NHI Standard Update – May June 2018

1. NHI Numbering Extension:

Background

1.1. What change is wanted, why and why now

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 to 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 7 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.

This option will:

- minimise the impact on sector systems (ie. it can be contained within the same space and within the same database field size as the existing identifier);
- maintain a similar look to the existing identifier;
- reduce the potential for issuing NHI numbers containing offensive expressions;
- require changing the present (modulus 11 based) check digit calculation to a modulus 24 approach;
- preserve the "Z" range of numbers as test identifiers.

Under this proposal and at current allocation rates, there would be sufficient NHI numbers to last another 130 years.

1.2. Effect of the change – local, national, other sector agencies

NHI numbers are used pervasively throughout the health and disability sector and systems are designed for a seven digit sequence. Because the identifier is used so widely and in so many systems there will be a significant programme of change required to update systems to use a new number format. It is important that this change is signalled early to provide the sector with sufficient lead time to investigate and implement required changes.

The Ministry is aware of the change implications and has recommended an option that is intended to minimise the burden on downstream systems and processes.

Considerations

1.3. Political implications

There are no immediate political implications from this action, although the failure to plan for the extension may have significant consequences longer term.

Public comment was sought on the proposed format change in late 2017. The comments received indicated a general acknowledgement of the issue facing the NHI and a high level of support for the proposed format change.

1.4. Privacy Act/Code implications

There are no privacy implications from this action. The NHI number already exists and is widely used. Assignment of NHI identifiers is governed by the Health Information Privacy Code.

1.5. Proposition value – locally/nationally

This action will safeguard the use of the NHI as a national patient identifier for next 100 plus years.

1.6. Cost and time implications

The change to the NHI system itself is relatively minor and can be implemented as part of the NHI upgrade 2018/19 project. There will however be a large number of client systems that need to be modified to accept the new NHI format. This change must be signalled early to provide the sector with sufficient lead time to investigate and implement required changes.

1.7. Adoption/Implementation implications

The time it will take to roll out the change is important. Implementation will almost certainly leverage the NCAMP process (National Collections Annual Maintenance Programme). Such changes are only undertaken annually (on 1 July) and as part of a pre-agreed schedule, although since the existing NHI format will be supported in parallel there is a degree of flexibility in when the sector implements support for the new format. However, a definitive implementation date must be communicated to ensure that systems and processes are properly prepared for the eventual transition.

2. Biological Sex recorded at Birth:

Background

2.1 What change is wanted, why and why now

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. This change would be implemented once the standard has been reviewed, expected to be later in 2018/2019. Adhering to the data standard would support data collection aligned with other government data sources.

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.

2.2 Effect of the change – local, national, other sector agencies

A clear understanding of the nature and extent of the issues facing intersex people across New Zealand is necessary for the development of comprehensive and evidence-based policies and practice.

It is expected that there would be minimal effect on the NHI system itself. Most effect will occur in adjusting interfacing systems (eg. at DHB and primary care agencies) to comply with the new recording requirement.

There are similar effects on other systems – notably National Collections. This action can be treated as a separate exercise although many of the same (mapping) activities will be required.

Adhering to a national standard would improve the ability to link data with other government agencies, as definitions would be consistent.

Considerations

2.3 Political implications

The development of the standard is in line with political commitment to improve data collection on LGBTQI+ communities, as recognised in the 2017 Labour manifesto.

The Human Rights Commission has also promoted the need to improve data collection on intersex New Zealanders.

2.4 Privacy Act/Code implications

There are no expected implications from this action.

It is possible that patients may not want a particular health professional to have access to data about their sexuality. This could be mitigated by including a ‘prefer not to disclose’ option.

2.5 Proposition value – locally/nationally

Collecting 'biological sex at birth' data would improve knowledge particularly of the intersex community. Currently there is no NHI based data on intersex people. Understanding this group better will support evidence based policy making for intersex New Zealanders, and ultimately health care.

2.6 Cost and time implications

Currently, we do not have details on the cost and time requirements, however changes to the NHI system and Standard are considered minor - provided the change is undertaken as a part of other updates to the NHI process. The ability to process this change at the same time as other changes to the NHI will depend on the standard being prepared in time.

Changes to other systems (HPI and national collections) will need to be pursued as a separate exercise.

2.7 Adoption/Implementation implications

The time taken to roll out the change is important. Such change will almost certainly be undertaken using the NCAMP process (National Collections Annual Maintenance Programme). As stated, such changes are only undertaken annually (on 1 July) as part of the pre-agreed schedule.

No discussion has been held on including this item in NCAMP – this should be part of a much higher level conversation when the scale of all changes to the NHI are known with more certainty.

Consideration may need to be given to what situations it would be necessary to display sex rather than gender. For example, at a clinical reception desk; or that treatment for a non-gender related ailment does not need to display a patient's sex as recorded at birth.

3. Gender Identity:

Background

3.1 What change is wanted, why and why now

The NHI system currently collects information on gender using the following codes developed in 2015[1]:

Code	Description	Comment	HL7 Administrative Gender
F	Female		F
M	Male		M
O	Other Gender		O
U	Unspecified or unknown	A proper value is applicable but not provided	UN

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.

The StatsNZ standard is currently as follows:

1. **Male**
   11 Male / Tāne
2. **Female**
   21 Female / Wahine
3. **Gender diverse**
   30 Gender diverse not further defined / Ira tāngata kōwhiri kore
   31 Transgender male to female / Whakawahine
   32 Transgender female to male / Tangata ira tāne
   39 Gender diverse not elsewhere classified / Ira tāngata kōwhiri kore

The StatsNZ standard adds another field for gender diverse people to identify as one of four general categories.

The opportunity to improve data collection is timely as we currently have a programme of policy work to improve gender affirming care, and political support to improve data. These changes are supported by the 2017 Labour manifesto commitments on the need to improve data collection on LGBTQI+, including transgender and gender diverse people.

Aside from the policy implications, data collection that does not capture transgender and gender diverse people can be non-inclusive as people may not be able to have their gender recognised. This issue was criticised by members of the transgender and gender diverse community when the 2018 Census did not capture gender diversity.

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[1] See: Section 2.4, Consumer Health Identity Standard: https://www.health.govt.nz/publication/hiso-10046-consumer-health-identity-standard

3.2 Effect of the change – local, national, other sector agencies

There is minimal effect on the NHI system itself. Most effect will occur in adjusting interfacing systems (eg. at DHB and primary care agencies) to comply with the new recording requirement.

There are similar effects on other systems – notably National Collections. This action can be treated as a separate exercise although many of the same (mapping) activities will be required.

