Response ID ANON-V12Z-6UWW-C

Submitted to HISO 10099:2022 NZ International Patient Summary (NZIPS)
Submitted on 2022-06-01 08:06:13

Introduction

1 What is your name?

Name:
Emily

2 What is your email address?

Email:
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3 What is your organisation?

Organisation:
University of Auckland

Purpose and scope

4 Are the opening pages of the document clear about the purpose, scope and origins of NZIPS - what would you change?

Purpose and scope:

anchored on recognised international standards "and being patient/whānau centered" . . .or, something, highlighting how this will have whānau and people at the core.

Te Tiriti and health equity

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

Māori-Crown, te ao Māori or equity viewpoint:

By translating most/all of the core concepts . . . or at minimum, starting with the concepts of kaupapa, will only enhance this project. Starting with Te Ao Māori concepts always enhance and improve non-Māori concepts. After-all, Hira is a concept that has enhanced the english words of 'an information system'! I am non-Māori, but always strive to be Māori guided and informed.

Interoperability Roadmap

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

Your comments on the roadmap:

Requirement for SNOMED CT

7 If you're someone who supplies or procures health software, are you familiar with the requirement for SNOMED CT?

Not applicable

8 Which of these resources are you aware of supporting SNOMED CT implementation?

9 Would you like to be added to our SNOMED CT mailing list?

Tick the box to be added:
No

10 Would you like a call to discuss SNOMED CT implementation with our team?

Tick the box to be contacted:
No

NZIPS use cases

11 Which of these use cases are most important to you? Select your top three.

Use case ranking - Consumer access to personal health information:
1

Use case ranking - Patient record transfer:
2

Use case ranking - Patient summary for unplanned care:

Use case ranking - COVID patient care in the community:

Use case ranking - Minimum data set for public health and population health:
3

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

Other possible use of the NZIPS:

Singular, dynamic (pull/push/source-of-reconciliation), Longitudinal Plan of Care: this tool, as described in literature, does not fully exist yet and it would be amazing if NZIPS could lead the world. This is NOT single 'Plans of Care' per problem, but a single and dynamic process that changes with changes in care, centered on patient-derived goals.

Adoption of the standard

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

Your comments on approach and timeframe for adoption:

Content areas

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

Content areas ranking - Demographics:
1

Content areas ranking - Problems:
2

Content areas ranking - Medications:
3

Content areas ranking - Allergies and adverse reactions:
5

Content areas ranking - Immunisations:

Content areas ranking - Smoking and vaping:

Content areas ranking - Measurements and vital signs:

Content areas ranking - Diagnostic results:

Content areas ranking - Care plans:
4

Content areas ranking - Recent encounters:

15 For a second edition of NZIPS, which three content areas would you add?

Content areas future scope - Care team:
1

Content areas future scope - Procedures:

Content areas future scope - Advance care plan:
2

Content areas future scope - Advance directives:

Content areas future scope - Child health:

Content areas future scope - Medical devices:

Content areas future scope - Family history:
3

Content areas future scope - Genomics:

Data set specification

16 Demographics (pages 17-18) - your comments

Demographics - your comments:

Fabulous that this is ONLY section with a value domain of 'text' under Gender description. Most sections will need an unstructured section, so delighted this precedent is set here. Unstructured may need to be character-limited, as of course structured is so important. However, it is the unstructured where the patient/person narrative is, and so is vital to this project. AI and other digital tools can help analyze meta-unstructured data, which will be rich and informative.

Finally, I assume that under 'Ethnic group code', there is the option of selecting multiple codes.

17 Problems (pages 19-20) - your comments

Problems - your comments:

Ironically, there is mention of 'person and their whānau . . . repeating their health story', and yet there is no value domain for a personal story. Please, Please, PLEASE . . we MUST have a value domain of 'text' for 'Problem'. This unstructured field is vital to convey HOW a diagnosis was arrived at (e.g., 'IHD': NSTEMI 1991, STEMI 2005 with CABAG x 4') This unstructured field is the quick, succinct information a clinician needs . . . rather than scrolling thru multiple entries for all individual events associated with the Problem code of 'IHD' . . .If I read this quick free-text narrative, unique to a person, when they present to me with new chest pain, I might get phone advice from an on-call cardiologist for medical treatment rather than immediately calling the ambulance. Patients cannot often summarize complex care they've received over the last decade or more. Great to have 'Problem manifestation code' as an option, though this language will likely need to be more user-friendly. There are important Problem codes that are signs or symptoms . . . this, too, will need unstructured to summarize where the patient is at: "recurrent abdo pain" - narrative 'H Pylori excluded 1995, endoscopies nad 2000, imaging nad 2005' . . .this summary would help me decide what, if anything, needs re-investigating (e.g. H Pylori).
Finally, Problem lists often are 'Active' vs 'Inactive' . . with the 'inactive' not always having a resolution date. Another key thing in Problem lists are 'highlighting' important 'inactives' such as past cancers. Not sure if these needs to be in data set, but 'active' vs 'inactive' for 'highlighted' are more important to me as clinician than 'resolution date'.

