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**Royal Australasian College of Physicians  
submission to the Ministry of Health**

**Proposed changes to the National Health Index  
(NHI) system and HISO 10046, the Consumer  
Health Identity Standard**

## Introduction

The Royal Australasian College of Physicians (RACP) welcomes the opportunity to submit feedback on the Ministry of Health's (the Ministry's) proposed changes to the National Health Index (NHI) system and HISO 10046, the Consumer Health Identity Standard.

The RACP works across more than 40 medical specialties to educate, innovate and advocate for excellence in health and medical care. Working with our senior members, the RACP trains the next generation of specialists, while playing a lead role in developing world best practice models of care. We also draw on the skills of our members, to develop policies that promote a healthier society. By working together, our members advance the interest of our profession, our patients and the broader community.

The RACP finds that the primary purpose of the NHI system is to hold key identifying information about individuals using health services. The NHI system enables a variety of health services (including hospitals, general practices, pharmacies and laboratories) to correctly and positively identify individuals. It has also reduced the likelihood of information being missing or incomplete, and as it is national, allows for a degree of consistency across the country. The proposed changes alter the primary purpose of the NHI system, from a central source of truth to link individuals with their identifying information, to a dataset which can inform decision-making and funding in health, social development, justice, Māori development, education and other departments as part of the Integrated Data Infrastructure (IDI).

The RACP does not comment on every proposed change; our submission is focused on those that we interpret as being essential changes to ensure relevance and application; and opportunities to eliminate inconsistencies. The RACP has identified a number of concerns related to the proposed changes, including

- Which data points are to be considered 'fixed' and which are to be updated at each encounter, and what are considered 'fluid' data Indicators
- How time-sensitive variables are recorded and whether these form a longitudinal 'time-stamped' record
- Resource implications for collection of data items and sensitivity as to who is expected to question and record them
- Reliability of connections to central NHI system, particularly if multiple data are being sought at every encounter
- How the NHI system is linked to the IDI
- How the NHI manages the potentially competing purposes of the data (decision-making and funding; tracking an individual's relative risk; as a central repository for health information and demographics)

## RACP comments on proposed changes

### NHI Numbering extension

The RACP is supportive of the changes proposed by the Ministry to extend the life of the NHI system.

Exhausting the existing supply of numbers by 2025 with no robust transition proposal in place is unfeasible. The RACP notes that the recommended alternative retains the 7-character length; requires no mapping between older format (AAANNNN) and newer format (AAANNAA); and enables NHI numbers to be in use for another 130 years.

The RACP notes the NHI is extensively used within the health sector and supports changes to make it as resilient a system as possible for New Zealand.

### Biological Sex recorded at Birth Gender Identity

The RACP supports the inclusion of biological sex recorded at birth and gender identity in the NHI system.

The RACP notes the proposed changes to move from a singular field “gender identity” to an expanded set of data identifiers of biological sex recorded at birth, gender identity and sexual orientation.

Acknowledging the fluidity and plurality of gender and sexuality is significant and enables greater recognition and inclusivity: for people with diverse gender identities, systems which include and “count” them as who they present to be, there is greater acknowledgement, visibility and authority within a system. Separating biological sex assigned at birth and gender identity into two distinct fields allows for these important aspects of an individual’s identity to be recorded as part of their health record. This is a critical issue for many New Zealanders, and the RACP supports increasing government efforts aimed at ensuring all New Zealanders are able to be counted and identified in ways which are safe and represent who they are.

For people who identify with a different gender, interactions with health services may not be culturally safe experiences. For example, people who identify as transgender may not experience equitable access, treatment or health outcomes, compared to people who gender-identify with the biological sex they were assigned at birth<sup>1</sup>  
<sup>2</sup>.

The RACP has concerns regarding data collection in categories which are dynamic and may vary over time, such as gender identity and sexual orientation. The NHI system is not designed to operate as a rolling survey (such as the annual updates to the NZ Health Survey), longitudinal data collection (as in the Dunedin Study), or provide a snapshot of a population (as in the NZ Census). All time-sensitive variables must be time-stamped at point of entry, to allow health professionals using the system to see when data was previously entered.

