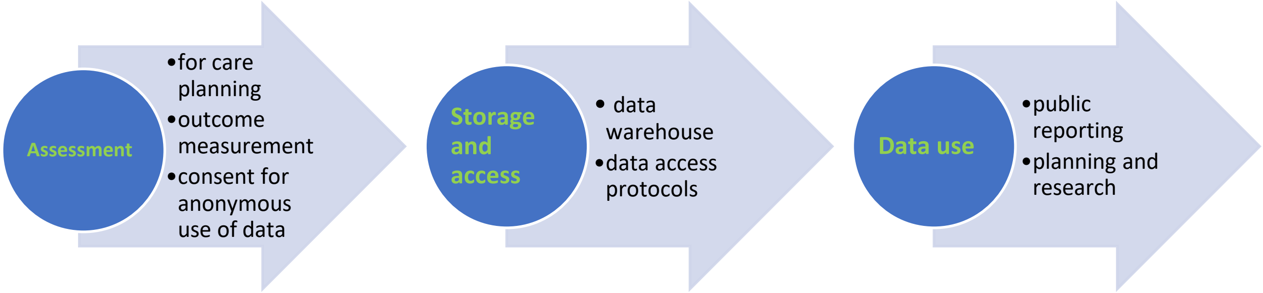
interRAI Data Access Protocols

October 2024



interRAI Services
Planning, Funding and Outcomes
Health New Zealand | Te Whatu Ora

Purpose

This paper outlines the guiding principles that Health New Zealand | Te Whatu Ora (Health NZ) will follow in making decisions about providing unit record interRAI data access to any party. The interRAI data warehouse is administered by Health NZ and contains all records from the interRAI assessment in New Zealand. This paper was last approved by the interRAI New Zealand Leadership Advisory Board on 19th December 2023.

1. Unit record data requests refer to data requests at the client/resident, Aged Residential Care (ARC) facility, and home and community support provider level for all interRAI assessment types in the suite of interRAI assessments. Data requests at that level, involve greater risks for both clients and organisations to be identified from a privacy and security perspective.

2. The interRAI data access protocols set out:

   2.1 The guiding principles that govern interRAI data use and access.

   2.2 Provisions to safeguard the privacy, security, and confidentiality of interRAI clients/residents, ARC facilities and home and community support providers who have provided the data in the first place.

   2.3 Provisions for the publication and release of reports using interRAI data.

   2.4 The application process to access, store and use interRAI data.

3. The previous protocols were approved in 2020 by the interRAI New Zealand Governance Board, the Joint ARC Steering Group and the Health of Older People (HOP) Steering Group.

4. This paper updates the previous protocols to incorporate the security and privacy requirements of new legislation and current best practice, as well as efficiency measures derived from nearly five years of service delivery.

Scope

5. The scope of the interRAI data access protocols includes:

   5.1 All unit record interRAI data requests for interRAI data from the Health NZ data warehouse.

   5.2 Data on all interRAI assessment types from the suite of interRAI assessments held in the data warehouse.

6. ARC facilities, ARC providers and Health NZ organisations can access their own interRAI assessment data via the interRAI software provided to them through the National interRAI Software Service. However, if ARC facilities and providers wish to receive their data analysed and packaged specifically to their needs, they can seek this service from the Health NZ Planning, Funding and Outcomes (PFO) and Data and Digital (D&D) at Health NZ.

Guiding principles to process data requests

7. The following outlines the approved principles interRAI Services, Health NZ will follow in making decisions about granting access to unit record data to all parties. It also sets out the principles for the effective and efficient use, management, storage, and publication of interRAI data.

Principle 1: Ownership of the data

8. All interRAI data collected in New Zealand on individual clients/residents, ARC facilities, and home and community support providers remain the property of participating clients/residents. The Data Steward (Group Manager interRAI Services New Zealand) acts as guardian of interRAI data in New Zealand. This is referred to as Stewardship.

Principle 2: Kaitiaki/Guardianship of the data

9. Once the requesting party receives access to interRAI data, it will act as guardian of that data and ensure:

    9.1 that the data is held and used in accordance with the principles and provisions of the protocols.

    9.2 that the data is analysed, interpreted, reported, and published in culturally appropriate ways.

Principle 3: Privacy of interRAI clients/residents, ARC facilities, home, and community support providers

10. The privacy of individual clients/residents, ARC facilities, and home and community support providers must always be preserved.

