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4 July 2022

s 9(2)(a)

By email: s 9(2)(a)
Ref: H202207833

Tēnā koe s 9(2)(a)

Response to your request for official information

Thank you for your request under the Official Information Act 1982 (the Act) to the Ministry of Health (the Ministry) on 13 June 2022 for information relating to surgical operations performed on children with intersex characteristics. You stated:

An article I have, dated February 18 2022 at 5:52pm, states that according to the ministry of health. there were 206 surgical operations performed on children under 15 years of age with intersex characteristics in 2017 and 2018. Further to this, 85 per cent of those 206 surgeries were on children under the age of 5 years.

You specifically requested:

*Were these 206 children from as far back as 2017 and as recent as 2018 asked if they knew what these surgeries are and were these children comfortable talking about it?
Did these children have their surgeries explained to them?
Did these children have a good understanding on the implications of what it might mean for them later on in life?
Were the parents and wider family members informed properly of the meaning of the surgeries by surgeons?
Were the parents and wider family members consulted with their children present and part of the conversation?*

The Ministry does not hold personal medical records. In order to respond to your request with specific reference to the individuals involved, this would require the Ministry to seek information from the district health boards (DHBs) to create information to answer your request.

By way of explanation, this would also require a complex reconciliation of personal information, medical and health records from each of the DHBs, and the prior approval of the Privacy Commissioner to allow the provision of such personal information to occur. Therefore, your request is refused under section 18(g) as the information requested is not held by the Ministry.

While the Ministry considered a transfer of your request to the DHBs, you may wish to approach the DHBs directly for this information or any further information relating to their records. Contact details for the DHBs are available at: www.health.govt.nz/new-zealand-health-system/key-health-sector-organisations-and-people/district-health-boards/district-health-board-websites.

This request may be also be refused in full by the DHBs under section 18(f) of the Act, as the information requested cannot be made available without reviewing and collating information for each of the 206 individual records to determine whether the information is within the scope of your request. Please note, the DHBs would also have to consider the privacy of these patients when formulating their response to your request.

However, you may be interested to know that recent work has been commissioned by the Ministry and carried out by a clinical network. This is specifically pulled together by the Paediatric Society of New Zealand (PSNZ) clinical networks group to look at initial clinical care of children with differences of sex development which is a very specialised area. Their guidelines have been published and can be found here:

www.starship.org.nz/guidelines/differences-of-sex-development-atawhai-taihemahema/

Only medically indicated interventions are recommended in early infancy/childhood with any further surgical work deferred to an older age. The guidelines provide advice around communication with the family who are, at that early stage, making decisions on behalf of their pre-verbal child.

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 website at: www.health.govt.nz/about-ministry/information-releases/responses-official-information-act-requests.

Nāku noa, nā

PP



Robyn Shearer
Deputy Chief Executive
Sector Support and Infrastructure