

# Auckland Regional Public Health Service

Rātonga Hauora ā Iwi o Tamaki Makaurau



Working with the people of Auckland, Waitemata and Counties Manukau

## Auckland Regional Public Health Service

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Health IT Investment and Standards  
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### Submission on Ethnicity Data Protocols for the Health and Disability Sector

Thank you for the opportunity for Auckland Regional Public Health Service (ARPHS) to provide a submission on Ethnicity Data Protocols for the Health and Disability Sector.

The following submission represents the views of the ARPHS and does not necessarily reflect the views of the three District Health Boards it serves. Please refer to Appendix 1 for more information on ARPHS.

The primary contact point for this submission is:

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Yours sincerely,

A handwritten signature in blue ink, appearing to read "Jane McEntee".

Jane McEntee  
General Manager  
Auckland Regional Public Health Service

A handwritten signature in blue ink, appearing to read "Dr. Catherine Jackson".

Dr. Catherine Jackson  
Medical Officer of Health  
Auckland Regional Public Health Service

## Summary and recommendations

The change to the protocols relates to the minimum requirements for recording ethnicity data suggesting a change from Level 2 (up to three ethnicities) to Level 4 (up to six ethnicities). It also addresses the requirements for electronic data collection, and who should collect ethnicity data. Also discussed is how often ethnicity data should be updated and the process to confirm existing data.

ARPHS is supportive of having ethnicity data collected at level 4. There are many situations in which Level 0 analyses are appropriate e.g. Māori vs Non-Māori, Pacific vs Non-Māori/Non Pacific for demonstrating and discussing inequities. However prioritised ethnicity goes against the principle of self-identification.

ARPHS supports a limited number of agencies collecting ethnicity data. We also support having a standard user interface, however, the updating via an interface should be as straightforward as possible.

The implementation of the new protocols is likely to be costly - ARPHS inquires whether the Ministry will be providing additional resources.

ARPHS supports three yearly collections of ethnicity data and suggests increased frequency of collection may be appropriate during the transition from adolescence to adulthood. A date of last recorded ethnicity may be needed to trigger when the next collection is due.

ARPHS recommends that:

- there is a standardised process for updating the NHI should a user of health services (that don't routinely collect ethnicity data) indicates that their recorded ethnicity is incorrect.
- data shared from the NHI database to all other health IT systems is at level 4 to maintain consistency across all data systems.
- a standard statistical method be developed for comparing total response outputs for different ethnic groups.
- implementation will need IT modifications and training.

Please see the attached submission form which contains ARPHS full comments on the proposed protocol.

Thank you for the opportunity to contribute a Submission on Ethnicity Data Protocols for the Health and Disability Sector.

## **Appendix 1 - Auckland Regional Public Health Service**

Auckland Regional Public Health Service (ARPHS) provides public health services for the three district health boards (DHBs) in the Auckland region (Auckland, Counties Manukau and Waitemata District Health Boards).

ARPHS has a statutory obligation under the New Zealand Public Health and Disability Act 2000 to improve, promote and protect the health of people and communities in the Auckland region. The Medical Officer of Health has an enforcement and regulatory role under the Health Act 1956 and other legislative designations to protect the health of the community.

ARPHS' primary role is to improve population health. It actively seeks to influence any initiatives or proposals that may affect population health in the Auckland region to maximise their positive impact and minimise possible negative effects on population health.

The Auckland region faces a number of public health challenges through changing demographics, increasingly diverse communities, increasing incidence of lifestyle-related health conditions such as obesity and type 2 diabetes, infrastructure requirements, the balancing of transport needs, and the reconciliation of urban design and urban intensification issues.



## Submission Form

Name: Jane McEntee and Dr Catherine Jackson

Organisation: ARPHS

Please tick which of the following best fits which group you identify with:

- Health care provider
- Consumer
- Vendor
- Researcher
- Government agency
- Other (please state) \_\_\_\_\_

Do you wish to receive a copy of the summary of submissions? If so please provide your email address or contact details so we can forward this to you.

