Hauora Health Privacy Working Group

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Sent by email to: standards@health.govt.nz

The Hauora Health Privacy Working Group of the Privacy Foundation of New Zealand provides the following response to consultation on the draft standard HISO 10099:2022 NZ International Patient Summary (NZIPS).

We welcome the opportunity to comment. We set out the questions from the online survey with our responses as follows:

Purpose and scope

Question 4. Are the opening pages of the document clear about the purpose, scope and origin of the NZIPS – what would you change?

No, we found the opening pages of the document confusing about the purpose, scope and origins of the NZIPS. Despite the section headings on pages 3-6, it is difficult to come to grips with the concept of the NZIPS, the standard and its proposed and potential future uses. This is because multiple points are covered for scope and purpose, in amongst a plethora of technical language and references.

Opening and Introductory information

We recommend the opening content is reordered and structured so that there is information given on:

1. The origin of the NZIPS and its current position – providing greater context on the need for the NZIPS.
2. What the NZIPS is. (And what it isn't)
3. How the NZIPS fits within the digital health framework and ecosystem.
4. How it will be operationalised – on the Hira platform
5. Defined primary use cases and secondary use cases in the first edition of NZIPS.
6. Potential future primary and secondary uses in subsequent editions and the long term objective of NZIPS
7. Summaries of what this means for consumers and clinicians.
8. Preamble

In discussion of purposes, and primary and secondary use cases of the NZIPS, it must be made clear what data will be available to be viewed in the NZIPS – i.e. a summary of current patient data/health status and not a longitudinal clinical or lifetime record. This clarity should help manage consumer expectations and concerns.

The use of NZIPS to replace GP2GP adds further confusion as to what data will be transferred. In that use case, is it a summarised version of everything on the clinical record or a summary of most important and/or recent data?

The draft standard is also confusing with its inconsistent use of terminology. In parts it is not clear whether terms are being used interchangeably and what the terminology means, such as 'core' personal health information, 'most important' health information, patient summary, and summary of current health status, and what 'recent' means in terms of recent health encounters.

We recommend that a glossary is included so that terms are clearly defined and understood by all stakeholders, and particularly consumers.

Digital transformation and relationship with Hira

Ultimately it would assist comprehension if there were simple infographics on how the NZIPS fits within other areas of the digital health system and especially its relationship with/dependence on Hira. We would like to see more in this regard, to give greater understanding of context and show the multiple touchpoints of the NZIPS.

Information on Use Cases

We would be concerned if the NZIPS is allowed to evolve to be the 'go to' clinical record by default. Steps need to be put in place to prevent this from happening as so much contextual and qualitative information about the patient will be missing. Clear expectations should be set for the primary use cases, with a specific focus on unscheduled/unplanned care and consumer access.

In line with the Health Information Privacy Code, clearly defined primary purposes for the collection, use and disclosure of health information need to be set. We are wary of 'scope creep' or other secondary purposes not being clearly defined and made transparent to consumers.

Consumer access to personal information

Given one of the main and high priority use cases for NZIPS is consumer access to personal information, it is unclear at this point how NZIPS will/may prescribe the format in which that information will be available to consumers accessing it via the Hira platform. We recommend that specific information is given about the Hira ecosystem so that the setting and connection is clear.

Providing further details about Hira should also provide better context for another use case simply referred to in the consultation document on page 12 as "*Hira use cases*".

Te Tiriti and health equity

Question 5. Let us know if you represent a Māori group or have suggestions to improve this standard from a Māori-Crown, te ao Māori or equity viewpoint.

We acknowledge the importance of working in partnership and through respectful connection, and that individual privacy rights need to be balanced with those of groups and collective rights.

Whilst we are not in a position to contribute specifically, we suggest that primary use cases of the NZIPS should clearly focus on kotahitanga, showing the ways in which the NZIPS will function to then derive individual and collective benefits.

Interoperability Roadmap

Question 6. Do you have any comments on the roadmap or its connection with NZIPS (pages 9-10)?