Adhering to a national standard would improve the ability to link data with other government agencies, as definitions would be consistent.

Considerations

3.3 Political implications

There is political support in the 2017 Labour party manifesto to improve data collection relating to rainbow New Zealanders.

3.4 Privacy Act/Code implications

There are no expected privacy implications from this action.

3.5 Proposition value – locally/nationally

Collecting data on gender diversity would improve knowledge of gender diversity in the health environment. Currently there is very little data or information on health care for transgender or gender diverse people. Understanding this group better will support evidence based decision making on the health needs of the trans and gender diverse population.

3.6 Cost and time implications

Currently, we do not have details on the cost and time requirements, however changes to the NHI standard and system are considered minor - provided change is undertaken as a part of other updates to the NHI process. The ability to process this change at the same time as other changes to the NHI will depend on the standard being prepared in time.

Changes to other systems (Health Provider Index [HPI] and national collections) will need to be pursued as a separate exercise.

3.7 Adoption/Implementation implications

The time it will take to roll out the change is important. Such change will almost certainly be undertaken using the NCAMP process (National Collections Annual Maintenance Programme). As stated, such changes are only undertaken annually (on 1 July) and as part of a pre-agreed schedule.

No discussion has been held on including this item in NCAMP – this should be part of a much higher level conversation when the scale of all changes to the NHI are known with more certainty.

4. Sexual orientation:

Background

4.1 What change is wanted, why and why now

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.

4.2 Effect of the change – local, national, other sector agencies

There is minimal effect on the NHI system itself. Most effect will occur in adjusting interfacing systems (eg. those in DHBs and primary care agencies). There will also be an administrative effect as health care practitioners/providers are required to adjust their systems to record more detail.

Considerations

4.3 Political implications

There is political support in the 2017 Labour party manifesto to improve data collection relating to rainbow New Zealanders.

4.4 Privacy Act/Code implications

There are no expected privacy implications from this change. However, it is possible that a patient may not want a particular health professional to have access to data about their sexuality. This could be mitigated by including a 'prefer not to disclose' option.

4.5 Proposition value – locally/nationally

This action will increase our knowledge of the Rainbow community and give us a more accurate picture of the New Zealand population. In turn, this will enable us to make better decisions about policy and programmes, both locally and nationally.

4.6 Cost and time implications

Currently, we do not have details on the cost and time requirements, however changes to the NHI standard and system are considered minor - provided change is undertaken as a part of other updates to the NHI process. The ability to process this change at the same time as other changes to the NHI will depend on the standard being prepared in time.

Changes to other systems (HPI and national collections) will need to be pursued as a separate exercise.

4.7 Adoption/Implementation implications

The time it will take to roll out the change is important. Such change will almost certainly be undertaken using the NCAMP process (National Collections Annual Maintenance Programme). As stated, such changes are only undertaken annually (on 1 July) and as part of a pre-agreed schedule.

No discussion has been held on including this item in NCAMP – this should be part of a much higher level conversation when the scale of all changes to the NHI are known with more certainty.

5. Ethnicity:

Background

5.1 What change is wanted, why and why now

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[2].

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.

This change would allow and improve consistency with other collections (eg. the National Enrolment service) thereby improving the quality of information upon which decisions are made – for example: funding allocations and the assessment of the equality of treatment.

While the change is not critical, there is an opportunity to minimise cost and inconvenience in making this change. This would utilise economies of scale factors with other more minor changes and enhancement to the NHI Standard/System.

5.2 Effect of the change – local, national, other sector agencies

There is minimal effect on the NHI system itself. Most effect will occur in adjusting interfacing systems (eg. at DHB and primary care agencies) to comply with the new recording requirement. There will also be an administrative effect as health care practitioners/providers are required to record more detail – particularly at renewal of enrolment information.

Considerations

5.3 Political implications

There are no immediate political implications from this action. Better quality information arising from this activity may inform future political and strategic choices.

5.4 Privacy Act/Code implications

There are no privacy implications from this action. This information is already held as a numeric value.

5.5 Proposition value – locally/nationally

This action will, over time, improve information quality. This in turn will provide a more reliable basis for decision making both locally and nationally.

5.6 Cost and time implications

Currently, there is no detail as to cost/time (resource) requirements although changes to the NHI Standard and system are considered minor – provided change action is undertaken as a part of other updates to the NHI process.

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[2] https://www.health.govt.nz/publication/hiso-10046-consumer-health-identity-standard

If approved in concept, the cost and time detail must be obtained before a final recommendation is made. The major resource (cost and time) implication arises for agencies that are to collect and provide this information to the Ministry. This must be established with a good degree of certainty as an essential prerequisite if this proposal is to move from 'desired' to 'in action'.

5.7 Adoption/Implementation implications

The public comment round (to follow consideration by working group) will establish the desire to undertake this change. This will provide a clear measure of agencies' appetite for this change. Failure to achieve positive public comment (or at the very least an absence of negative feedback) will contribute significantly to the decision to proceed.

The time it will take to roll out the change is important. Such change will almost certainly be undertaken using the NCAMP process (National Collections Annual Maintenance Programme). As stated, such changes are only undertaken annually (on 1 July) and as part of a pre-agreed schedule. No discussion has been held on including this item in NCAMP – this should be part of a much higher level conversation when the scale of all changes to the NHI are known with more certainty.

5.8 Additional comment

The following additional information has been provided to support this proposal.

5.8.1 Providers/collectors of ethnicity report that consumers are often frustrated when they provide an ethnicity for example "German" but what is recorded in patient management systems and reported back to them on pre-printed forms etc. has something different, in this example "Other European".

Coding at level 4 improves this situation but there are still many responses that will be assigned a code with a description different to what the patient has provided

For example all the following responses are coded to the level 4 code 44414 Pakistani

Pakistan
Pakistani
Muslim Pakistan
Pakastani

and all 23 of the following descriptions are coded to the level 4 code 44499 Asian Not Elsewhere classified

Kazakh	Tajik	Tajek
Maldives	Tartar	Turkmenian
Singapore	Tatar	Bhutan
Uzbek	Uzbeqi	Azeril
Bhutanese	Kazahstani	Buryat
Maldivian	Kyrgyz	Wakhi
Mongolian	Macanese	Yakut (Sakha)
Ossetian	Pathan	

All of these ethnicity responses have been supplied in a NZ census.

Having the text the person responded with allows systems to present the information to their patients as they supplied it and still be able to use the classifications to analyse the data in meaningful ways.

Having the text the person has supplied would help meet the Health Information Privacy Code Rule 7. *People can correct their information if it's wrong*.
and Rule 8. *We can make sure health information is correct before we use it*.