Tracey Poole  
 Policy Analyst  
 Auckland Regional Public Health Service  
[tpoole@adhb.govt.nz](mailto:tpoole@adhb.govt.nz)

	Responses to Key Issues and Questions
Frequency of collection	<p>1. Is the proposed interval of three years appropriate?</p> <p>ARPHS supports three yearly collection of ethnicity.</p>
	<p>2. Are there alternative intervals that should be considered?</p> <p>Increased frequency of collection may be appropriate during the transition from adolescence to adulthood, as young people transition from ethnicity being provided by a proxy (i.e. parent or guardian) to being self-identified.</p>
	<p>3. Are there any issues you can identify with how this might work in practice?</p> <p>The process for knowing when ethnicity data were last collected may make the implementation of this recommendation complicated or impractical. For example, if the NHI database becomes the gold standard source, our service would not currently know when that was last updated.</p>
Process for confirming or correcting existing data	<p>4. What are your thoughts on the process for undertaking ethnicity re-collection?</p> <p>ARPHS supports the recommendation that all agencies that collect</p>

	<p>Responses to Key Issues and Questions</p> <p>ethnicity data re-collect these data using the standard ethnicity question at the next patient contact after 1 July 2017.</p> <p>ARPHS understands that recollection will be a challenging process due to volume. However, limiting this to providers who scored moderate or poor would only be helpful if this is determined by an audit at Level 4. Agencies that score highly on audit, unless they are collecting at level 4 already, will still need to re-collect.</p> <p>Re-collection could be limited to those whose data is currently aggregated at level 2, for example Middle Eastern, Latin American, Other Pacific etc. This would obviate the immediate need to re-collect data for people who only self-identify as NZ European, or Māori, or Samoan, etc.</p>
	<p>5. What are your thoughts on the process for confirmation of existing data?</p> <p>It is unclear from the draft protocol whether or not confirmation of existing data is intended as a replacement for re-collection. The circumstances for its use are also not clear. If an agency such as ARPHS, which currently uses secondary data from the NHI, chooses to confirm ethnicity during a client contact, clear processes would need to be in place for correcting data that were identified as incorrect. This is particularly important if a limited number of agencies are tasked with collecting ethnicity data.</p> <p>The draft protocol states 'It may be possible to design forms used to confirm demographic details with a printout of the details and include a standard ethnicity question with directions to complete this if the current details are incorrect'. ARPHS recommends that a standard process be developed for confirmation and included in the final protocol to avoid agencies approaching this in different ways and potentially biasing ethnicity data. ARPHS supports the forms design described above as the standard process and suggests the wording be amended to read <i>"Forms used to confirm demographic details must include a printout of the currently recorded ethnicity at Level 4 and the standard ethnicity question with directions to complete this if the current details are incorrect."</i></p>
	<p>6. Are there alternatives that need to be considered?</p> <p>ARPHS recommends that a standard process for confirmation be implemented (see response to question 5).</p>
	<p>7. Are there any tools that could assist with the process? Eg, changes to forms?</p> <p>ARPHS recommends that a standard process for confirmation be implemented (see response to question 5).</p>

	Responses to Key Issues and Questions
	<p>8. In practical terms, how could the process of re-collection be managed?</p> <p>Re-collection could be undertaken at the next contact with the health service. Re-collection could be limited to those whose data is currently aggregated at level 2, for example Middle Eastern, Latin American, Other Pacific etc. This would obviate the need to re-collect data for people who only self- identified as NZ European, or Māori, or Samoan, etc.</p>
	<p>9. What will the impact of these changes be on your organisation?</p> <p>The impact of these changes will depend on whether or not Public Health Units are tasked with the collection, re-collection, or confirmation of ethnicity data.</p> <p>ARPHS currently sources the majority of its ethnicity data from the NHI database. If existing historical ethnicity data holdings are to be revised, this would have significant impacts. However, from the submission document it appears that re-collection will only occur from 1 July 2017 and not include pre-existing data.</p> <p>ARPHS does collect ethnicity data for contacts of cases that do not currently have a NHI. Additional training will be required for ARPHS frontline staff once the changes for the Ethnicity Data Protocol have been implemented.</p>
Changes to the minimum requirements for recording ethnicity data	<p>10. What impact will these changes have on you and/or your organisation?</p> <p>ARPHS biggest patient information system collects data at Level 4; however older legacy systems do not and will need to be updated. This is likely to be costly.</p> <p>In addition, all APRHS current systems only collect 3 ethnic groups; they will all need to be updated. As parts of this work may need to be completed by external vendors, there would be some unknowns around cost. In addition, it appears from the draft protocol that an additional free text field will be required to collect the details of "Other ethnicity". ARPHS systems do not currently have this, however the addition will allow us to undertake quality checks of how staff code to level 4. Adding additional fields will incur additional costs to develop, implement and audit. In addition, there may be challenges if respondent's free text is not in English or is misspelled (see question 12 for examples).</p>
	<p>11. What elements of the change process need to be addressed?</p> <p>ARPHS will need to investigate if it has the capacity to update all of its systems in one go considering funding and resource constraints; a</p>