The Ministry’s consultation document refers to work undertaken by Statistics NZ on the inclusion of biological sex, gender identification and sexual orientation in the 2018 Census. The standard developed by Statistics NZ was ultimately not included in the 2018 Census due to concerns about the data quality and sensitivity in a self-reported questionnaire<sup>3</sup>. The media release confirming Statistics NZ would not be including questions regarding biological sex, gender identity or sexual orientation notes that “other agencies, such as the Ministry of Health, collect data about these topics”<sup>4</sup>.

In its current state, the NHI system is not used to collect data about the gender identities of New Zealanders, as the current system uses the 2015 codes of “Male”, “Female”, Other Gender” or “Unknown/unspecified”. These categories are very different to the more nuanced categories proposed by the Statistics NZ standard, and while the NHI proposed changes align with the Statistics NZ standard, it is incorrect for Statistics NZ to state that the Ministry of Health collects this data currently. Considering this information, the Ministry’s proposal appears to try to address a gap in existing data which runs counter to the status quo portrayed by Statistics NZ.

## Sexual Orientation

The RACP is not yet persuaded that the NHI system the most appropriate means and method to collect this data. The perspectives of lesbian, gay, bisexual, transgender, queer, intersex, asexual, takatāpui, fa’afafine and other orientations (LGBTQIA+) should be sought to inform this proposed change.

The RACP strongly supports the provision of equitable and safe health care for people with diverse gender identities and LGBTQIA+, and recognises that the development of policy to improve gender-affirming health care in New Zealand must be informed by robust data collection.

The RACP posits that the question in relation to a sexual orientation Identifier (and to some extent, the Identifiers for gender identity and biological sex at time of birth) is not whether or not the data should be collected; rather, is the NHI system the most appropriate means and method to collect this data?

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<sup>1</sup> Roberts TK, Fantz CR. Barriers to quality healthcare for the transgender population. Clin Biochem [Internet] 2014; 47(10-11):983-7. <https://www.ncbi.nlm.nih.gov/pubmed/24560655>.

<sup>2</sup> Riggs DW, Coleman K, Due C. Healthcare experiences of gender diverse Australians. BMC Public Health. 2014; v14. Available from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3973980/>.

<sup>3</sup> Statistics NZ. 2018 Census report on final content. Wellington: Statistics NZ; 2017. Available from <https://www.stats.govt.nz/methods/2018-census-report-on-final-content>.

<sup>4</sup> Statistics NZ. Sex, gender and sexual orientation. Updated 25 January 2018. Available from <https://www.stats.govt.nz/reports/sex-gender-and-sexual-orientation>.

As highlighted above, the NHI is not designed to operate as a population Census, or as a sample population (to be generalised for the total population). If the intention is for the NHI database to contribute to the Integrated Data Infrastructure (IDI), this is not immediately apparent – the IDI is referred to in regard to iwi and disability Identifiers, but no others in the proposed changes. However, the RACP notes that the consultation documents state that sexual orientation data will inform policies and programmes in health “as well as areas such as social development and justice”<sup>5</sup>. Further, the NHI system is not included in the Data in the IDI summary infographic published by statistics NZ in June 2018<sup>6</sup>.

LGBTQIA+ communities have advocated for questions on sexual orientation to be included in health surveys as a means to understand the health risks, behaviours and outcomes they face, and for this data to inform policies and programmes designed to improve health outcomes<sup>7 8 9</sup>. While there are benefits and value for this data to be added, there are inherent risks when sensitive information is disclosed. These include the possibility that identifiable data is extracted to inform other sectors, such as Social Development and Justice, as identified in the consultation document. How information is secured and how it is accessed will require review, as the sensitivity and breadth of potential data included in the NHI is expanded.

## Ethnicity

The RACP supports the proposed changes to the Ethnicity identifier. That the RACP recognises that quality ethnicity data in healthcare is essential in achieving equity and monitoring equitable delivery of services. The RACP encourages accuracy in current NHI ethnicity dataset through widespread recording of Level 4, self-identified Identifiers over and above any additional proposed changes.

Ensuring consistency across other datasets (such as the National Enrolment service, as stated in the consultation document) as well as offering researchers a degree of qualitative data by including text fields rather than only numerical fields, are benefits which can be derived from the proposed change.

The document notes that the proposed changes to the Ethnicity identifier will improve the “quality of information upon which decisions are made – for example: funding allocations and the assessment of the equality of treatment”. The RACP contends that rather than equality of treatment (everyone receives the same health care services and treatment), variables such as ethnicity should inform evidence of equity of outcomes.