5.8.2 The Ethnicity Protocol review group included Statistics NZ. The Statistics NZ representatives reported that considerations were being given to running census less frequently and that administrative collections such as the NHI and the PHO registers would be used to get intermediate calculations of NZ demographics. The NHI could be a crucial input into this process if it collected the person's actual response in the same way that the NZ digital census collected it and retained the text response for classification and further response.

5.8.3 To improve the ethnicity classification system, having the text would provide researchers with valuable information to ensure the classification was working well for the health domain.

If for example health could demonstrate that substantial numbers of patients were responding as "Bhutanese" and that the Bhutanese group had health concerns that required targeted funding or targeted clinical treatment then the classification system could be improved to give "Bhutanese" its own level 4 code. Health could respond by immediately recoding previous responses from the text response and allow systems to respond appropriately.

If we do not retain the text it is almost impossible to determine accurately how often these responses have been made in order to improve the classification and when such classifications are added it would not be reflected in our systems until providers re-collected ethnicity from this group, which may take many years.

6. Country Code:

Background

6.1 What change is wanted, why and why now

The NHI system and the Consumer Health Identity Standard (HISO 10046[3]) currently both hold Country information as two distinct elements. HISO 10046 section 2.3.4 holds the patient's 'Country of Birth' and HISO 10046 section 3.8 holds "a code for the Country that forms part of a [physical mail] address".

In both cases, the code table used as the source standard is: "ISO 3166-1:2006 Codes for the representation of names of countries and their subdivisions – Part 1: Country code"[4]. A 'free' (and somewhat restricted) alternative example is also available[5].

Both system and standard use alpha-2 characters to record country. The issue to be addressed is that other Ministry systems use different values to record the same information – for example:

- Health Providers Index (HPI):
  While HISO standard 10046 incorporates the same alpha-2 as referred to in the NHI Standard above, the HPI system actually stores a four digit numeric code. This is based on the Statistics New Zealand classification – Country 4 Numeric (NZSCC4N99)[6]
- National Collections (for example: National Minimum Data Set, Mortality and Cancer):
  These collection examples all use a three digit numeric code – as per the ISO reference above

While none of these are wrong, 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

While the change is not critical, there is an opportunity to minimise cost and inconvenience in making this change. This would utilise economies of scale factors with other more minor changes and enhancement to the NHI Standard/System.

6.2 Effect of the change – local, national, other sector agencies

There is minimal effect on the NHI system itself. Most effect will occur in checking and as necessary, adjusting interfacing systems (eg at DHB and primary care agencies) to comply with the confirmed recording requirement.

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[3] https://www.health.govt.nz/publication/hiso-10046-consumer-health-identity-standard

[4] http://www.iso.org/iso/country_codes.

[5] https://en.wikipedia.org/wiki/ISO_3166-1#Current_codes

[6] http://archive.stats.govt.nz/methods/classifications-and-standards/classification-related-stats-standards/country.aspx

For other systems, a mapping between the alpha-2 and the numeric-4 code will probably need to be constructed to update existing records. There will also be an administrative effect as health care practitioners/providers are required to confirm existing record detail – particularly at renewal of enrolment information. The above particularly applies to other systems – notably the HPI and National Collections. This action can be treated as a separate exercise although many of the same (mapping) activities will be required.

Considerations

6.3 Political implications

There are no immediate political implications from this action. Better quality of and therefore confidence in, information held arising from this activity would provide better information for future political and strategic choices.

6.4 Privacy Act/Code implications

There are no privacy implications from this action. This information is already held – it is a matter of storage consistency that is to be addressed.

6.5 Proposition value – locally/nationally

This action over time is expected to improve our confidence and knowledge of country information within the patient environment. This is turn will provide a more unbiased recording of patient information leading to more informed decision making both locally and nationally.

6.6 Cost and time implications

Currently, there is no detail as to cost/time (resource) requirements although changes to the NHI Standard and system are considered minor – provided change action is undertaken as a part of other updates to the NHI process. Changes to other systems (HPI and National Collections) will need to be pursued as a separate exercise.

If approved in concept, this detail must be obtained before a final recommendation is made. The major resource (cost and time) implication arises for agencies that are to collect and provide this information to the Ministry. This must be established with a good degree of certainty as an essential prerequisite if this proposal is to move from ‘desired’ to ‘in action’.

6.7 Adoption/Implementation implications

The public comment round (to follow consideration by working group and HISO review) will establish the desire to undertake this change. This will provide a clear measure of agencies’ appetite for this change. Failure to achieve positive public comment (or at the very least an absence of negative feedback) will contribute significantly to the decision to proceed.

The time it will take to roll out the change is important. Such change to other (non NHI systems) will almost certainly be undertaken using the NCAMP process (National Collections Annual Maintenance Programme). Such changes are only undertaken annually (on 1 July) and as part of a pre-agreed schedule. No discussion has been held on including this item in NCAMP – this should be part of a much higher level conversation when the scale of all changes to the NHI are known with more certainty.

7. Language Code:

Background

7.1 What change is wanted, why and why now

The NHI system currently holds information on the language spoken by the patient. Multiple languages can be recorded. The format required is set out in section 4.1 of the Consumer Health Identity Standard[7].

The code table used as the source standard is: "ISO 639-1 : Codes for the representation of names of languages – Part 1: Alpha-2 code, 2002."[8]. An alternative example is available[9].

The key here is the current prescription to use 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. What is needed is to change the source standard reference (as above) to read ISO 639-2[10] and to use these Alpha-3 values to populate the field. Incidentally, this table shows a very clear comparison of language codes that exist in Alpha-3 but not in Alpha-2.

This change would allow patients from the above three countries (and possibly others) to record their own spoken language. It will remove a bias against languages not currently listed and improve equity of treatment for these individuals – particularly if there is a need for a translator during treatment.

While the change is not critical, there is a least cost/inconvenience opportunity to make this change utilising economies of scale factors with other more minor changes and enhancement to the NHI Standard/System.

7.2 Effect of the change – local, national, other sector agencies

There is minimal effect on the NHI system itself. Most effect will occur in adjusting interfacing systems (eg. at DHB and primary care agencies) to comply with the new recording requirement. Translation between the 2 and 3 character code will be needed to update existing records. There will also be an administrative effect as health care practitioners/providers are required to record more detail – particularly at renewal of enrolment information.

Considerations

7.3 Political implications

There are no immediate political implications from this action other than the positive message that the health and disability system is taking action to be more inclusive of Pasifika languages. Better quality information arising from this activity may inform future political and strategic choices and to better identify where a language translator may be required.

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[7] https://www.health.govt.nz/publication/hiso-10046-consumer-health-identity-standard

[8] http://www.iso.org/iso/language_codes.

