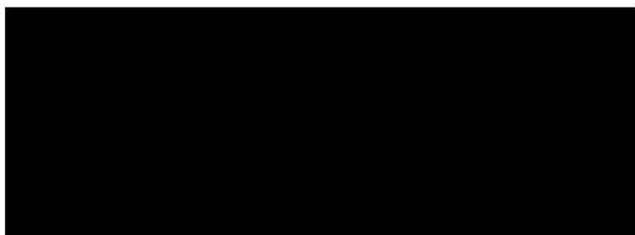


8 April 2019



### Response to your request for official information

I refer to your request of 7 March 2019 under the Official Information Act 1982 (the Act) for:

*“How many babies were born in each of the years 2001, 2016, 2017, 2018 ?  
What percentage of those babies for each year were born biologically  
“intersex” ?  
What are the medical conditions included in the Ministry’s definition of  
“Intersex” used to generate that statistic?*

*for each of the years 2001, 2016 & 2018, What was the number of births for  
each intersex condition?  
for the years 2001 and 2016 & 2018, How many of those intersex babies had  
“corrective” genital surgery performed in the first year after their  
birth (percentage)?”*

The information relating to this request is itemised below, with copies of documents attached.

*How many babies were born in each of the years 2001, 2016, 2017, 2018?*

According to the National Maternity Collection, the number of live births in the four years you have specified was:

2001: 56,129  
2016: 59,871  
2017: 59,752  
2018: 58,158

The National Maternity Collection identifies births based on lead maternity carer (LMC) claims information, and the National Minimum Dataset (NMDS) hospital records. Because LMC claims are typically submitted within six months of the birth, and hospitalisations may take some time to all be reported, the 2018 number is likely to be an undercount.

*What percentage of those babies for each year were born biologically “intersex” ?*

The Ministry of Health (the Ministry) collects information on sex/gender (different collections use different definitions). This classification does not have a value for intersex, so these fields cannot be used to identify these cases.

The hospital data the Ministry collects is coded using the World Health Organisation's (WHO) International Statistical Classification of Diseases and Related Health Problems (ICD). The Ministry uses the Australian Modification of this system (currently 8th edition, though the data below was extracted using 2nd edition, as that was the most recent version available for 2001 data).

The Ministry does not have a formal definition of what ICD codes constitute intersex.

Within this classification system there is a code for *Indeterminate sex and pseudohermaphroditism* (Q56). However, there may be other conditions of relevance that you may be interested in. Therefore, we looked for all publicly funded hospital discharges with both this diagnosis code and the code for *Liveborn infants according to place of birth* (Z38). The number of hospitalisations we found were:

2001: 1  
2016: 9  
2017: 4  
2018: 1

The numbers of these events fluctuates from year to year. The biggest change between 2001 and 2018 occurred between 2005 (where there were 11 cases) and 2006 (where there was only 1), so some care should be taken if trying to extrapolate trends from this data.

As you have specifically requested percentages, the percentages using the data above (to 2 decimal places) are:

2001: 0.00%  
2016: 0.02%  
2017: 0.01%  
2018: 0.00%

*What are the medical conditions included in the Ministry's definition of "Intersex" used to generate that statistic?*

As stated above, we used the code for *Indeterminate sex and pseudohermaphroditism* in this response. There are five subcodes to this code:

Q56.0: Hermaphroditism, not elsewhere classified  
Q56.1: Male pseudohermaphroditism, not elsewhere classified  
Q56.2: Female pseudohermaphroditism, not elsewhere classified  
Q56.3: Pseudohermaphroditism, unspecified  
Q56.4: Indeterminate sex, unspecified

Please note that the coding manual specifically notes that this excludes:

- female pseudohermaphroditism with adrenocortical disorder
- male pseudohermaphroditism with androgen resistance
- pseudohermaphroditism with specified chromosomal anomaly.

The first two exclusions are coded into *Androgenital disorders* (E25) and *Androgen resistance syndrome* (E34.5) with other non-pseudohermaphroditism codes. The third exclusion is coded to one of *Turner's syndrome* (Q96), *Other sex chromosome abnormalities, female phenotype, not elsewhere classified* (Q97), *Other sex chromosome abnormalities, male phenotype, not elsewhere classified* (Q98), or *Other chromosome abnormalities, not elsewhere classified* (Q99).

*For each of the years 2001, 2016 & 2018, What was the number of births for each intersex condition?*

All of the hospitalisations referred to above were reported with the code *Indeterminate sex, unspecified* (Q56.4). There were no codes in these three years with any of the other four codes.

*For the years 2001 and 2016 & 2018, How many of those intersex babies had "corrective" genital surgery performed in the first year after their birth (percentage)?*

This part of your request is refused pursuant to section 18(f) of the Act, as the information requested cannot be made available without substantial collation or research.

This is because the hospital data the Ministry holds does include procedure codes that indicate what procedures were performed. These procedures are coded, though the codes are largely neutral to the reason for which the procedure was performed. In addition, assessing whether surgery was performed on an individual involves linking multiple records together.

I trust this information fulfils your request. You have the right, under section 28 of the Act, to ask the Ombudsman to review any decisions made under this request.

Please note this response (with your personal details removed) may be published on the Ministry of Health website.

Yours sincerely

A handwritten signature in black ink, appearing to read 'SH' with a stylized flourish at the end.

Shayne Hunter  
**Deputy Director-General**  
**Data and Digital**