## Iwi Classification

The RACP strongly supports the proposal for the NHI to include iwi as a core variable/attribute, and encourages the Ministry to prioritise this Identifier.

Māori are tangata whenua and Treaty Partners; for government agencies to engage effectively with Māori, plan services and respond to the health needs of their communities the NHI must record iwi affiliation, and include multiple fields to allow people to include all iwi to which they whakapapa.

The RACP strongly recommends the Ministry considers the impact of all proposed changes on Māori from an Indigenous Data Sovereignty perspective; “missing from those conversations have been the inherent and

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<sup>5</sup> Ministry of Health. NHI Standard Update May June 2018 consultation document. Available from <https://consult.health.govt.nz/hiso/proposed-changes-nhi-hiso10046/>.

<sup>6</sup> Statistics NZ. Overview of current IDI datasets. June 2018. Available from [http://archive.stats.govt.nz/browse\\_for\\_stats/snapshots-of-nz/integrated-data-infrastructure/idi-data/idi-data-overview.aspx](http://archive.stats.govt.nz/browse_for_stats/snapshots-of-nz/integrated-data-infrastructure/idi-data/idi-data-overview.aspx).

<sup>7</sup> Sell RL, Holliday ML. Sexual orientation data collection policy in the United States: Public Health Malpractice. Am J Public Health [Internet] 2014; 104(6): 967-69. Available from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4061997/>.

<sup>8</sup> Semlyen J. Recording sexual orientation in the UK: pooling data for statistical power. Am J Public Health. [Internet] 2017; 107(8):1215-1217. Available from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5508175/>.

<sup>9</sup> Callander D, Bourne C, Pell C, Finlayson R, Forssman B, Baker D. Recording the sexual orientation of male patients attending general practice. Fam Pract [Internet] 2015; 32(1):35-40. Available from <https://www.ncbi.nlm.nih.gov/pubmed/25236604>.

inalienable rights of indigenous peoples relating to the collection, ownership and application of data about their people, lifeways and territories”<sup>10</sup>.

The inclusion of an Iwi Classification Identifier requires open, supportive and ongoing engagement with iwi, Te Mana Raraunga the Māori Data Sovereignty Network, the Data Iwi Leaders Group and Māori academics to ensure that protocols for this Identifier and others meet the needs of whānau, and have appropriate protection of the data. The RACP views the equitable participation and expert engagement Māori in the co-design and implementation of the change as fundamental to its success, and not a negotiable factor as suggested by the consultation document.

## **Disability status**

The RACP supports the proposed inclusion of Disability status as an Indicator in the NHI system.

The inclusion of Disability status will enrich the existing data on disability in New Zealand, particularly regarding unmet need, how the needs of people with disabilities change over time, and how policies and programmes improving the health and wellbeing for disabled people. Quantitative data will lead to improvements in monitoring the implementation of the New Zealand Health Strategy, the New Zealand Disability Strategy and New Zealand’s reporting to the United Nations on its obligations under the Convention on the Rights of Persons with Disabilities.

The RACP does note that Disability status is a time-based variable, and one that would be particularly reactive to age-related changes, such as difficulty seeing or hearing, despite using glasses or a hearing aid. The proposed questions are based on the Washington Group Short Set (WGSS), which were also included in the 2018 Census.

## **Opt-out status indicator**

The RACP finds the proposed opt-out status indicator and to what it applies unclear.

Further, the wider interpretation of an opt-out clause may cause confusion. For example, in what ways does the opt-out status interact with the introduction of a “prefer not to disclose” clause in relation to sensitive data indicators? If a person enters “prefer not to disclose” in relation to their sexual orientation (for example), is this response included in data extracted for use by a third party, or does a person have to enter “prefer not to disclose” as well as “opt-out” to ensure their data is not made available?

While the use of an Opt-out status indicator is cited as being “traditionally very low” in the consultation document, its inclusion as an option introduces the risk of some datasets being less complete than others – particularly those that may include more sensitive information (sexual orientation, gender identity, advance care planning, etc.), as there is a risk for a two-tiered system to be introduced. The RACP encourages the Ministry to consider carefully how this Indicator might be implemented, and how its use is communicated to users, including researchers.

## **Delegation rights – General**

### **Delegation rights – Advance Care Planning**

Delegation rights, or a record of authority were supported by members of the RACP, but noted that caution was needed to ensure that records remained current; like other variables, there is potential for change as to who is assigned delegated authority.

