

Summary of public comment received on proposed changes to the National Health Index system and HISO 10046 – the Consumer Health Identity Standard

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Summary of public comment received on proposed changes to the National Health Index system and HISO 10046 – the Consumer Health Identity Standard

During July and August 2018, the Ministry of Health (the Ministry) sought public comment at a concept level on 16 possible changes to the National Health Index (NHI) system and the Consumer Health Identity Standard (HISO 10046). This standard is a data set specification for patient/consumer identity and demographic information as recorded by the National Health Index (NHI) system.

In seeking public comment, the Ministry noted that:

1. Detailed costing and adoption/implementation information related to each proposal had not been prepared at the time of the request. Likewise, a timeframe for introducing changes had not been determined.
2. There was no priority or preference implied or expressed in the order of presentation of the listed items.
3. Not all changes can or will be progressed at one time. Funding is limited and there is an increased risk arising from making multiple changes at one time.
4. Assessment factors to determine which changes will progress to a more detailed stage include appropriateness, affordability, practicality, training, public comment, and time required to implement.

The public comment period began on 9 July 2018 and closed on 24 August 2018.

The Ministry is grateful for the interest of the public and acknowledges the 130 responses received. This document summarises the responses received and provides the themes and general level of public support identified for each individual proposal as follows:

Appendix 1 summarises the number and types of responses received.

Appendix 2 provides a summary of responses received by topic, with a selection of comments providing a general sense of the mood of respondents.

Next steps: The Ministry Executive Leadership Team completed a review of the summary information and determined the following action to be taken for each of the 16 potential changes.

- **Group 1:** The following topics are approved to proceed through detailed design and then to implementation:
 - NHI numbering extension

- country code
 - language code.
- **Group 2:** The following potential change topics are approved to proceed to the next stage. This comprises forming a working group to develop supporting information covering detailed design (including further public consultation as needed), costing, timing, training, agency support, adoption and implementation planning:
 - ethnicity
 - gender identity
 - iwi classification
 - residency status
 - opt-out status indicator
 - Cook Islands, Niue and Tokelau cross reference
 - MedicAlert cross reference.
- **Group 3:** The remaining potential changes are acknowledged but are NOT approved to proceed to the next stage at this time. While these items will remain part of the Ministry's ongoing work plan, there is no immediate intention to further develop these topics:
 - biological sex recorded at birth
 - sexual orientation
 - disability status
 - delegation rights – general
 - delegation rights – advance care planning
 - height and weight.

Appendix 1 Summary of the source and responses received

Response analysis – as at 28 August 2018

	Response type	Number of responses
Responder source	Government agencies	4
	Health sector	66
	Non-government	32
	Personal	28
	Total responses	130

Survey responses question	Response analysis			
	Agreed/ supported	Opposed	No comment	Comment(s) to review
1. NHI numbering extension	51	0	35	22
2. Biological sex recorded at birth	41	22	23	55
3. Gender identity	43	19	14	59
4. Sexual orientation	27	34	19	53
5. Ethnicity	33	6	26	29
6. Country code	30	1	30	16
7. Language code	29	1	31	10
8. Iwi classification	48	0	24	29
9. Disability status	31	10	24	39
10. Residency status	24	4	30	22
11. Opt-out status indicator	10	20	27	32
12. Delegation rights – general	20	10	21	27
13. Delegation rights – advance care planning	44	7	23	36
14. Cook Islands, Niue and Tokelau NHI cross reference	25	1	29	10
15. Height and weight	16	29	21	41
16. MedicAlert ID cross reference	22	10	24	23
Totals				503

Note: There can be more than one comment/observation for each survey response received.

Appendix 2: Summary of responses received by individual topic

#1: NHI numbering extension – as originally published

The National Health Index (NHI) has assigned the majority of the currently available NHI numbering range. At current rates of allocation there are sufficient available NHI numbers for another 7–8 years. All existing NHI numbers are forecast to be exhausted around 2025.

Several options have been considered for extending the numbering range. These include removing or changing the check digit sum, moving to an extended character number sequence, or reconfiguring the current seven character number sequence.

The Ministry’s recommended option is to change the check digit algorithm and number format within the existing NHI identifier length of seven characters, from AAANNNN to AAANNAA. The transition would occur once the existing number range is exhausted and the old format would be retained alongside the new format. No mapping between NHI numbers would be required.

