

15 April 2024

Response to Ombudsman's Provisional Opinion

Reference number **605471**

Thank you for your letter of 2 Apr 2024.

You have given a provisional response from the Ombudsman and asked for my comments. You have noted that Health New Zealand (HNZ) has provided information in the form of trigrams and quadgrams on 25 Jan 2024 and explained why it may be unable or unwilling to provide the full information as requested.

You state the information provided 'allows [me] to understand the content of the free text boxes'. This is absolutely not the case. The data that has been provided is meaningless and bordering on useless without more context and information.

Employing such a cryptic methodology to provide the content of the free text survey responses does beg the question as to whether these responses were ever intended to be analysed, summarised or acted upon.

In order to improve the transparency intended under the OIA, if the trigrams and quadgrams are all that HNZ is willing to provide, can it please explain the information in more detail by answering the following questions in a timely manner. The original request for the information was made on 26 November 2022.

Questions:

Do the data provided in the trigrams and quadgrams relate to and include all 200,000 survey responses?

How has the content of the boxes been sanitised? For example, only symptoms (sore, swollen, pain etc.) but no diagnoses (blood clot, myocarditis, stillbirth) are referred to. Have diagnoses been excluded during the sanitising process?

Please explain the process behind the determination of the 'key words'. Which words are included and which are excluded?

According to the PVSC Medsafe results pages, there were 100,996 'yes reaction' responses to the survey about doses 1,2 and boosters 1 and 2 combined ; 29,149 'yes reaction' responses to the bivalent survey; and 5,057 'yes reaction' responses to the child survey. That is a total of 135,202 'yes I had a reaction' responses. Where do the other approx. 65,000 responses come from? Are they from data that have not yet been published?

What number of people reporting 'yes, I had a reaction' filled out a free text box?

There are 466 quadgrams and 1229 trigrams, so 1695 total three or four word sequences. Does this mean that that is the total number of text boxes filled out, or is this just a selection of the 200,000 boxes?

Is there overlap between the trigrams and quadgrams i.e. will there be some of the same boxes referred to in both? If so, which ones? How was it decided which responses should become a trigram and which a quadgram?

Can HNZ provide 10 varied examples of what is actually in the free text box and how that comes out as a trigram and 10 examples for a quadgram?

Can HNZ confirm that no-one has reported/mentioned a miscarriage, stroke, Bell's palsy, heart attack, myocarditis, seizure, stillbirth, blood clot, tinnitus or ringing in the ears, haemorrhage, menstrual disturbance, Guillain Barre syndrome, tingling or numbness or death (or synonyms of those words) after the vaccine in the free text boxes?

It is odd that no-one has reported headache though this was a common adverse effect. In addition, 'fatigue' and 'tired' are mentioned just once each in the quadgrams; neither is mentioned in the trigrams but these were common reactions. Is there an explanation?

There is 'chest pain day 4' and 'chest pain day 5'. Does that mean no-one wrote 'chest pain day 1' or 'chest pain day 3' etc.?

What does '5 day post' or '24 hour injection' or '1 5 day' mean? Those excerpts do not provide any useful information.

How is it possible to decipher which dose is referred to or how long after the injection the symptoms took place?

What is the difference between 'sore arm chest pain' and 'chest pain sore arm'?

How do I conclude which 3 or 4 words have been picked out of a box? e.g. 'day 2 3' appeared three times. What did the rest of the three boxes say – presumably all different things?

How is it possible that the free text box could identify an individual given that this is the only data field being provided? Can you provide an example (with details changed) of how privacy could be breached?

It is important to reiterate that the people of NZ who filled in those surveys and free text boxes did so for the benefit of fellow New Zealanders. They expected the results to be shared and available.

In your response you report that extracting this information would "prove an unacceptable impediment to business as usual" for HNZ. This again underlines the inaccessibility of the data that was gained from New Zealanders, a lack of skill as regards data handling and belies a blatant disregard for any harm reported by the population.

Given that a large proportion of the reports that included "pain" were actually chest pain and that a number of other very serious symptoms appeared in these free text boxes, HNZ are displaying a damning lack of due diligence supported by section 16(2)(a) of the OIA.

I remain unsatisfied with the trigrams and quadgrams and would prefer the Ombudsman insist that HNZ release a simple spreadsheet with the free text comments in full.

Thank you.

Regards,