The RACP is supportive of the proposed change to incorporate an Indicator for Advance Care Planning (ACP), but acknowledges that further information is required to inform health professionals and patients how it will be integrated, and how the information would be used. Our 2016 discussion document, Improving Care at End of

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<sup>10</sup> Kukutai T, Taylor N (eds). Indigenous data sovereignty: towards an agenda. Research monograph No. 38. Canberra: Centre for Aboriginal Economic Policy Research, College of Arts and Social Sciences; 2016.

Life: Our Roles and Responsibilities identifies core skills in communication, facilitation, planning and management for the provision of good end of life care<sup>11</sup>. We find that clinicians should be able to:

- Provide clinical leadership to sensitively, openly and honestly discuss and document prognosis, treatment, end-of-life care and the patient's preferences, needs and values.
- Actively seek to understand the wishes of patients nearing the end of life who are no longer capable of expressing them, including seeking documentation of advance care planning and consulting with family/whānau and carers
- Facilitate (or participate in) ACP discussions with patients and their important others, and assist with documentation of patient wishes if the patient so chooses. This includes communication and coordination with other treating health professionals such as General Practitioners.
- Commit to reviewing end-of-life care plans as these may change over time, taking into consideration the trade-offs between right place of care and other factors such as good symptom management and burden on family/whānau.

The RACP notes the current proposed changes regarding ACP in the discussion document state that the political implications are minimal. Currently, ACP is well-supported by the health sector and backed by a robust international evidence base, but there is not a singular, centralised means of knowing if a person has an ACP in place. The proposed changes to the NHI system goes some way to mitigate this variance.

While ACP is increasingly a part of the patient journey and forward planning for family and whānau to acknowledge the wishes of their loved one, the RACP recommends that there are measures put in place to ensure that ACP is not conflated with euthanasia. The RACP acknowledges that patients may raise these matters in the context of an ACP discussion; but for clarity states that the following actions do not constitute euthanasia or physician-assisted death:

- a) Refusing life-sustaining treatments: patients with capacity have the right to refuse treatment including the provision of medically assisted nutrition and/or hydration.
- b) Withholding or withdrawing treatments that are not benefiting the patient: physicians have a duty to consider the benefits and harms of any treatments including the provision of medically assisted nutrition and/or hydration before instituting them. The benefits and harms of ongoing treatment should also be regularly reviewed. They should not be provided if they are not offering benefit to the patient.
- c) Providing appropriate palliative sedation to manage refractory symptoms.
- d) Titrating treatment to relieve symptoms<sup>12</sup>.

## Height and Weight

The RACP supports the proposal for height and weight being a data Indicator in the NHI system.

In the RACP's position statement on obesity (2018), our recommendations included<sup>13</sup>:

- The Ministry of Health in New Zealand embeds a consistent national growth standard for child development based on the WHO standards and definitions for obesity

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<sup>11</sup> The Royal Australasian College of Physicians. Improving Care at End of Life: Our Roles and Responsibilities. A discussion document. Sydney: The Royal Australasian College of Physicians; 2016. Available from <https://www.racp.edu.au/advocacy/policy-and-advocacy-priorities/end-of-life>.

<sup>12</sup> Ibid.

<sup>13</sup> The Royal Australasian College of Physicians. Action to prevent obesity and reduce its impact across the life course. Sydney: The Royal Australasian College of Physicians; 2018. Available from <https://www.racp.edu.au/advocacy/policy-and-advocacy-priorities/obesity>.



The RACP recommends the height and weight of children and young people aged 0-19 is plotted against the WHO Growth Standards and Reference Points for underweight, healthy weight, overweight and obesity. In the NHI system, the RACP recommends the Ministry of Health uses these growth standards.

- Clinical guidelines for weight management of adults incorporate monitoring of weight as a vital sign to prevent age-related weight gain

The RACP recognises the importance of early intervention to reduce the risk of people developing chronic, life-limiting conditions which impact their wellbeing and quality of life. Obesity is a risk factor in an extensive list of noncommunicable diseases, including cardiovascular disease, type 2 diabetes, several common types of cancer, obstructive sleep apnoea. People with obesity may experience musculoskeletal conditions and chronic pain, and osteoarthritis. People with obesity may also live with depression, anxiety or other mental health conditions<sup>14</sup>.