Response summary

Responses	Total number	Distribution of responses			
		Government	Health sector	Non-government	Personal
This section:					
• agreed / supported	51	2	32	10	7
• opposed	0	0	0	0	0
• no comment	35	1	13	10	11
• comments given	22	1	16	2	3

The key comments received covered the following points:

- Providing funding for non-Ministry agencies if they need to undertake necessary systems upgrade and provide training.
- The need for early commitment to ensure this activity is completed well before the current system numbers are exhausted.
- The possibility of reusing/recycling numbers.

Next steps: The Ministry Executive Leadership Team determined that action in respect of NHI numbering extension should proceed immediately to detailed design and then implementation.

#2: Biological sex at birth – as originally published

Statistics New Zealand (StatsNZ) is about to review the standard for biological sex recorded at birth, and will be considering a third category for people who are intersex as part of this review.

Currently the NHI does not capture sex, instead it only captures gender. Capturing data on intersex people would enable health care that better meets their particular needs, and assist in the implementation of frameworks to uphold the rights of intersex New Zealanders.

Response summary

Responses	Total number	Distribution of responses			
		Government	Health sector	Non-government	Personal
This section:					
• agreed	41	1	23	8	9
• opposed	22	1	8	5	8
• no comment	23	0	15	2	6
• comments given	55	2	26	14	13

The key comments received covered the following points:

- This is a difficult policy area which deserves a more consultative approach. This should not be a HISO decision.
- A need to be advised/informed by what is happening with the Births, Deaths, Marriages and Relationships Registration Bill (Government Bill 296-1). This Bill has passed its first reading and is at Select Committee stage. A report is due 10 August 2018. Making changes before the outcome of this Bill is known is premature and must not be actioned.
- Many major concerns regarding privacy and concerns about individuals' safety.
- Biological sex at birth is not a Māori concept.
- Complications that should be addressed first, eg, if a person's gender on their NHI record is set to Indeterminate or Unknown, they cannot access special authority on medications from PHARMAC. This needs to be fixed with this review.
- Producing and agreeing a better definition of 'unknown' is an essential prerequisite.
- A need to test why such information is needed to be generally available at the identity phase.

Next steps: The Ministry Executive Leadership Team determined that no further action on this topic would be taken at this time.

#3: Gender identity – as originally published

Currently the NHI system offers and records four values for gender. We propose that the NHI is changed to reflect the Statistics New Zealand (StatsNZ) standard. In 2015, StatsNZ developed a national standard to improve data collection on trans and gender diverse New Zealanders. The standard has been developed through consultation and testing.

Response summary

Responses	Total number	Distribution of responses			
		Government	Health sector	Non-government	Personal
This section:					
• agreed	43	2	27	9	5
• opposed	19	1	5	6	7
• no comment	14	0	11	2	1
• comments given	59	3	26	14	16

The key comments received covered the following points:

- Dropping the word 'identity' from the title [Note: this word does not appear in the standard – it should not have been placed in the consultation document].
- Sticking with the existing 4 options. This is a sort-of subset of the StatsNZ list and is sufficient even if we tie the list to the Stats Standard. Do not add the 'Gender diverse' option but consider adding a 'did not state' option.
- Emphasising the "as self-identified" or "prefer not to state" words in the standard. You may need more text to explain this.
- The StatsNZ standard is fundamentally incorrect and offensive. This has still not been formally adopted by StatsNZ.
- Undertaking further consultation, including gender-based advisory groups and the Human Rights Commission.
- Looking at the 'Births, Deaths, Marriages and Relationships Registration Bill' (Government Bill 296-1).

Next steps: The Ministry Executive Leadership Team determined that this topic requires further advice and consideration. Accordingly, a working group will be established in the near future to solicit further and more focused comment.

#4: Sexual orientation – as originally published

The NHI system does not currently hold information about patients' sexuality, or sexual orientation. Sexual orientation covers the ways in which a person's sexuality is expressed, and the terms they choose to identify with. Sexual orientation includes heterosexual, gay, lesbian, bisexual, pansexual, and asexual, among others.

Statistics New Zealand (StatsNZ) has developed a framework for sexual orientation, and sought public feedback. StatsNZ will analyse the feedback it received, and work with other organisations to develop a new statistical standard for sexual identity, which is to be released later in 2018. We propose the NHI collect data on sexuality according to this standard.

Accurately collecting statistical data on the Rainbow community means that government agencies can take an evidence-based approach to policy formation and programme development in health, as well as in areas such as social development and justice. This data will aid our understanding of the population and help our work in addressing equity issues.