[9] https://en.wikipedia.org/wiki/List_of_ISO_639-1_codes

[10] https://www.loc.gov/standards/iso639-2/php/code_list.php .

7.4 Privacy Act/Code implications

There are no privacy implications from this action. This information is already held – it is just that a greater range of values and specificity will be available.

7.5 Proposition value – locally/nationally

This action will improve our knowledge of languages held and spoken within the patient environment. This in turn will provide a more unbiased recording of patient information leading to more informed decision making both locally and nationally.

7.6 Cost and time implications

Currently, there is no detail as to cost/time (resource) requirements although changes to the NHI Standard and system are considered minor – provided change action is undertaken as a part of other updates to the NHI process.

If approved in concept, this detail must be obtained before a final recommendation is made. The major resource (cost and time) implication arises for agencies that are to collect and provide this information to the Ministry. This must be established with a good degree of certainty as an essential prerequisite if this proposal is to move from ‘desired’ to ‘in action’.

7.7 Adoption/Implementation implications

The public comment round (to follow consideration by working group) will establish the desire to undertake this change. This will provide a clear measure of agencies appetite for this change. Failure to achieve positive public comment (or at the very least an absence of negative feedback) will contribute significantly to the decision to proceed.

The time it will take to roll out the change is important. Such change will almost certainly be undertaken using the NCAMP process (National Collections Annual Maintenance Programme). As stated, such changes are only undertaken annually (on 1 July) and as part of a pre-agreed schedule. No discussion has been held on including this item in NCAMP – this should be part of a much higher level conversation when the scale of all changes to the NHI are known with more certainty.

8. Iwi Classification:

Background

8.1 What change is wanted, why and why now

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.

Iwi recognise the importance of data and having robust information to underpin development and decision making. Many iwi have developed, and continue to develop, their capability and capacity to engage with and use data. A key administrative data collection, such as the NHI system, leading the way in the collection of iwi statistics/data will begin the much needed change to the wider data eco-system in New Zealand.

With the advancement of technologies to link data and interpret it through different tools, there is a greater need to ensure that the data our country collects and holds reflects the voices of our communities and therefore will be responsive to us. The Integrated Data Infrastructure (IDI) at Statistics New Zealand currently holds over 40 different datasets from across different government sources and is being used as a powerful tool for planning, wellbeing investment and monitoring. Currently the IDI has considerable limitations in its utility for, and use by, iwi. The (now five year old) 2013 Census is the only source of iwi data that sits in the IDI. A more consistent and regular administrative collection of iwi data would transform this tool into a powerful information tool for iwi.

As one of the key administrative data collections across government, if the Ministry of Health looked to add iwi as a variable/attribute to the NHI system there would be a strong possibility for New Zealand to have a future information infrastructure that was responsive to its Treaty Partners and world leading in reducing the global indigenous data gaps.

8.2 Effect of the change – local, national, other sector agencies

It is recommended that the Statistics New Zealand’s iwi and iwi-related groups statistical classification as set out in IWI_IRGv1.0[11], is used to provide consistency of collection across the wider government data system.

Across the health and disability sector the main issue will be the necessary changes that will need to be made to the interfacing systems that update the NHI system. There may also be some initial resistance with health organisations and providers having to collect more detailed data but with greater awareness of the growing need, in alignment with the growing population demographic changes, this should reduce considerably.

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[11] See: http://archive.stats.govt.nz/tools_and_services/classificationcodefinder.aspx?

Considerations

8.3 Political implications

There are always political implications when it comes to iwi development. However, short term tensions that may exist will be far outweighed by the long term benefits of the collection of this data and the ultimate outcomes it will be able to measure and add value to.

8.4 Privacy Act/Code implications

There are no obvious privacy implications from this action.

8.5 Proposition value – locally/nationally

This is about making data and information relevant to the different levels of decision makers, importantly in the area of health and wellbeing, but it is also about future-proofing the data eco-system of New Zealand to be more reflective and therefore responsive to communities, to iwi, to the government's Treaty Partner.

Health funding is often population based and therefore more accurate Māori and iwi data would allow greater visibility of the level of health need that sits across each iwi. This then also provides the opportunity for continued partnerships with iwi entities that have capacity to provide additional support to their own whānau members.

This will also assist with more culturally appropriate services at different points of the provision of care as well as research for iwi outcomes.

8.6 Cost and time implications

This would take time to roll out across the country, particular the required changes to interfaces but also socialising the need and importance of the collection of this data by the providers. Iwi would need to be willing to work with the Ministry on growing awareness for the data need and the resulting benefits for iwi and Aotearoa.

8.7 Adoption/Implementation implications

It will be important to note that the general public comment on this may receive feedback from those small fractions of society who lack the knowledge and understanding of the future focus of the Treaty of Waitangi. This should be considered when interpreting public feedback on desired change. But equal, if not higher, weight and consideration should be given to those providers who work in the communities with iwi and witness the transformation that occurs from true partnership, co-design and collaboration.

8.8 Other comments

If needed, Māori data practitioners, including technicians from the Data Iwi Leaders Group, would be willing to attend any meeting to further reiterate this data need and elaborate on uses of the data and information.

9. Disability status:

Background

9.1 What change is wanted, why and why now

What is disability?

Disability is an impairment that may be cognitive, developmental, intellectual, mental, physical, sensory, or some combination of these. It significantly affects a person's life activities and may be present from birth or occur during a person's lifetime. In 2013, 24 percent of the New Zealand population were identified as disabled, a total of 1.1 million people.[12] People with disabilities generally have poorer health and greater unmet needs, and often report seeking more health care than non-disabled people.

There are multiple benefits to collecting disability status in the NHI system

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.

The NHI system does not currently hold disability information. Disability status should be collected alongside other important demographic variables. Having a disability identifier in the NHI will address the strong need in New Zealand for better information and data about disabled people and would deliver many tangible benefits such as:

- enabling more accurate representation of the New Zealand disabled population and analyses of health, disability and wellbeing
- understanding a disabled person’s journey through the health and disability system over their lifetime
- supporting the production of statistical publications and facilitating research and evaluation
- better understanding the outcomes disabled people get from their health care and disability supports
- using data and evidence to inform policy, planning and decision making
- linking data to other major databases, for example through the Integrated Data Infrastructure (IDI)[13], and enable broader disability population analysis across different sector services
- supporting the monitoring of progress and results of both the New Zealand Disability Strategy and the New Zealand Health Strategy
- helping to meet New Zealand's international disability reporting obligations, including through the United Nation’s Convention on the Rights of Persons with Disabilities (CRPD).

