

PO Box 25496 Wellington 6146 New Zealand

T: +64 4 901 6040 F: +64 4 901 6079 E: info@hqsc.govt.nz W: www.hqsc.govt.nz

4 December 2020



Dear

## Official Information Request - Reference HQSC147 - 2020

I refer to your official information request dated 23 November requesting the following:

The total number of abortions reported to your Commission for the period from 2010 to 2017 that were done where the unborn child was diagnosed as having Down syndrome, cleft pallet, a cleft lip or club foot.

The Health Quality and Safety Commission (Commission) is unable to provide you with the data you have requested. As you know, the Perinatal and Maternal Mortality Review Committee (PMMRC) is not subject to the Official Information Act 1982 (OIA) due to the personally identifiable, confidential nature of the information that it collates.

PMMRC was established by the Commission under section 59E of the New Zealand Public Health and Disability Act 2000 (NZPHD Act). The Committee is not part of the Commission but, rather, is an individual statutory entity. As such, the information you have requested is not held by the Commission.

PMMRC produce an annual report. The most recent report is the PMMRC 13<sup>th</sup> Annual Report<sup>1</sup>, released in October 2019. This report includes data on all perinatal death from 20 weeks gestation up until midnight on the 27<sup>th</sup> day of life.

You will see in this report that congenital abnormality is reported as the leading cause of perinatal death, and accounts for 75 percent of terminations of pregnancy after 20 weeks gestation.

 $<sup>\</sup>underline{https://www.hqsc.govt.nz/assets/PMMRC/Publications/13thPMMRCreport/13thPMMRCAnnualReportWebFINAL.pdf}\\$ 

Table 3.3: Perinatal related deaths by perinatal death classification (PSANZ-PDC) 2017

Perinatal death classification (PSANZ-PDC)	Fetal deaths							
	Termination of pregnancy n=133		Stillbirths n=287		Neonatal deaths		Perinatal related deaths (total)	
	Congenital abnormality	100	75.2	26	9.1	31	18.1	157
Perinatal infection	4	3.0	17	5.9	7	4.1	28	4.7
Hypertension	<3	X	10	3.5	<3	X	13	2.2
Antepartum haemorrhage	<3	×	37	12.9	39	22.8	78	13.2
Maternal conditions	11	8.3	11	3.8	6	3.5	28	4.7
Specific perinatal conditions	3	2.3	45	15.7	16	9.4	64	10.8
Hypoxic peripartum death	2	2	4	1.4	9	5.3	13	2.2
Fetal growth restriction	<3	X	33	11.5	6	3.5	41	6.9
Spontaneous preterm	10	7.5	20	7.0	47	27.5	77	13.0
Unexplained antepartum death	-		84	29.3	-	-	84	14.2
No obstetric antecedent		2	-	-	8	4.7	8	1.4

<sup>&#</sup>x27;x' indicates percentage suppressed due to small numbers.

Source: PMMRC's perinatal data extract 2017.

## Congenital abnormality includes the following:

- Structural anomalies including anomalies such as nervous system, cardiovascular system, genitourinary system, gastrointestinal system, musculoskeletal (including diaphragmatic hernia, gastroschisis/omphalocele), respiratory system, haematological, multiple congenital abnormality etc
- **Chromosomal anomalies** including anomalies such as Down syndrome, Edward syndrome, Patau syndrome, other trisomies and partial trisomies, monosomies, Turner syndrome, Klinefelter syndrome, Fragile X syndrome etc
- Genetic anomalies including Genetic conditions such as Tay-Sachs disease and cystic fibrosis.

The PMMRC 12th Annual Report<sup>2</sup> includes a breakdown of congenital anomaly specific perinatal related mortality rates. This shows the overall perinatal related death rate and is further broken down into which of those deaths were by termination of pregnancy, stillbirth or neonatal death.

The data intentionally does not identify the specific anomaly. The reason for this is to avoid this information from becoming identifiable. It is important to acknowledge that there is a proportion of these congenital anomalies that would be incompatible with life.

<sup>&</sup>lt;sup>2</sup> https://www.hqsc.govt.nz/assets/PMMRC/Publications/12th-PMMRC-report-final.pdf

Perinatal related death and congenital anomalies

Stillbirths Termination of pregnancy Perinatal related deaths Neonatal deaths 3.5 3.0 2.5 rate/1000 births 2.0 0.5 0.0 2011 2012 2007 2008 2009 2010 2013 2014 2015 2016 Year of death

Figure 2.2: Congenital anomaly specific perinatal related mortality rates (per 1000 births) 2007–2016

In regards to the second part of your question, relating to cleft lip, pallet and club foot (talipes), the PMMRC does not collect this information.

Please note that the Commission publishes some of its OIA responses on its website, after the response is sent to the requester. The responses published are those that are considered to have a high level of public interest. We will not publish your name, address or contact details.

You have the right, by way of complaint under section 28(3) of the Official Information Act 1982 to the Ombudsman, to seek an investigation and review of the Commission's decision. Information about how to make a complaint is available at <a href="https://www.ombudsman.parliament.nz">www.ombudsman.parliament.nz</a> or 0800 802 602.

Yours sincerely

Dr Janice Wilson Chief Executive