Response summary

Responses	Total number	Distribution of responses			
		Government	Health sector	Non-government	Personal
This section:					
• agreed	27	2	11	8	6
• opposed	34	2	18	5	9
• no comment	19	0	13	4	2
• comments given	53	1	25	12	15

The key comments received covered the following points:

- This is simply not identity information.
- Heavy, detailed and emphatic opposition to this field, particularly as an identity field but even for a clinical field in general terms. Use only if essential and even then with a 'better-than-average' reason to include.

Next steps: The Ministry Executive Leadership Team determined that no further action on this topic would be taken at this time.

#5: Ethnicity – as originally published

The NHI system currently holds ethnicity information based on self-identification provided by the patient. At least one and up to six ethnicities may be recorded. The format required is set out in section 2.5 of the Consumer Health Identity Standard. (<https://www.health.govt.nz/publication/hiso-10046-consumer-health-identity-standard>).

The suggestion is that in addition to recording a numeric interpretation of the ethnicity value, the raw text as provided by the patient should also be recorded/stored.

Response summary

Responses	Total number	Distribution of responses			
		Government	Health sector	Non-government	Personal
This section:					
• agreed	33	2	23	7	1
• opposed	6	0	4	0	2
• no comment	26	1	11	8	6
• comments given	29	1	20	5	3

The key comments received covered the following point:

- Providing funding for non-Ministry agencies if they need to undertake necessary systems upgrade and provide training.

Next steps: The Ministry Executive Leadership Team determined that this topic requires further advice and consideration. Accordingly a working group will be established in the near future to solicit further and more focused comment.

#6: Country code – as originally published

The NHI system and the Consumer Health Identity Standard (HISO 10046)¹ currently both hold Country information. Other Ministry systems use different values to record the same information. The existence of the varying ways of recording the same information is clumsy and invites comparison and other errors. The recommendation is to:

- move to a single and consistent basis for all Country code records
- standardise on the ISO code list – the alpha-2 variant.

Response summary

Responses	Total number	Distribution of responses			
		Government	Health sector	Non-government	Personal
This section:					
• agreed	30	0	22	7	1
• opposed	1	0	1	0	0
• no comment	30	1	15	8	6
• comments given	16	1	10	2	3

The key comments received covered the following points:

- Providing funding for non-Ministry agencies if they need to undertake necessary systems upgrade and provide training.
- This is basically a minor correction to an existing field.

Next steps: The Ministry Executive Leadership Team determined that action in respect of country codes should proceed immediately to detailed design and then implementation.

¹ <https://www.health.govt.nz/publication/hiso-10046-consumer-health-identity-standard>

#7: Language code – as originally published

Currently the NHI uses Alpha-2 characters to record language. This code list does not include, for example, codes for Cook Island Māori; Tokelauan, Niuean, or Tuvaluan.

The suggestion is to move to Alpha-3 that does include codes for these languages. Note that the NHI Standard/System both already provide a five character space for recording language information and therefore no change to the NHI system is required.

Response summary

Responses	Total number	Distribution of responses			
		Government	Health sector	Non-government	Personal
This section:					
• agreed	29	0	22	6	1
• opposed	1	0	0	1	0
• no comment	31	1	16	8	6
• comments given	10	1	7	2	0

The key comments received covered the following points:

- Providing funding for non-Ministry agencies if they need to undertake necessary systems upgrade and provide training – noted as an implementation issue.
- This is basically a minor correction to an existing field.
- It would be good to have stated which language entry is the preferred language.

Next steps: The Ministry Executive Leadership Team determined that action in respect of language codes should proceed immediately to detailed design and then implementation.

#8: Iwi classification – as originally published

There is a strong need for the NHI system to include 'iwi' as a core variable/attribute.

The NHI system is an essential planning tool for the provision of health services and understanding health needs and outcomes in New Zealand. For iwi (as Treaty Partners, and as emerging providers of health and social services) to engage effectively in the current and future provision of health services to whānau and individual iwi members, they need robust data and information.

Adding iwi as a core variable/attribute to the NHI system will be hugely beneficial to inform and measure the impact of iwi investment in wellbeing. It will also highlight intervention opportunities for collaboration with the Ministry of Health and other health organisations.

Response summary

Responses	Total number	Distribution of responses			
		Government	Health sector	Non-government	Personal
This section:					
• agreed	48	0	26	18	4
• opposed	0	0	0	0	0
• no comment	24	2	11	7	4
• comments given	29	0	16	11	2

The key comments received covered the following points:

- Providing funding for non-Ministry agencies to undertake necessary systems upgrade and provide training.
- Make it clear that ethnicity is not equivalent to iwi.
- Use the StatsNZ iwi classification.
- How will some systems handle macrons – an essential point to fix.
- Need to have an ability to record multiple iwi – suggest six instances.

