

22 August 2018

Ted Christiansen
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Ministry of Health

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Proposed changes to the National Health Index (NHI) system and standard

Dear Ted,

The New Zealand Medical Association (NZMA) wishes to provide feedback on the above consultation. The NZMA is New Zealand's largest medical organisation, with more than 5,000 members from all areas of medicine. The NZMA aims to provide leadership of the medical profession, and to promote professional unity and values, and the health of all New Zealanders. Our submission has been informed by feedback from our Advisory Councils and Board, as well our colleagues in the wider health sector.

We are generally supportive of the changes that are being proposed. We believe that collecting data on several proposed additional areas (such as disability status, advance care planning, MedicAlert) and improving data collection in existing areas (such as ethnicity, language code) would enable better care at the point-of-care and facilitate the development of better evidence-based policies around the planning and provision of health services, including addressing inequities. We have some concerns, however, at the relevance, accuracy and meaningfulness of some of the proposed changes (such as collection of information on sexual orientation). The key requirement for the collection of identifiable health information is absolute clarity about its purpose.¹ We elaborate on our feedback in the following paragraphs.

NHI numbering extension.

We have previously welcomed work to extend the range of NHI numbers that will be available. In progressing this work, we asked that all system vendors across the health sector be consulted as to whether the proposed format change is workable. We also seek further information on the impact to providers during implementation of this change. Specifically, will there be any activity / cost that providers will be obliged to undertake or incur?

¹ Rule 1 in Health Information Privacy Code. Available from <https://www.privacy.org.nz/assets/Files/Codes-of-Practice-materials/Consolidated-HIPC-current-as-of-28-Sept-17.pdf>

Biological sex recorded at birth

Currently, the NHI does not capture sex; it only captures gender. We note that the consultation is proposing collecting biological sex recorded at birth, and including a third category “for people who are intersex”. There are concerns that the term for this third category may be inappropriate. Intersex is a medical umbrella term for a range of conditions expressed over life, not a category. International classification has moved away from pathologising identity variations. While there is a need for more data to support better health care for this community, this requires a range of information; categorising sexuality at birth is unlikely to contribute the data most needed to inform policy about the health and support services needed.

Gender Identity

We support amending the current collection of publicly expressed gender identity data to align with the Statistics New Zealand standards, but note that these are currently under review. We ask that any changes be incorporated into the proposals. Collecting more robust data on gender diversity would improve knowledge of gender diversity in the health environment and better support evidence-based decision making on the health needs of the gender diverse population.

Sexual orientation

The NHI does not currently hold information about patients’ sexual orientation. We are aware of privacy concerns at the proposed collection of this parameter, as well as challenges relating to the fluidity of sexual orientation. We are not convinced of the purpose and relevance for collecting these data. Currently, NHI data including age, ethnicity etc are routinely checked on presentation at a health service. In small, rural or remote communities, and/or in areas where there is limited opportunity to ask questions in a manner respectful of privacy, collecting data on sexual orientation is potentially challenging. There are concerns about how such disclosure would be managed with younger patients. If this parameter is to be included, we believe that a ‘prefer not to disclose’ option is essential.

Iwi Classification

While we strongly support measures that will improve the health of Māori, there are concerns about the purpose of collection of these data and who has asked for them – Māori or the Government? Furthermore, to ensure complete, accurate and meaningful information, it will be necessary to address issues such as how to record multiple iwi affiliations, whether there will be a prioritisation or privileging system as to which is listed as the primary affiliation (and how this would be decided) and what options exist for someone who identifies as Māori but does not know or does not actively identify with an iwi?

Disability status

We strongly support the proposed inclusion of additional information on disability as part of the upgrade to the NHI system. While we acknowledge that it is not possible to collect complete information on all disabilities, we believe that the proposed Washington Group Short Set of Questions on Disability (WGSS) will not provide sufficient information to usefully inform policy. The high threshold for defining disability ie, identifying “a lot of difficulty” in response to at least one of the questions, is likely to lead to a gross under-estimate of the prevalence of disability in the population. It does not capture those with disabilities who have access to assistance/aids which enable them to manage. The WGSS model also excludes psychiatric disorder/disability which are not necessarily those of cognition. It is also unclear how conditions such as autism, dementia, or unconsciousness might be represented in this model. We ask that more work be done to develop a more inclusive and useful parameter on disability.

Delegation rights – general

It is unclear whether the intention here is to signal the presence of such documents/authorities or to have the specifics accessible and linked to the NHI. If the latter, then the question is raised as to who takes responsibility for ensuring that the information is updated and maintained?

Cook Islands, Niue and Tokelau NHI cross reference

We support this proposed change which is a logical measure towards reducing duplication.

Height and Weight

We are aware of concerns about the rationale for collecting non-demographic data such as height and weight as part of the NHI when that data is variable, available elsewhere (eg, in practice management systems) and only provides a snap shot at a particular time. Given the variability in weight, it would need to be re-checked and entered at every presentation, requiring considerable additional work for variable direct benefit. Given that height and weight is already held in different patient management systems, the inclusion here appears redundant.

Medic alert cross reference

We strongly support the proposal to cross reference the MedicAlert ID in the NHI. This should expedite information gathering at the point-of-care for patients who cannot otherwise be identified or who cannot communicate.

We hope our feedback has been helpful and would like to be kept informed of this work as it progresses.

Yours sincerely

A handwritten signature in blue ink that reads "K. Baddock". The signature is fluid and cursive, with a long, sweeping tail on the final letter.

Dr Kate Baddock
NZMA Chair