18 Medications (pages 21-22) - your comments

Medications - your comments:

Again, I'd prefer an unstructured field for what has long been part of prescribing: "Sig" is short for the Latin "signetur." This means "let it be labeled." This is where I use patient's own words to describe what a treatment is for, and how it will be used in their case. It is not on every script, but this is an important patient-facing piece. Other clinicians can then say, "so, the medication that is for x" . . . and use the patient's own words . . . across settings!!! That would be magic. Medication names, especially generics, are mouthfuls even for clinicians.

19 Allergies and adverse reactions (pages 23-24) - your comments

Allergies and adverse reactions - your comments:

Again, need an unstructured field, please. Just one, can be character limited. There will be some reaction that is really important, that cannot be structured.

20 Immunisations (pages 25-26) - your comments

Immunisations - your comments:

This section just highlights to me that lots of fields are possible for each set . . so, please, please at least 1 x unstructured field for each set!!! I'm not a vaccinator, so not sure if free-text required for immunizations, but maybe??

21 Smoking and vaping (pages 27-28) - your comments

Smoking and vaping - your comments:

For both, I usually document amount on a date, as a way to track usage for a patient. This would, also, require a free-text field (e.g., Smoker: 20g/week May 2022). Free-text also means can define loose tabacco that's measured in grams vs tailor-made, which is number cigs/day. OR, 'smoker: 'smokes 5-10cig/week with etoh' Also, definitely need to ensure field exists for 'never smoker' as this doesn't exist in the PMS I'm using . . .

22 Measurements and vital signs (page 29) - your comments

Measurements and vital signs - your comments:

The only place only structured is probably accurate ;) The only reading that is caveat-ed that I can think of is oxygen saturation which may be either on 'room air' or on 'oxygen x %'.

23 Diagnostic results (page 30) - your comments

Diagnostic results - your comments:

Will this include radiology reports? Those are lots of unstructured text.

24 Care plans (page 31) - your comments

Care plans - your comments:

Though I feel strongly about unstructured text in almost every dataset, it is MOST important for care plans . . . 'Patient Goal' at minimum, as this is the core of what we are trying to achieve . . .empower people and their unique stories. Research abounds that clinicians look for the 'impression' summary from another clinician that is unstructured, because we are humans and we understand and synthesis information best in narrative form . . . NOT scrolling through lines and lines and lines of structured data. So, this set needs likely two key unstructured text value domains: 1) Patient Goal and 2) Impressions/clinician summary and recommendations. Also, if this were to be truly patient-centered, an individual care plan (e.g., encounter note, referral, discharge summary) will START with the patient's complaint . . . which might be a range of symptoms, best summed up in a free-text, character-limited value domain . . . then have (often) multiple problem codes for a single encounter (e.g., 1) chest pain ?COPD ?GORD ??cardiac/PE ??anxiety; 2) sore leg ?DVT ??injury; 3) unknown CVD risks). . .and ENDS with a free-text, character-limited Clinician summary/impression and, ideally, the recommended actions. . . .some of which are easily structured like lab form request, some which is NOT well structured (e.g., 'discussed with patient about safety plan when they are at home without access to transport). As this section is so important, I think more fields are required (look how many immunizations have!) . . .the 'encounters' data set could actually be pulled from the care plan set to reduce data entry for clinicians. Finally, please, please, work towards this set being part of a future 'single dynamic longitudinal plan of care', as I've described previously . . . as, our digital RAM and hardware is going to be saturated with a plethora of care plans for an individual patient, with tons and tons of repetition of structured data, that is near impossible to search thru, if we are not careful . . . the scenario of 30 + care plans per patient is the status quo in the US . . a nightmare to be avoided.

25 Recent encounters (page 32) - your comments

Recent encounters - your comments:

as above . . .

Any other comments

26 Let us know any other thoughts you have

Other comments:

Definitely keen to be part of this conversation, and how the final NZIPS data element specifications are decided.