	<p>Responses to Key Issues and Questions</p> <p>transition plan will be required and should be considered as part of the Ministry of Health implementation plan.</p> <p>To support the change; it would be useful for the Ministry of Health to develop resources to support upskilling frontline staff and end users of ethnicity data. Preference should be given to standardised online e-learning modules and resources.</p>
Requirements for electronic data collection	<p>12. What are your thoughts on the electronic collection guidance?</p> <p>ARPHS supports a standard user interface and recommends that this is scalable for use on smaller mobile devices.</p> <p>ARPHS supports consideration of the implications free text entry and mapping to appropriate codes if these are misspelled or if there is more than one other group entered.</p> <p><b>Note:</b> trial of the current interface results in “chnese” (misspelled) being coded as “97777 Response Unidentifiable” and French Irish (no comma) as “97777 Response Unidentifiable”. Whereas “French, Irish” codes correctly. Note, variable coding also occurs for “fijian indian” vs “Fijian-indian” vs “Fijian, indian”.</p> <p>ARPHS suggests that free text data be retained for later audit, as in both of the examples above, having a standard approach, or fuzzy matching logic, would mean that these two examples could have been captured correctly and not resulted in a “97777 Response Unidentifiable” outcome. We suggest there is a risk of increasing the proportion of unidentifiable data using the current standard user interface. It may be preferable to show a wider array of level 2 options than are currently shown.</p> <p>ARPHS also notes that “kiwi” is classified in level 4 as 61118 New Zealander, but in level 2 as 11 NZ European. The level 4 prefix suggests that at level 2 they should be 61 ‘Other ethnicity’.</p> <p>Will there be standard user interfaces built for people with English as a second language to complete, particularly mandarin?</p>
	<p>13. Are there any issues not currently addressed?</p> <p>See also comments under question 12 regarding the risk of increasing the proportion of “97777 Response Unidentifiable”.</p> <p>Random reduction if there are more than six ethnicities is not discussed in the submission template in any detail. ARPHS assumes existing processes will be used; however in reality it is unclear who makes these decisions, the client or the data entry person? Even using existing processes to select those ethnic groups that would be prioritised as high to select from first become more complicated at</p>



	<p>Responses to Key Issues and Questions</p> <p>Level 4 due to the larger number of options available.</p> <p>ARPHS recommends that any free text entry of ethnicity be retained in information systems, allowing the principle of self-identification to be honoured, and for coding at Level 4 to be audited periodically.</p>
	<p>14. Are there any barriers to integrating the Standard User Interface into your relevant IT product of application?</p> <p>We can embed a Web interface into our system. This does raise the question of how we keep our local databases current for internal reporting as ethnicity data can change over time and in different contexts.</p>
Who should collect ethnicity data?	<p>15. Should a limited number of agencies collect ethnicity data?</p> <p>ARPHS supports a limited number of agencies collecting ethnicity data so long as interfacing to the NHI database is straightforward.</p> <p>The submission guidance suggests that “many health agencies will be able to access and update the NHI directly, including ethnicity. This may mean not all agencies will need to collect ethnicity data.” This raises concerns. If an organisation can access and update the NHI directly without needing to implement a standardised collection tool, ARPHS is concerned that this has the potential to introduce inconsistent data.</p> <p>ARPHS recommends there be a standardised process for updating the NHI should a user of health services indicate that their recorded ethnicity is incorrect.</p> <p>This should be clarified in the updated Ethnicity Protocol.</p>
	<p>16. Do you have any comment on the agencies/groups indicated in the box on page 10 (list of agencies/groups required to collect ethnicity data)? In particular, are any missing?</p> <p>ARPHS supports the listed agencies as being appropriate.</p>
	<p>17. Are there any implications for some agencies/groups only being able to lookup or transfer information?</p> <p>ARPHS currently uses ethnicity data in this manner and is unclear of the expectations around confirmation. This protocol should make this clear to agencies that use NHI as the “one source of the truth” for ethnicity data.</p> <p>ARPHS recommends that data shared from the NHI database to all other health IT systems be at level 4 to maintain consistency across all data systems.</p>

