

NZNO and Te Rūnanga o Tōpūtanga Tapuhi o Aotearoa Submission response to Paerewa Parongo Hauora - Health Information Standards Organisation (HISO) Māori Descent and Iwi affiliation Data Protocols. Policy Contact: Belinda Tuari-Toma – [belinda.tuari-toma@nzno.org.nz](mailto:belinda.tuari-toma@nzno.org.nz)

Sections	Responses to section 1-7
1:	<p><b>Purpose statement:</b>            NZNO is the leading professional nursing association and union for nurses in Aotearoa, New Zealand, representing 51,000 nurses, midwives, students, kaimahi hauora and health workers on professional and employment matters. NZNO embraces te Tiriti o Waitangi (Te Tiriti) and contributes to improving the health status and outcomes for all Aotearoa New Zealanders through influencing health, employment, and social policy development. Furthermore, we share the Ministry of Health’s definition of equity, which equally applies to NZNO work across professional, industrial and member activities. As health professionals and specialists in health care, we strongly advocate for any change that seeks to improve the public health care and practices that support the wellness of a growing diverse community.</p> <p>The HISO data protocol's purpose is to set out standard protocols for collecting and recording Māori descent and iwi affiliation in the health and disability system. We support this shift and the decision to affirm the sovereignty rights and interests of Māori in the collection, ownership, and application of data. As specified in the recommendations of the Wai 2575 - Health Service and Outcome Kaupapa Inquiry, of which our nurses are claimants. It was found that the Crown did not sufficiently collect qualitative and quantitative data to inform the performance of how the primary health care sector was meeting the needs of Māori. Nor did the system effectively utilise or make easy access available. Further, we appreciate that there is a focus to ensure the data drives equity-led decisions that will better inform measurement outcomes relative to Māori health wellness. We are interested in understanding how the Health Reform will apply the recommendations of Wai2575 and the Health and Disability System Review, specific to data sovereignty, to guarantee tino rangatiratanga to meet the obligation of Te Tiriti.</p>
2:	<p><b>Scope:</b>            interested to see how the new Iwi Statistical Standard and Classification criteria model will translate te ao Māori values and principles. Criteria must be led by iwi and hapū under the proviso of the overarching guidance that Te Tiriti should provide. The opportunity for tangata whenua to control reporting and monitor the health and disability system outcomes in terms of Māori as consumers/end users (<i>consumer includes all organisations, providers, health professionals and specialists, iwi, hapū, and Marae based services</i>). Assures the systems effectively and efficiently record and communicate data that support the well-being and aspirations of Māori. We also anticipate that all future policies and decisions will be better informed by reasonable, equitable, disaggregated data sets.</p>
3:	<p><b>Background:</b>            As we navigate the Covid-19 pandemic response, our health workforce intensively continues to provide a duty of care to protect and prevent the spread of the virus. However, the potential exposure to Maori and Pacific communities could be devastating, so it is essential to identify who is in our communities. We are pleased with the extensive response to addressing</p>

	<p>how Māori data is recorded and shared. There is a sense of urgency to improve our health legislative Bills, acts, regulatory systems, monitoring and evaluation mechanisms due to the global pandemic and escalation of extremities with poverty leading to poor health, economic, social, cultural, and environmental outcomes. We commend how the system is changing to improve the quality of data reporting for quantitative and qualitative data that includes diversity for ethnic communities. Especially if that means Māori retain their tino rangatira active protection right to be recognised as tāngata whenua, Te Tiriti partners to the Crown. For instance, increasing knowledge and information that provides conceptual te ao Māori understandings means we are sustaining our right to protect our taonga tuku iho. Therefore, advocating for the freedom for all Māori respondents to access their statistical data, ensuring access to their intellectual property by providing the option to request information. This change assures equity is being met where solutions address unfair and unjust rights for Māori and other demographics such as Pacific, Asian, and Migrants.</p> <p>The appetite to make extreme changes to how the narrative of Māori is communicated through collection, recording and the outputs generated from the data is increasing and overdue.</p>
4:	<p><b>Protocols for collection Māori descent and iwi affiliation data:</b></p> <p>Including words such as whakapapa, tipuna, hapū, and of course, iwi is revolutionary for any data analysis system. Therefore, signalling a commitment to te Tiriti and partnership of Māori and the Crown bi-cultural and bilingual obligations. We agree with the section that addresses the relationship between Māori descent and iwi affiliation data identification. In particular, many Māori individuals and collectives who are or have yet to discover their Tūrangawaewae, however, are Māori, and there should be a standard option for them to identify still who they are, as their cultural, biological identity is essential. The fluidity of whakapapa assures those who are Māori who have yet to confirm that iwi or hapū will eventually be connected. We also encourage disclosure statements such as the statement for the reference list that says: “This list is for reference purposes only and is not a full list of all iwi or iwi related groups – see the guide notes for a list of iwi”. Cultural safety for our nursing workforce is always up for discussion and of absolute significance. It provides a guide for our workforce Māori and non-Māori to provide appropriate information and safe environments for our clients and whānau to disclose information. We would recommend increasing te reo literacy opportunities for all levels of te reo Māori.</p> <p>Additionally, we would be interested in understanding the Cook Island communities, opinion on whether they are happy to be identified as Cook Island ‘Māori’. This is because they too identify with their islands, cultural community and effectively could become independent from Aotearoa, New Zealand. Therefore, their identity should be acknowledged appropriately under the obligation of Te Tiriti.</p> <p>Moreover, we would like to see more technology options made available to those with disabilities, particularly Māori who have recorded to have the highest rates of people with disabilities (14% tamariki; 32% young Maori and Māori of working age; 62% for seniors) compared to non-Māori statistics, which there is a considerable gap.</p>

5:	<p><b>Protocols for classifying, coding a recording Māori descent and iwi affiliation data:</b></p> <p>We support the protocol requirements for recording iwi affiliation particularly with the level 1 and 2 identification process which assures any data captured is best reflected as much as it can through the classification process that aims to record where ever possible.</p>
6:	<p><b>Output of Māori descent and iwi affiliation data:</b></p> <p>We commend efforts to set out the purposes specified under tino rangatiratanga and active protection of Te Tiriti, guarantee self-determination, mana motuhake and adhere to the Crown’s commitment as a partner to Te Tiriti to provide Māori health equity. As one of the most significant health professionals in Aotearoa, New Zealand, and a bi-cultural organisation between New Zealand Nurses Organisation and Te Rūnanga o Tōpūtanga Tapuhi Kaitiaki o Aotearoa. We are very keen to see how this relationship continues to support transforming the data narratives to meet the health aspirations of Māori and all New Zealanders. Our constitution and Te Rūnanga Ngā Ture obligation demonstrate our commitment to this Te Tiriti partnership.</p>
7:	<p><b>Adoption an Implementation:</b></p> <p>As the Health Reform progresses with the work of the transitional unit and the introduction of Pae Ora – Healthy Futures Bill, currently with the select committee with submissions to close on 9 December and the Pae Ora Select Committee to convene report back to the cabinet by April 2022. We will be keeping a watching brief on the data digital capabilities that the new entities Health NZ and the Māori Health Authority will be implementing these standards, with the Ministry of Health, Public Health Business unit, who we understand will support this capability or be a monitoring mechanism to support the entities and government reporting. We are currently working on the submission for the Pae Ora Bill and have included recommendations regarding data sovereignty.</p>