11. The management of all interRAI data in the Health NZ data warehouse will be consistent with the Privacy Act which took effect 1 December 2020. The Privacy Act 2020 repealed and replaced the Privacy Act 1993. It promotes early intervention and risk management by agencies (the name used for any organisation or person that manages personal information) and enhances the role of the Privacy Commissioner. The key changes that have implications for interRAI data include:

    - Requirements to report privacy breaches: If an agency has a privacy breach that causes serious harm or is likely to do so, it must notify the people affected and the Commissioner.
    - Strengthening cross-border protections: New Zealand agencies will have to take reasonable steps to ensure that personal information sent overseas is protected by comparable privacy standards. The Act also clarifies that when a New Zealand agency engages an overseas service provider, it will have to comply with New Zealand privacy laws.

12. The management of all interRAI data in the Health NZ data warehouse will comply with the Health Information Governance Guidelines, prepared by the Health Information Standards Organisation (HISO).

13. Ethnicity data is subject to the HISO 10001:2017 Ethnicity Data Protocols.

14. The management of data to preserve Māori Sovereignty is subject to the HISO 10094:2022 Maori Descent and Iwi Affiliation Data Protocols.

15. The royalty-free licence agreement between the Ministry of Health and interRAI requires transfer of anonymous data annually.

16. The data set available to interRAI as part of the licence agreement with the Ministry of Health is the same as that provided to Statistics New Zealand for the Integrated Data Infrastructure (IDI). The IDI is a research database designed to explore anonymous data at a high level. This data does not include:

    16.1 Names of individual

16.2 National personal identifier(s) (e.g., National Health Index)

16.3 Date of birth – Replace with age (in years).

16.4 Ethnicity of individual

16.5 Language further defined than ‘English’ and ‘other.’

17. The IDI is currently the most suitable environment for accessing full anonymous interRAI data. Those requesting a duplicate copy of the interRAI data warehouse will be directed to the IDI.

18. The data collected from and about interRAI clients/residents, ARC facilities, home and community support providers is used for purposes of quality improvement, research, service planning and development and to improve the health outcomes of assessed people.

19. Any interRAI client/resident who has not consented for their anonymised personal information to be used for planning or research purposes is excluded when making unit record data available to any party.

Principle 4: Security of interRAI data

20. The interRAI data held in the Health NZ data warehouse is managed under Health NZ privacy and data security processes.

21. The level of data released will be dependent on criteria reflecting the status of the requester. There are five categories:

    a) A Health NZ organisation or provider requesting their own data,

    b) Recognised repeat requesters attached to recognised institutions engaged in research or planning,

    c) Requesters of data related to formal research or planning,

    d) Ad hoc request for data related to a specific topic,

    e) Requesters of data for commercial purposes.

22. Once interRAI Services, Health NZ approves interRAI data access, the data will be transferred by secure transmission processes to the requesting party.

23. Once interRAI data is received, the requesting party must keep the data safe by use of a secure data network and password protected devices must be used. All information (e.g., National Health Index of clients/residents) will be encrypted during transfer, and only authorised users will be able to access it.

    23.1 Category **a** may keep their data for use under their own Health NZ organisation or Provider privacy and security protocols and use for multiple data activities.

    23.2 Category **b** may keep their data set for use under their own institution’s privacy and security protocols for multiple data use activities, provided data is not transferred elsewhere. interRAI Services, Health NZ is advised of each new project/activity and information about the finished work is provided to interRAI Services, Health NZ.

    23.3 Category **c**, **d**, and **e** requesting parties will manage their data under their own institution’s privacy and security protocols and take the necessary steps to destroy the data within 12 months of the completion of the study. The requesting party will inform interRAI Services, Health NZ by written email once done. Failure to comply may impact on future requests. interRAI Services, Health NZ keeps a record of when data is due for destruction and will send a reminder email.

Principle 5: Confidentiality when disseminating interRAI data

24. When the requesting party publishes any analysis or reports from the use of interRAI data, they must take all reasonable and practicable industry standard measures to minimise the possibility of data being identified. Analysis and reporting may include tables of data, data cubes, journal articles, conference abstracts and presentations, theses, or dissertations.

25. The requesting party must ensure that release of interRAI data complies with the Official Information Act 1982, Privacy Act 2020, Health Information Privacy Code 1994, and any other relevant legislation.