We support the NZIPS being a deliverable of the Roadmap. However, we have noted that outside of the specific health setting there is the development of a consumer data right (CDR), providing a mechanism for consumers to securely share data held about them with trusted third parties. We query how the Roadmap may overlap with a CDR and how this has been considered.

Privacy rights and principles are also relevant in this context, for example where the right of access to personal and health information is specifically enshrined in law. We expect that in considering interoperability as part of the development of the NZIPS that explicit consideration has been given to the privacy context, to avoid any conflict or overlap with privacy rights.

Requirement for SNOMED CT

Outside of the specific survey questions to confirm familiarity with SNOMED CT, we wish to comment as follows:

We support use of SNOMED CT in the NZIPS to provide a single clinical language, but are concerned there may be clinical risks, particularly at point of care, if there is over-emphasis on SNOMED codes and their reliability is overstated. It is not a certainty that the SNOMED CT Codes will be used consistently and correctly and allowances need to be made for this.

Further, there is a very real risk that the wrong care or treatment may be perpetuated if there is an absolute reliance on the data available in NZIPS; that it is infallible. Patients may not want to tell the same story repeatedly; however, clinicians have a professional duty to assess and check, not just accept coded data on the screen without question.

NZIPS Use cases

Question 11. Select the top 3 use cases for the NZIPS.

Use cases: Consumer access to personal health information; Patient record transfer; Patient summary of unplanned care; COVID patient care in the community; Minimum data set for public health and population health

1. Patient summary for unplanned care

2. Consumer access

3. Covid patient care in the community – noting that this is already a use case.

Our further comments here:

- The next preference is for Patient Record Transfer as it replaces an existing use; subject to clarification about data to be transferred as discussed earlier.
- We require further information about what may comprise the Minimum data set for public health and population health.

Q12. Tell us about any other possible use of the NZIPS you see as important.

Given that data will be more readily available for statistical, analysis, reporting and research purposes we query how use of NZIPS data may be considered/used in the research context. Use for research purposes must have absolute clear boundaries, and we expect clear requirements for transparency and accountability to be documented and published (similarly for any use for Public Health and Population Health purposes).

Adoption of the Standard

Q13. Let us know what for you would be a reasonable approach and timeframe for adoption of the standard.

We are not in a position to comment on the timeframe for adoption of the standard. However, we expect that consumers will be involved in the trial proposed as part of adoption of the standard.

Content Areas

Q14. Of the content areas making up the first edition of the NZIPS, which are the five most important to you?

Content areas: Demographics; Problems; Medications; Allergies and adverse reactions; Immunisations; Smoking and vaping; Measurements and vital signs; Diagnostic results; Care plans; Recent encounters

1. Demographics
2. Medications
3. Allergies and adverse reactions
4. Diagnostic results
5. Problems

Q15. For a second edition of the NZIPS, which three content areas would you add?

Content areas: Care team; Procedures; Advance care plan; Advance directives; Child health; Medical devices; Family history; Genomics

1. Care team
2. Procedures
3. Advance care plan

Further Comments

- Possibility of combining Advance care plan and advance directives but this would depend on what is intended re data set specification
- Medical devices – implantable devices
- Genomics – the scope is potentially very broad

Data Set Specification

In each area, we seek your comments to tell us where anything has been missed, seems to be superfluous or could be improved. It may be useful to ask whether the data set could be populated in your setting today or whether something needs to be done to get us there.

Q16. Demographics (pages 17-18)

We note the wording in the text at the top pg 17 needs to be changed to align with wording in Pae Ora (Healthy Futures) Act. We suggest – *"…….for everyone receiving ~~public~~ publicly funded health services".*

We link to our comments below at question 26 - noting that individuals may want certain data elements under this data set to remain confidential and not be visible, given the sensitivities around the data and/or to protect individual safety. E.g. gender, address, contact details. There must be a process for 'blocking' or withholding data if consumers choose to do so.

