 2019 for:

"I'd like to request the following medical information. The following questions pertain to the most recent reported statistical time period:

- 1. Number of people who have been assessed by neurology in New Zealand.*
- 2. Gender statistics - how many females and how many males were assessed by neurology.*
- 3. Of the above, how many received a diagnosis of FND (functional illness or functional neurological disorder), broken down by gender and region.*
- 4. How many people with FND died, broken down into male and female.*
- 5. How many people in New Zealand have a Periodic Paralysis diagnosis - broken down by gender and region.*
- 6. How many people in New Zealand have a POTS (postural orthostatic tachycardia syndrome) diagnosis - broken down by gender and region.*
- 7. How many people are diagnosed with a rare disease.*
- 8. How much is spent on people with rare diseases.*
- 9. Of those with a rare disease, how many are men and how many are women."*

On 23 May 2019 your request was transferred to the Ministry of Health (the Ministry) from the Department of Internal Affairs.

The Ministry is able to supply information on the number of people hospitalised for a specific condition. The Ministry's hospitalisation data is coded using the International Statistical Classification of Diseases and Related Health Problems (ICD). ICD-10-AM-VIII is the current version reported to the Ministry.

My responses relating to your request are as follows:

1. *Number of people who have been assessed by neurology in New Zealand.*
2. *Gender statistics - how many females and how many males were assessed by neurology.*

The Ministry is able to supply the number of attendances with a purchase unit code of *Neurology - 1st attendance* (M45002) and a neurology specialty code (M45-M49). In the 2017/18 financial year there were 16185 of these attendances, 9034 were female and 7151 were male.

3. *Of the above, how many received a diagnosis of FND (functional illness or functional neurological disorder), broken down by gender and region.*
4. *How many people with FND died, broken down into male and female.*

The Ministry does not hold information on the number of people that have been diagnosed with a functional neurological disorder. Therefore, we cannot supply the number that have died. Hospitalisations of functional neurological disorder would be coded to various sub-codes within *Dissociative [conversion] disorders* (ICD-10 code F44), so cannot be easily identified. These parts of your request are therefore refused under section 18(g) of the Act.

5. *How many people in New Zealand have a Periodic Paralysis diagnosis - broken down by gender and region.*

The Ministry does not hold information on the number of people that have been diagnosed with *Periodic paralysis*. We are able to identify publicly funded hospital discharges where any diagnosis of *Periodic paralysis* (ICD-10 code G72.3) were reported. There were 22 people with a reported diagnosis in the 2017/18 financial year. They are broken down by District Health Board (DHB) region and gender in the below table.

Extracted 7 June 2019	<i>Periodic paralysis hospitalisations by gender</i>	
	Female	Male
Northland		1
Waitemata	1	
Auckland		4
Counties Manukau	1	2
Waikato	1	2
MidCentral		1
Capital and Coast	1	1
Hutt Valley		1
Wairarapa		1
Nelson Marlborough		1
Canterbury		2
Southern	1	1

6. *How many people in New Zealand have a POTS (postural orthostatic tachycardia syndrome) diagnosis - broken down by gender and region.*

The Ministry does not hold information on the number of people that have been diagnosed with postural orthostatic tachycardia syndrome. Hospitalisations of postural orthostatic tachycardia syndrome are coded to *Other disorders of autonomic nervous system* (ICD-10 code G90.8), so cannot be easily identified. This part of your request is therefore refused under section 18(g) of the Act.

7. *How many people are diagnosed with a rare disease.*
8. *How much is spent on people with rare diseases.*
9. *Of those with a rare disease, how many are men and how many are women.*

The Ministry can only identify hospitalisations for a condition if there is a specific ICD code for it. There is no standardised criteria for defining a condition or disease as 'rare' so we cannot supply this information. These parts of your request are therefore refused under section 18(g) of the Act.

I trust that this information fulfils your request. Under section 28(3) of the Act you have the right to ask the Ombudsman to review any decisions made under this request.

Please note that this response, with your personal details removed, and attachments may be published on the Ministry website.

Yours sincerely



Shayne Hunter
Deputy Director-General
Data and Digital