	Responses to Key Issues and Questions
	<p>Occasionally a client informs us, or staff identify, that the ethnicity data on record for them is incorrect. ARPHS recommends there be a standardised process for updating the NHI should a user of health services that don't routinely collect ethnicity data indicate that their recorded ethnicity is incorrect.</p>
Refreshed guidance on the output of ethnicity data	<p>18. The refreshed protocols separate Statistics New Zealand standard aggregation and output groupings and non-standard groupings. Is this a useful distinction?</p> <p>ARPHS supports the description of output groupings, and suggests emphasising the importance of the appropriate use of denominators generated using the same methodology when calculating incidence and prevalence.</p>
	<p>19. Are there any alternatives that need to be considered?</p> <p>No</p>
	<p>20. What are your thoughts on the recommendation for routine data to be reported at Level 1 rather than the non-standard super-aggregate Level 0 variable categories often used in health?</p> <p>As indicated in the submission template, outputs are "determined by the purpose for which the data is being analysed and presented". There are many situations in which Level 0 analyses are appropriate e.g. Māori vs Non-Māori, Pacific vs Non-Māori Non Pacific for demonstrating and discussing inequities.</p> <p>However, in routine reporting ARPHS supports Level 1, albeit whilst acknowledging the ongoing issues of numerator denominator mismatch for smaller ethnic group e.g. MELAA and Other ethnicities, particularly in subgroup analyses for example children.</p>
	<p>21. Prioritisation is maintained as an output different from the Statistical Standard for the health and disability sector. Do you have any comments about this?</p> <p>ARPHS seldom uses prioritised ethnicity as this methodology goes against the principle of self-identification and is exclusionary (e.g. approx. 22,000 Pacific Peoples in the ARPHS region are 'lost'). To effectively work with our communities, ARPHS needs to identify the total numbers that self-identify as each ethnic group. This is particularly important in identifying and addressing health inequalities.</p> <p>ARPHS recommends that total response and single/combined ethnicity be endorsed as standard health outputs with a planned phasing out of</p>

	Responses to Key Issues and Questions
	<p>the prioritised classification. Guidelines and standards on the use of these ethnicity classifications are required, particularly in regards to appropriate statistical methodologies (e.g. confidence intervals and risk ratios).</p> <p>The change in collection and reporting of ethnicity should also be aligned to Ministry of Health contracted annual outputs from Statistics New Zealand on subnational ethnicity population estimates.</p>
	<p>22. How might prioritisation work practically in the context of Level 4 ethnicity coding?</p> <p>As per question 21, ARPHS seldom uses prioritised ethnicity as it's not an appropriate output for public health purposes. ARPHS does not support the continued use of prioritised ethnicity data.</p>
	<p>23. Are there other clarifications required for the output of ethnicity data?</p> <p>The importance of the appropriate use of denominators generated using the same methodology when calculating incidence and prevalence should be emphasised.</p>
Implementation	<p>24. What are the key issues to be addressed in order to achieve successful implementation of the refreshed protocols?</p> <p>Implementation will depend on decisions made regarding who is able to collect and update ethnicity data, and how re-collection and confirmation will occur.</p>
	<p>25. What practical resource materials would be helpful?</p> <p>It would be useful for the Ministry of Health to develop resources to support training and upskilling of frontline staff, information systems developers, and end users of ethnicity data. Preference should be given to standardised online e-learning modules and resources. These resources should cover collection, recording, and output of ethnicity data.</p>