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[12] See Disability Survey 2013 – http://archive.stats.govt.nz/browse_for_stats/health/disabilities/DisabilitySurvey_HOTP2013.aspx

[13] The IDI combines information from a range of organisations to provide the insights government needs to improve social and economic outcomes for New Zealanders.

Disability status can be collected using a short set of six questions

We suggest that disability status is collected in the NHI system from patients using the Washington Group Short Set (WGSS) of questions[14]. The Washington Group on Disability Statistics, comprising over 100 representations (of national statistical offices and international non-governmental and disability organisations), developed the WGSS for countries to use in surveys of the general population. The WGSS is a set of six short questions designed to identify people with a disability. The questions ask whether people have difficulty performing basic universal activities (walking, seeing, hearing, cognition, self-care and communication).

The WGSS has been recognised as the standard tool internationally for collecting data on disability status and has been vigorously tested and validated. It is increasingly being included in population surveys in New Zealand such as Census 2018, the New Zealand Health Survey, the General Social Survey and the Household Labour Force Survey.

9.2 Effect of the change – local, national, other sector agencies

Collecting NHI disability information would radically transform our national capability to collect data and track the lives of people with disabilities over their lifetime. This would greatly assist with developing policy, facilitating research, supporting the planning and performance monitoring of health and disability support services, and help meet our international obligations to improve national disability data collection.

Considerations

9.3 Political implications

The inclusion of disability information in the NHI system is consistent with the vision outlined in the New Zealand Disability Strategy and the CRPD[15]. The information would support the government's goals for improving outcomes for disabled people.

9.4 Privacy Act/Code implications

There are no privacy implications from this action.

9.5 Proposition value – locally/nationally/ internationally

This action will provide better information about disabled people both locally and nationally, and help meet our growing international disability reporting requirements.

9.6 Cost and time implications

There will be a cost and time implication for the collection of this additional information. The patient will need to respond to six questions to provide their disability status information.

9.7 Adoption/Implementation implications

It is important to consult with the disability sector to ensure acceptability of the proposal.

It should be noted that the WGSS will not identify all disabled people. This can only be done with a long set of questions, such as in the New Zealand Disability Survey.

Disability status of a person can also change over their life course so it would be important to collect and then update this information regularly.

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[14] See here for more information on the WGSS: http://www.washingtongroup-disability.com/washington-group-question-sets/short-set-of-disability-questions/

[15] CRPD: Convention on the Rights of Persons with Disabilities

9.8 Other comments

Note that a simple yes / no question asking if someone is disabled would not be acceptable because it isn’t always accurate. The WGSS is the recommended tool for collecting disability status. Below are the WGSS questions. Different thresholds can be applied to the answers to define disability status. The international experts recommend an individual needs to answer “a lot of difficulty” to at least one of the questions to be defined as disabled for the purposes of the survey.

The six WGSS questions are:

1. Do you have difficulty seeing, even if wearing glasses?
2. Do you have difficulty hearing, even if using a hearing aid?
3. Do you have difficulty walking or climbing steps?
4. Do you have difficulty remembering or concentrating?
5. Do you have difficulty (with self-care such as) washing all over or dressing?
6. Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?

And, the multiple choice answers are:

a. No - no difficulty

b. Yes – some difficulty

c. Yes – a lot of difficulty

d. Cannot do at all.

10. Residency Status:

Background

10.1 Context

The National Health Index contains a “Residency Status” attribute. This attribute is intended to identify a patient’s permanent resident status and is commonly used to establish eligibility for publicly funded health services.

Under the existing definition a permanent resident is a person who:

(a) resides in New Zealand; and

(b) is not a person to whom section 7 of the Immigration Act 1987 applies or a person obliged by or pursuant to that Act to leave New Zealand immediately or within a specified time or deemed for the purposes of that Act to be in New Zealand unlawfully.

If the attribute is “Y” the patient is deemed to be a permanent resident (New Zealand citizen or classified as ‘ordinarily resident in New Zealand’).

If the attribute is “N” the patient is deemed to be a temporary resident (not a New Zealand citizen, does not have New Zealand ‘ordinarily resident’ status)

Over 7.1 million ‘live’ NHI records currently have the residency status set as “Y” and 900,000 as “N”, however the quality of the information that has been captured is dubious. The definition of residency is often interpreted differently and there have been historic cases of integrating systems defaulting the residency status to “Y” for all patients

In 2011, during the last NHI upgrade, the Heath Identity Programme (HIP) Sector Advisory Group and HIP Governance Group agreed that the Residency Status attribute should be deprecated and replaced by other ‘evidence of eligibility’ fields. A decision was taken to enable the storage of two new data elements to assist with the eligibility decision-making process:

(a) Place of Birth (Locality & Country); and

(b) NZ Citizenship Status

Currently, Residency Status in the NHI can only be updated via legacy HL7 messaging and this is largely restricted to DHBs. The Ministry’s newer SOAP[16] web service APIs[17] do not include Residency Status (although they do include Place of Birth and NZ Citizenship Status).

10.2 Decision Required

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

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[16] SOAP – Simple Object Access Protocol – a messaging protocol specification for exchanging structured information

[17] API – Application Programming Interface - a set of clearly defined methods of communication between various software components

Considerations

10.3 Political implications

There are no obvious political implications from this decision.

10.4 Privacy Act/Code implications

There are no obvious privacy implications. Residency Status is an existing NHI attribute and widely used by legacy HL7 users. However, depending on how the Residency Status is defined and used going forward there may need to be a reassessment of the privacy implications.

10.5 Proposition value – locally/nationally

Residency Status is a key element in legacy HL7 NHI messages, but is not included in the newer SOAP web service APIs. However, there remains a widespread demand within the sector for information pertaining to a person's Residency Status as input to determining a person's eligibility status.

10.6 Cost and time implications

Residency Status is an existing attribute within the NHI. The cost and time implications relate more to the development and adoption of new APIs to allow systems to access and update the status. The development and integration of new APIs would be managed over a period of years.

10.7 Adoption/Implementation implications

The definition of Residency Status is somewhat ambiguous and needs to be reviewed. The existing data quality is also dubious. Future APIs will need to make use of the Residency Status 'source' field to show the provenance of the information. The source field is not currently exposed via legacy HL7 messaging, but is an important element for establishing "trust" in the authenticity of the information.

Deprecation of existing NHI interfaces and roll-out of new APIs will almost certainly leverage the NCAMP process (National Collections Annual Maintenance Programme). Such changes are only undertaken annually (on 1 July) and as part of a pre-agreed schedule. The inclusion of Residency Status would be packaged with other proposed changes and the roll-out and integration managed over a period of years.