Next steps: The Ministry Executive Leadership Team determined that this topic requires further advice and consideration. Accordingly, a working group will be established in the near future to solicit further and more focused comment.

#9: Disability status – as originally published

New Zealand has significant limitations in its national disability data collection and capability in establishing data on disabled people. In particular, the lack of disability identification in national health and disability surveys is a major barrier to understanding and measuring outcomes for disabled people.

Response summary

Responses	Total number	Distribution of responses			
		Government	Health sector	Non-government	Personal
This section:					
• agreed	31	1	22	5	3
• opposed	10	0	6	2	2
• no comment	24	1	8	7	8
• comments given	39	1	27	6	5

The key comments received covered the following points:

- If included, what provision would there be for funding non-Ministry agencies to undertake necessary systems upgrade and provide training. It is envisaged that there would be a high administrative burden collecting/recording this information.
- There needs to be a 'prefer not to say' option equivalent to iwi.
- Would be better in a medical warning type system.
- A significant number of negative views expressed about the ability of the WGSS recording system to collect what is needed – WGSS is not good enough.

Next steps: The Ministry Executive Leadership Team determined that no further action on this topic would be taken at this time.

#10: Residency status – as originally published

Over the next 2–4 years the Ministry plans to deprecate the legacy HL7 NHI messages and transition integrating systems to the newer APIs. A decision is therefore required on whether to persist with deprecating the Residency Status attribute or provide continued support in future APIs.

Response summary

Responses	Total number	Distribution of responses			
		Government	Health sector	Non-government	Personal
This section:					
• agreed	24	1	16	6	1
• opposed	4	0	2	1	1
• no comment	30	1	17	7	5
• comments given	22	2	13	4	3

The key comments received covered the following points:

- Continuing with the residency attribute as there is concern with the handling of eligibility for free health care treatment.
- Making sure we record long-term visa residency, and also add an end date for these type of temporary attributes.
- Getting this sorted to remove an irritation for a number of public visits to hospitals.

Next steps: The Ministry Executive Leadership Team determined that this topic requires further advice and consideration. Accordingly, a working group will be established in the near future to solicit further and more focused comment.

#11: Opt-out status indicator – as originally published

This field is based on the Health Information Governance Guidelines (HISO 10064:2017, section 4.3.2) that allows a person to set a 'do not disclose' option. This would mean that information would be collected and held on the NHI, but consideration can be given to whether individuals should be able to opt-out from information held about them on the NHI being disclosed to third parties.

Response summary

Responses	Total number	Distribution of responses			
		Government	Health sector	Non-government	Personal
This section:					
• agreed	24	1	16	6	1
• opposed	4	0	2	1	1
• no comment	30	1	17	7	5
• comments given	22	2	13	4	3

The key comments received covered the following points:

- 'Text provided is unclear – cannot allow opt out of the NHI itself. Wording provided in the consult document is almost leading to a particular conclusion.'
- Is this 'all' information or just some health information?
- Develop as part of the upcoming her.
- You need to map how this would work between Hospital/lab/GP – can they each look at different part of the information held or is there a consistent blanket cover?
- At what age can a person opt out?
- Introduces too much risk to the person and the treating clinician from possibly missing vital information – who carries the risk?
- There are currently silos of opt out in the sector already, eg, clinical data repositories, and that these are typically more clinically relevant against each discipline.

Next steps: The Ministry Executive Leadership Team determined that this topic requires further advice and consideration. Accordingly, a working group will be established in the near future to solicit further and more focused comment.

#12: Delegation rights – general – as originally published

This field is based on the concept of the NHI holding a record of an authority to act on behalf of someone.

Response summary

Responses	Total number	Distribution of responses			
		Government	Health sector	Non-government	Personal
This section:					
• agreed	20	1	16	2	1
• opposed	10	0	7	2	1
• no comment	21	1	9	7	4
• comments given	27	0	20	5	2

The key comments received covered the following points:

- There needs to be more work to clarify what actually is wanted here and what is the desired patient benefit?
- We need to ensure that this covers health care issues and not property rights stuff.
- The administrative consequences of adding this to any system will be significant.
 - Administrative resource to enter and maintain up to date information.
 - How do you keep this up to date?
 - How do you know where it is held?
 - It is not clear if the intention is to just recognise the existence of a general delegation (power of attorney) to hold a copy of it or to point to where it is held, etc.
- If really needed, this is better placed in something like the Medical Warning System.
- This should be merged with the process to handle Advance Care Planning documents.
- This will not work well with Māori – not realistic – as it will need to define next-of-kin.