The RACP has highlighted gaps in the existing infrastructure for recording height and weight with the Ministry, notably on the absence of a national comprehensive, consistent standard for recording child growth and development. The RACP has recommended the Ministry make a decision to use the World Health Organization (WHO) Growth Standards and Reference charts for growth and body mass index (BMI) cut-offs for children aged 0-19 years. Currently, District Health Boards (DHBs) capture height and weight data in a variety of practice management systems; channelling all data on height and weight to the NHI will standardise where data is stored may remove some of the existing technical difficulties in allowing systems to communicate to each other.

The consultation document implies that height and weight will be able to be monitored over time using data input into the NHI system. It is essential that all time-sensitive variables entered into the NHI system are time-stamped accordingly.

We note that height and weight are variables which change over time. Many people will have episodic interactions with the health system, and may go long periods of time with no contact with any level of health care services. While this may be because they are generally well and manage their own health care needs, it may also be due to the cost and expense of accessing care. The New Zealand Health Survey shows that 14.3 per cent of New Zealanders were unable to access a General Practitioner due to cost in 2016/17<sup>15</sup>. At a population level, data on height and weight may not be as robust as other Indicators for use in third party research studies, as the NHI is not designed to function as a health survey, longitudinal study or Census. This may impact some of the intended proposition value, such as being able to track national-level weight changes over time for some ethnicities, and regional and local data.

## Other areas for development

### Smoking status

According to the New Zealand Health Survey, in 2016/17 around 15.7 per cent of New Zealanders identified as current tobacco smokers, with 13.8 per cent of these people smoking daily<sup>16</sup>. New Zealand has a goal of Smokefree 2025 – where less than 5 per cent of New Zealanders are current smokers. While some progress is being made, a health equity approach is needed to ensure that all groups experience the improved outcomes and health benefits derived from smoking cessation. Smoking status is a powerful indicator of an individual's

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<sup>14</sup> Ibid.

<sup>15</sup> Ministry of Health. New Zealand Health Survey: Annual update of key results 2016/17. Available from [https://minhealthnz.shinyapps.io/nz-health-survey-2016-17-annual-data-explorer/ w\\_b0823295/#!/explore-topics](https://minhealthnz.shinyapps.io/nz-health-survey-2016-17-annual-data-explorer/ w_b0823295/#!/explore-topics).

<sup>16</sup> Ministry of Health. New Zealand Health Survey: Annual update of key results 2016/17. Available from [https://minhealthnz.shinyapps.io/nz-health-survey-2016-17-annual-data-explorer/ w\\_b0823295/ w\\_9d099802/#!/explore-topics](https://minhealthnz.shinyapps.io/nz-health-survey-2016-17-annual-data-explorer/ w_b0823295/ w_9d099802/#!/explore-topics).

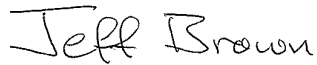
overall health, and until recently was the greatest risk factor for health loss for New Zealand adults (attributable to 8.7 per cent of overall health lost), when it was overtaken by high BMI at 9.3 per cent<sup>17</sup>.

There is currently no Indicator for tobacco use (current or in the past) in the NHI system. The RACP encourages the Ministry of Health to add smoking status to the NHI, to align with recent New Zealand Censuses, and to ensure a degree of consistency at a national level, if Censuses are undertaken with decreased frequency in the future.

## Conclusion

The RACP thanks the Ministry for the opportunity to provide feedback on this consultation. To discuss this submission further, please contact the NZ Policy and Advocacy Unit at [policy@racp.org.nz](mailto:policy@racp.org.nz).

Yours sincerely



NZ President  
**The Royal Australasian College of Physicians**

**Attached for information:** Kukutai T, Taylor N (eds). Indigenous data sovereignty: towards an agenda. Research monograph No. 38. Canberra: Centre for Aboriginal Economic Policy Research, College of Arts and Social Sciences; 2016.

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<sup>17</sup> Ministry of Health. Health loss in New Zealand 1990-2013. A report from the New Zealand Burden of Diseases, Injuries and Risk Factors Study. Wellington: Ministry of Health; 2016. Available from <https://www.health.govt.nz/nz-health-statistics/health-statistics-and-data-sets/new-zealand-burden-diseases-injuries-and-risk-factors-study>.