11. Opt-Out status Indicator:

Background

11.1 What change is wanted, why and why now

This field is based on the Health Information Governance Guidelines (HISO 10064:2017[18], 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.

11.2 Effect of the change – local, national, other sector agencies

The creation of an NHI is not an interference with personal privacy, and has four primary benefits:

- Reducing the risk of a health provider making errors based on wrong or incomplete information;
- Maintaining the privacy of a person's health information;
- Assisting with the planning, co-ordination and provision of health and disability services; and
- Identifying information held in the Medical Warning System.

The NHI number enables individuals to be positively and uniquely identified for the purpose of treatment and care, and for maintaining their medical records. Healthcare providers can also be sure they are talking about the correct person therefore reducing the chance of making a clinical decision based on wrong information.

Further, the NHI number is fundamental for healthcare services such as pharmacy, laboratory, and admissions to link this information in order to get a better understanding of their needs.

Considerations

11.3 Political implications

None.

11.4 Privacy Act/Code implications

The NHI is a unique identifier in accordance with Rule 12 of the Health Information Privacy Code[19], which is used to help identify people in the health system.

If the NHI or information about the NHI is not disclosed, then in addition to the enhanced risks to the care of those individuals, there is also an enhanced risk of possible breaches of privacy, either though the need of providers to use other identifiers in place of the NHI, or the enhanced risk of confusion with the NHI of another person.

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[18] https://www.health.govt.nz/our-work/ehealth/digital-health-sector-architecture-standards-and-governance/health-information-standards/approved-standards/hiso-100642017-health-information-governance-guidelines

[19] https://www.privacy.org.nz/the-privacy-act-and-codes/codes-of-practice/health-information-privacy-code-1994/

11.5 Proposition value – locally/nationally

There is no current power for “opt-out” from the NHI, given the particular purposes of the NHI.

The inclusion of an “opt-out” option for information held within the NHI may assist in enhancing trust and confidence in the NHI system. While a facility to have an “opt-out” option may be included, use of such options are traditionally very low.

However, the risks of inclusion of such an option are significant, given the purpose of the NHI system. If an “opt-out” option is included which restricts NHIs or supporting identifying information from being disclosed appropriately, then this may create significant risks to health care from providers and others not being able to rely on NHI information or its accuracy. Enabling an “opt-out” option will raise questions about the completeness of data included in the NHI and remove the benefits for treatment, planning and co-ordination.

11.6 Cost and time implications

No comment.

11.7 Adoption/Implementation implications

No comment

12. Delegation rights - general:

Background

12.1 What change is wanted, why and why now

This field is based on the concept of the NHI holding a record of an authority to act on behalf of someone. Examples of such authorities include:

- Power of Attorney - ordinary general (PPPR Act[20])
- Power of Attorney - enduring (property, personal care) (PPPR Act)
- Welfare guardian (PPPR Act)
- Guardianship orders (Care of Children Act)
- Custody orders (Oranga Tamariki Act)

12.2 Effect of the change – local, national, other sector agencies

The purpose for the change, and its potential effect, is not clear. Currently, it is to enable users to identify when such rights may exist, or to be able to assign rights within the NHI system.

Considerations

12.3 Political implications

No comment.

12.4 Privacy Act/Code implications

The Act/Code both provide for, and recognise, representatives being able to act on behalf of individuals that lack capacity, so inclusion of this information has the potential to better assist health practitioners to identify persons with decision making responsibilities for individuals.

12.5 Proposition value – locally/nationally

To be effective and to be able to be relied upon, delegation rights need to be kept up to date. Otherwise the decisions of health practitioners will be compromised by incorrect consultation, along with potential liability to those practitioners (such as by way of complaint to the Health and Disability Commissioner), on the basis of reliance on incorrect information.

12.6 Cost and time implications

No comment.

12.7 Adoption/Implementation implications

Maintenance of the delegation rights will require health practitioners to keep the information up to date, but they will often not have the up to date information that enables them to do this.

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[20] Protection of Personal and Property Rights Act 1988 see http://www.legislation.govt.nz/act/public/1988/0004/latest/whole.html

13. Delegation Rights – Advance Care Planning:

Background

13.1 What change is wanted, why and why now

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.

ACP is the process of thinking about, talking about and planning for future health care and end of life care.

It involves an individual, family/whānau and health care professionals. ACP gives people the opportunity to develop and express their preferences for future care based on:

- their values, beliefs, concerns, hopes & goals
- a better understanding of their current & likely future health
- the treatment and care options available.

Over 3000 health care workers have been trained in advanced care planning across the country.

DHBs have funded the Health Quality & Safety Commission (the Commission) to manage the national ACP programme until the end of December 2019. Further funding will be sought after that. A five-year strategy for ACP is currently being implemented.

One of the work streams of the strategy is to develop and/or work with existing systems and processes to maximise DHBs' investment in advance care planning. Currently, there is no one central way of knowing if someone has an advance care plan, or to obtain access to it.

Having an ACP alert on the NHI system would, for the first time create a consistent, nationwide way for clinicians to know that a patient has a plan and where that plan is kept.

13.2 Effect of the change – local, national, other sector agencies

Local: Clinicians will be able to tell whether an ACP exists and where it is held. Once accessed, they will know a patient's wishes for their care, particularly as they approach the end of their lives.

National: Having an ACP alert on a national database means clinicians will be able to tell if a person has an ACP, even if they become ill outside their DHB of domicile. A national alert would also enable us to count the number of people who have ACPs. Being able to show steady increase in ACPs will make continued funding for the programme more likely.

Sector: Sector effects would be similar to those noted under national.

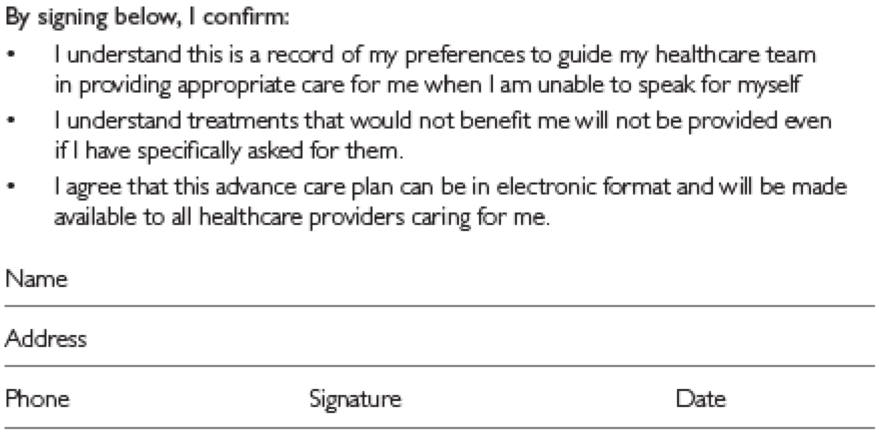
Considerations

13.3 Political implications

Political implications are minimal if not zero. DHBs have all adopted the ACP programme at some level and it has wide sector support.