Next steps: The Ministry Executive Leadership Team determined that no further action on this topic would be taken at this time.

#13: Delegation rights – advanced care planning – as originally published

The advance care planning (ACP) movement is gathering considerable momentum. Information such as whether an advance care plan exists must be available to all DHBs so a person's wishes for their final months and weeks of life are known.

Response summary

Responses	Total number	Distribution of responses			
		Government	Health sector	Non-government	Personal
This section:					
• agreed	44	1	32	7	4
• opposed	7	0	6	1	0
• no comment	23	1	9	9	4
• comments given	36	1	25	6	4

The key comments received covered the following points:

- There is a danger of scope creep in the NHI and its stated aims. Better to consider this in the context of a supporting medical system, which would require specific approval from the patient.
- Note there is a danger that people think an ACP is only for palliative care situations – it is not just end of life situations.
- Depending on what is to be captured/held, there will a large administrative task in keeping the held information up to date and available. Out of date information is possibly worse than no information.

Next steps: The Ministry Executive Leadership Team determined that no further action on this topic would be taken at this time.

#14: Cook Islands, Niue, and Tokelau NHI cross reference – as originally published

The Cook Islands, Niue and Tokelau currently use different health identification systems in their respective countries. The identification numbers used locally in these countries are different and are not linked to the NHI system in New Zealand.

Response summary

Responses	Total number	Distribution of responses			
		Government	Health sector	Non-government	Personal
This section:					
• agreed	44	1	32	7	4
• opposed	7	0	6	1	0
• no comment	23	1	9	9	4
• comments given	36	1	25	6	4

The key comments received covered the following points:

- Is there a political desire to provide this service?
- There are other ways to do this. Would it not be easier to grant 'the islands' access to the NHI rather than incorporate further information in the NZ system?
- What do the island indigenous people want? (rather than the New Zealand view)
- If done, to make it useable the islands would require online access to the NHI.
- We would need a Privacy Impact Assessment before granting offshore access to the NHI – possible cloud system?

Next steps: The Ministry Executive Leadership Team determined that this topic requires further advice and consideration. Accordingly, a working group will be established in the near future to solicit further and more focused comment.

#15: Height and weight – as originally published

Height and weight are continuous measures. Health risk increases with increasing weight for height (or with very low weight). Children (and adults) do not become obese overnight. Weight generally increases gradually. By regularly monitoring height and weight and growth, we can identify abnormal growth (crossing centile lines), and intervene earlier to prevent excess weight gain.

Response summary

Responses	Total number	Distribution of responses			
		Government	Health sector	Non-government	Personal
This section:					
• agreed	16	0	11	5	0
• opposed	29	0	22	4	3
• no comment	21	2	7	7	5
• comments given	41	1	29	7	4

The key comments received covered the following points:

- Exceeds the scope of the NHI mandate.
- Better (more useful) to record blood type.
- Height maybe but weight, no. Possibly record BMI if essential.
- Changes to weight are frequent and this would be an administrative challenge to record at each visit.

Next steps: The Ministry Executive Leadership Team determined that no further action on this topic would be taken at this time.

#16: MedicAlert cross reference – as originally published

The Foundation holds vital information for its members for prevention of avoidable harm, which in addition to information such as Conditions and Medications also includes patient centric information such as Allergies, Warnings, Implanted devices, Written Advance Directives, EPOA, POA, and Emergency Action Plans.

Access to this information could be lifesaving and including the MedicAlert ID in the NHI would assist to facilitate wide access to the data through new technologies currently in development by health providers.

Response summary

Responses	Total number	Distribution of responses			
		Government	Health sector	Non-government	Personal
This section:					
• agreed	22	0	16	5	1
• opposed	10	0	7	3	0
• no comment	24	1	11	8	4
• comments given	23	0	17	5	1

The key comments received covered the following points:

- This is based on a single provider of this service – it cannot be restricted in this fashion, ie, if 'in' then any provider of this type of service should be allowed to participate.
- There will be an additional administrative workload to maintain a good quality of information.
- It would require a formal information sharing agreement with MedicAlert – needs a Privacy Impact Assessment and input from the Privacy Commissioner.

Next steps: The Ministry Executive Leadership Team determined that this topic requires further advice and consideration. Accordingly, a working group will be established in the near future to solicit further and more focused comment.