Q17. Problems (pages 19-20)

In recording long term/permanent conditions under problems, we are especially concerned about people with disabilities - if and/or how their impairments will be 'codified' so that the whole person is fairly represented and considered in an inclusive and appropriate way without simply 'clinicalising' or medicalising the individual. Have the views of the disability community been sought?

Where sexual and/or reproductive health data points and information are recorded, there must be a process for these to be blocked or withheld by consumers if they choose to do so

Q24. Care Plans (page 31)

Where all the data here is represented by SNOMED data coded elements, patients and whānau must be able to understand these codes, otherwise the care plan(s) is meaningless.

Q25. Recent Encounters (page 32)

Patients are likely to have an understanding of what an encounter is in their everyday world but may be puzzled, confused or even alarmed by the use of 'encounter' in this setting; "Disposition encounter" is doubly confusing. While these may be standard terms in the health standards environment, we recommend that both 'encounter' and "recent" are defined.

Any other comments

Q26. Let us know any other thoughts you have

<u>Population Health and Public Health purpose and adding clinical data to the NHI for this.</u>

We note in the document that a purpose of the NZIPS is to inform work to define a standard primary care data set for public health and population health purposes, **and** a high-level use case is to provide a minimum data set for public and population health purposes.

It is not clear whether these are interrelated, or the same outcome is sought. We recommend that an explanation is given of the above.

Addition of clinical data to the NHI and NES

We are extremely concerned that it is proposed to add clinical data to the administrative data held in the NHI and NES for public health and population health purposes. No information is given as to what clinical data is proposed and the justification for its inclusion.

Clinical information has never been recorded on the NHI and for many years the Ministry of Health has made it very clear/assured New Zealanders that no clinical information is held on the NHI. This proposal intends to change the long standing social contract with New Zealanders, risks moving the NHI even further away from its original purpose as an identity tool and has the potential to undermine public confidence and trust in the NHI.

Allowing clinical data to be added to the NHI will open up a floodgate of requests for further clinical information to be added because the NHI appears to be seen as a convenient data repository. We are opposed to this proposal and strongly recommend that an alternative data repository to the NHI be used for the requisite clinical information.

We note the NES is the single source of enrolment data informing Capitation Based Funding (CBF) calculations. The addition of clinical data for a population and public health data set would add a new purpose to the NES which has not been explained and/or justified. This is a concern.

Ability to block or withhold information

The right of patients to be respected and to have their data treated with respect is critical. It is important that their right to have meaningful control of their information is enabled.

As noted earlier, there must be a process by which individuals can make information confidential, or withhold it, if they do not wish to have it shared. The background information to the Standard should at the very least, acknowledge this, and indicate that relevant information about the process will be the responsibility of the Hira programme.

Accuracy and currency of information

We recommend that information is included in the opening section of the document to explain the data sources that provide the data sets (again noting links and connections to Hira as necessary), and how accuracy and currency of the data are ensured.

Patients and consumers will need to clearly understand the pathway for correction of data.

Emphasis on individuals and a patient centred approach

The fundamental relationship between health care provider and patient is one of trust. Anything that undermines this trust will impact detrimentally on the outcome. The development of the NZIPS must take into account each patient as an individual.

We are concerned that the drivers of interoperability and digital ease could overshadow the individual patient and care relationships. We would like to see specific public input and other information that demonstrates the commitment to data as taonga, and shows how information is being/will be understood and respected.

For any specific stakeholder groups with special interests, we recommend these be specifically and individually identified, and each then assessed for whether the current design accommodates or supports these. What is documented can then be made available to the public.

In preparing our comments on the NZIPS, it is acknowledged that ultimately a number of the areas we have raised are within the scope of the Hira and will need to be addressed under that programme, however it is apparent that the NZIPS and Hira do not stand in isolation of each other.

Submitted by Rebecca Hawkins, on behalf of the Hauora Health Privacy Working Group.