13.4 Privacy Act/Code implications

People who sign an ACP agree their plan can be in an electronic format and made available to all health care professionals providing their care (see below). An NHI alert will show if someone has an ACP and where it is stored. The alert will not provide any details about the content of an ACP or access to it.



By signing below, I confirm:

- I understand this is a record of my preferences to guide my healthcare team in providing appropriate care for me when I am unable to speak for myself
- I understand treatments that would not benefit me will not be provided even if I have specifically asked for them.
- I agree that this advance care plan can be in electronic format and will be made available to all healthcare providers caring for me.

Name

Address

Phone Signature Date

13.5 Proposition value – locally/nationally

In order for an ACP to be useful, it must be able to be accessed when required, especially when a person cannot speak for themselves. Delegated authority and/or power of attorney is captured in an ACP, therefore there will be an increase in the availability of this information if ACPs are more widely accessible.

If an ‘ACP yes/no’ option is attached to each NHI, this will greatly increase the visibility of the programme. If the ACP ‘yes’ option is selected, the system would then show where the ACP is stored. For example; the contact details of a GP or the holder of an enduring power of attorney.

The addition of this alert would be expected to have the flow on effect of increasing the number of ACPs developed and subsequently accessed.

13.6 Cost and time implications

We would anticipate that adding an ACP alert to the NHI would be relatively straightforward, with minimal costs. Costs would potentially be absorbed into the wider NHI review.

Time requirements for clinicians or administration staff would be the time it takes to input that a person has an advance care plan and where it is held. This would be no different to how names and addresses etc., are currently updated.

13.7 Adoption/Implementation implications

Many clinicians across the country are already completing ACPs with their patients, the only action required to adopt would be to capture this information on the organisations patient management system.

13.8 Other comments

Having an ACP alert linked to the NHI would have a very positive impact on the experience of New Zealanders when they are provided with care, particularly towards the end of their lives. It is expected the alert would result in the wishes of a number of people being taken into account in the delivery of health care, that otherwise would have been overlooked because providers would not have known they had an advance care plan.

Globally, there is growing evidence that people do not get the care they want or need towards the end of life. Evidence has found that ACP increases patient and family satisfaction, decreases depression and increases quality of life. There is also evidence to say ACP reduces costs to the health system because people choose less intensive treatment.

14. Cook Islands, Niue and Tokelau NHI cross reference

Background

14.1 What change is wanted, why and why now

New Zealand holds a special link with the Pacific through shared history, culture, politics and demographics. In particular, New Zealand has a unique relationship with the Cook Islands, Niue and Tokelau.

The Letters Patent Constituting the Office of the Governor-General of New Zealand (2006) identifies the Realm of New Zealand, made up of New Zealand, Cook Islands, Niue, Tokelau and the Ross Dependency[21]. Citizens of all of these countries also hold New Zealand citizenship.

This proposal seeks to cross-reference health identification numbers for citizens of the Cook Islands, Niue and Tokelau with the NHI system in New Zealand.

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.

The duplication of health identification numbers for citizens of these countries in isolation from New Zealand's NHI system is inherently inefficient. This creates duplication of effort, wastes resource and time, and limits key health information sharing. This is especially important in relation to the two-way flow of migrant populations entering New Zealand, and with New Zealanders leaving to these Realm countries.

The New Zealand Ministry of Health is currently engaged with the Cook Islands Ministry of Health on updating a shared work programme under the Agreement of Health Co-operation (2008). The increased level of engagement with overseas representatives provides a strong opportunity for ongoing discussion regarding any potential changes to the NHI system in New Zealand, as well as changes in the Realm countries.

14.2 Effect of the change – local, national, other sector agencies

The suggested change:

- relates to linking or cross-referencing identification numbers in the Realm countries with the NHI system in New Zealand. There is expected to be minimal effect on the function of the NHI in practice
- is likely to result in some alterations to the health identification systems currently in place in the Realm countries and New Zealand, in order to allow for secure and functional information sharing.

Considerations

14.3 Political implications

There are no immediate political implications from this action, however there is likely to be support from local and international stakeholders. This proposal is in line with the Ministry of Foreign Affairs' recent Pacific 'reset' which is about increasing New Zealand's support, focus and partnerships with Pacific countries.

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[21] The Cook Islands and Niue are self-governing states in free association with New Zealand. Tokelau is non self-governing and subject to constitutional control by New Zealand at executive and legislative level. It has an administrative and law-making system that operates independently of New Zealand for most practical purposes.

This change to the NHI would also be consistent with support provided by the Ministry of Health New Zealand to the Ministry of Health Cook Islands via the Agreement of Health Co-operation (2008).

14.4 Privacy Act/Code implications

There may be some Privacy Act implications, mainly from ensuring any linking or cross-referencing between the systems in the Realm countries and New Zealand adheres to the respective privacy legislation for each country. Privacy legislation in each Realm country may differ from one other, and may also differ to privacy standards and practises in New Zealand.

14.5 Proposition value – locally/nationally

This action is expected to markedly improve key health information sharing with the Realm countries. This in turn has several benefits that supports a more effective and efficient health system both here in New Zealand and in the Cook Islands, Niue and Tokelau. Some benefits from improved information sharing include:

- Less duplication of effort in gathering health information
- Improved continuity of care for Realm country citizens travelling between New Zealand and the Realm countries
- Improved accuracy of population demography – includes more accurate number of enrolled population, ethnicity, migration details etc.
- Improved appropriateness of health care
- Increased opportunities for monitoring and quality improvement
- Improved patient centeredness.

14.6 Cost and time implications

Currently, there is no detail as to cost/time (resource) requirements. Linking health identification numbers between the Realm countries and New Zealand may require moderate resource for planning, consultation and implementation – particularly with this change involving overseas governments and stakeholders.

If approved in concept, detail regarding cost/time must be obtained before a final recommendation is made. This must be established with a good degree of certainty as an essential prerequisite if this proposal is to move from ‘desired’ to ‘in action’.

14.7 Adoption/Implementation implications

The public comment round (to follow working group consideration) will establish the desire to undertake this change. This will provide a clear measure of agencies appetite for this change. Failure to achieve positive public comment (or at the very least an absence of negative feedback) will contribute significantly to the decision to proceed.

It is also important to note, that any suggested changes would require agreement from the respective governments of the Cook Islands, Niue and Tokelau. The Ministry of Health has sought preliminary comment from officials from the respective Realm countries regarding the suggested change. The initial feedback has been positive and supportive. Should this proposal be approved in concept, further consultation and discussions will be required with these overseas officials.

15. Height and Weight:

Background

15.1 What change is wanted, why and why now

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.

Currently there is a disconnect between patient/client databases (eg. Maternity, Wellchild, and Patient Management Systems in primary care and secondary care) which means that there is no systematic way to track growth/weight change without manually copying height and weight (if available via a referral letter), which is subject to error. Ready access to up to date and historical height and weight information would enable identification of trends in a person's weight journey and earlier intervention. Patients who are highly mobile are also vulnerable to 'slipping through the cracks' and not having their growth tracked over time.

Height, especially once adulthood is reached is an important identifier, hence why it is collected on passports.

Weight is an important health variable and change in weight can indicate a range of acute and chronic health issues including mental illness, stress, physical illness and /or infection, poor nutrition, energy imbalance or side effects of pharmacotherapy. Weight is also important for the correct dosing of some medications; ready access to a recent weight may be useful in some emergency situations for correct dosing.

Why now?

The Ministry of Health has released updated Clinical Weight Management Guidelines for both children and adults which recommend regular monitoring of height and weight, tracking change over time, and offering brief advice and support earlier rather than waiting till someone is obese to intervene. Currently weight is not always routinely collected for people considered to be a 'healthy weight'. Including height and weight on the NHI identifies these as important variables.

Additionally, child wellbeing is a new Government priority. Healthy growth is an important indicator of well children. An unhealthy weight is associated with physical and mental illness in children.

15.2 Effect of the change – local, national, other sector agencies

Individual: May reduce need for repeat weight and height to be collected by multiple providers. Enables opportunity for early identification of weight change, appropriate investigation and earlier identification of health issues, along with the opportunity for appropriate intervention.

National: Ability to monitor individual weight change at a population level to better target resources and interventions.

Primary and Secondary Care: Better continuity of care between providers.

Considerations

15.3 Political implications

There are no immediate political implications from this action although it aligns well with current political priorities. National level collection of height and weight and changes amongst individuals over time may provide better information to inform future direction and investment of resources.

15.4 Privacy Act/Code implications

No privacy implications have been identified from this action. This information is already held in different patient management systems.

15.5 Proposition value – locally/nationally

The value to the individual and local systems is:

- improved patient care and management, continuity of care, and earlier intervention
- easy access to height and weight in an emergency situation for patient management.

The value nationally is:

Ability to track at a national level weight change over time over the population particularly for minority ethnic groups, and provide better regional and local population data.

15.6 Cost and time implications

The data is, or rather should be, routinely collected by health care providers. Including it on the NHI is unlikely to result in any significant extra time required unless practices are not routinely undertaking this.

There is a possibility that some dual recording between NHI and patient management systems may occur.

It may save time repeating height and weight due to inability to access a recent record.

15.7 Adoption/Implementation implications

Consideration would need to be given as to how the data could be plotted graphically over time to better communicate with patients/clients on their growth/weight journey.

16 MedicAlert ID cross reference

Background

16.1 What change is wanted, why and why now

The MedicAlert® Foundation (the Foundation[22]) has a long history of supporting New Zealanders dating back to 1962. The Foundation has been on Schedule 2 of the HIPC 1994 for a number of years and is already classified as a Health Information Agency. With the increasing nationwide focus on connected health over recent years, the Foundation has received increasing requests that a Health Consumers MedicAlert® Member Identification Number, be added to the NHI.

Why now?

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. The Foundation also notes that this recommendation is in line with the current NZ Health Strategy Roadmap to integrate wider health information into a more comprehensive care plan for the patient.

16.2 Effect of the change – local, national, other sector agencies

There is minimal effect on the NHI system itself. Most effect will occur in adjusting interfacing systems (e.g. within DHB and Primary Care Health IT systems) to comply with adding the new field and possibly mapping to SMART® on FHIR functionality to improve timely access to data.

The Foundation already has limited accesses the NHI record, however the ability to utilise the Foundations FHIR connectivity (currently in development) to disclose and acquire a wider data set would be entirely in line with the recommendations of adoption by HINZ/HL7 to the Clinical Trials Action Group.

Considerations

16.3 Political implications

There are no known political implications from this action.

16.4 Privacy Act/Code implications

There are no known privacy implications from this action. The Foundation is already classified as a Health Information Agency and is listed on Schedule 2 of HIPC 1994. The Foundation seeks informed consent from health consumers, including publishing Terms and Conditions and a Privacy Statement on its public facing website. The

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[22] MedicAlert Website: http://www.medicalert.co.nz/content/about-medicalert/news-and-press/default.aspx

Foundation's Privacy Statement was developed in consultation with the Office of the Privacy Commissioner.

16.5 Proposition value – locally/nationally

By integrating data acquired from the Foundation into the NHI data set (a MedicAlert Profile) and allowing the Foundation to acquire data from the NHI, all parties utilising the NHI would be privy to more timely access to an accurate, complete and correct data set for health consumers, who utilise the Foundation's services. In addition, the adoption of a search field by all NHI FHIR connected agencies which includes the MedicAlert® ID, may expedite information gathering at the point of care, for health consumers who cannot otherwise be identified, or who cannot communicate. This is turn can provide more informed decisions locally and nationally and when need be internationally, should the Health Consumer Travel overseas.

16.6 Cost and time implications

Currently, there is no detail as to cost/time (resource) requirements although changes to the NHI Standard and system might be considered minor – provided change action is undertaken as a part of other updates to the NHI process. The preferred method of integrating this information would be the utilisation of HL7/HINZ recommended FHIR Connectivity.

If approved in concept, this detail will be obtained before a final recommendation is made. The major resource (cost and time) implication arises for agencies that are to collect and provide this information to the Ministry. This must be established with a good degree of certainty as an essential prerequisite if this proposal is to move from 'desired' to 'in action'.

16.7 Adoption/Implementation implications

The Foundation cannot foresee that there would be substantive objections to such a change to the NHI. It is a charity that works in the best interests of registered Health Consumers (be it a child at school, a businessman travelling nationally and abroad, or a retiree enjoying added protection).

The Foundation delivers considerable value to the national health system, as evidenced in a Feb 2018 PWC Economic Impact Assessment Report.

- reduce risk and harm to the patient at the point of care,
- create efficiencies in the broader Health Care system and
- reduce the costs associated (in Health Care) for the patient and the government.

The Foundation is open to all discussions for adoption and implementation as is necessary.