26. The requesting party must acknowledge the use of interRAI data by quoting the source and enable interRAI Services, Health NZ the opportunity to proof any reference to the assessment process and/or education.

    Health NZ National Artificial Intelligence and Algorithm Expert Advisory Group (NAIAEAG) does not endorse the use of Large Language Model (LLMs) or Generative Artificial Intelligence (AI) tools where non-public information is used to train the model or is used within the context of the model. This is due to the risks around breach of privacy, inaccuracy of outputs, bias, lack of transparency, data sovereignty and the intellectual property rights of interRAI.

    Health NZ employees and contractors must not:

    Enter any personal confidential or sensitive patient/client/resident/ or organisational data into LLMs or Generative AI tools.

    https://www.tewhatuora.govt.nz/our-health-system/digital-health/national-ai-and-algorithm-expert-advisory-group-naiaeag-te-whatu-ora-advice-on-the-use-of-large-language-models-and-generative-ai-in-healthcare/

Principle 6: Linking interRAI data with other data sets

27. interRAI data can be linked at various levels to several other health data sets such as Pharmacy, National Minimum Data Set (NMDS), and mortality.

28. The requesting party must explicitly state the data sources they intend to link interRAI data to in their application for data request. Data linkages are encouraged if the provisions in Principles 3, 4 and 5 are maintained.

Principle 7: When there is a breach of data access protocols

29. Once a breach of the data access protocol is identified, Health NZ will immediately conduct a risk assessment of the breach and will take necessary steps to minimise the identified risks. Health NZ will inform all parties of the breach according to the Privacy Act 2020 including informing the Data Steward and the Ministry of Health.

30. As a result, the Group Manager responsible for interRAI Services may grant no further access to interRAI data to the requesting party.

31. If the breach is not resolvable from within Health NZ, the matter will be raised with the Data Steward. The Data Steward will take the necessary steps to minimise risks and issue instructions for actions to be taken accordingly.

Appendix One
Process for interRAI data requests

Applying for access to interRAI data set(s)

Note: each applicant completes an electronic form

1. To apply for access to interRAI data set(s), a requesting party must complete the process set out on the website www.interrai.co.nz.

2. For category **a,** approval is required from a relevant senior manager from the requesting organisation.

3. Category **b** requesters are expected to have internal process that meet the requirements for security and privacy, including ethics approval. The expectation is that they will advise interRAI Services, Health NZ of each new project/activity, using the previously provided data and share information about the outcome described in Principle 5.

4. Requirements for all categories **c, d** and **e** includes completing the data request templated form that includes:

   4.1 A project proposal outlining the study that the requesting party intends to conduct using the data. The project proposal should highlight any data linkages intended with other health data set(s).

   A Health and Disability Ethics Committee (HDEC) approval if required. The HDEC provides protection for participants in study in the health and disability sector. The requester must state their obligations for whether a study requires HDEC ethics approval or not.

   4.2 A list of the interRAI assessment variables required for the study.

   4.3 Contact details for the requesting party. interRAI Services, Health NZ expects that the requesting party is aware of the principles and provisions of the data access protocols and has the skills and experience to interpret interRAI data.

5 For unit level data this includes access to the relevant *Assessment Form and User's Manual* for the intent, definition, and coding of each item. These manuals can be purchased from www.interrai.org or interrai@tas.health.nz

6 A supplementary electronic workbook, *Interpreting interRAI Assessment Outputs – Researchers and Data Analysts Edition* is available from interRAI Services, Health NZ, on request interrai@tas.health.nz.

7 Inexperienced users of interRAI data for research are encouraged to collaborate with experienced users; complete an on-line training programme detailing interRAI assessment methodology, outputs and the national software or obtain support through interRAI Services.

8 Name and contact details of two referees for first time data requestors. The Privacy Act 2020 requires that Health NZ can verify the identity of the requesting party.

9 Provide a reference list of papers and reports that have been produced that may be made available to the Data Steward (when the study is completed).

10 Category **e** requesters of data for commercial purposes must confirm that the outcome will meet Privacy Act 2020 requirements and will result in benefits for assessed persons experience of care, capability of the workforce, better health for

the New Zealand population or better value for the health system. Data may not be used to limit or reduce the commercial reputation of others.

When a data request application form is received

11 Once a data request application is received, interRAI Services, Health NZ interRAI Data Analysts will review the application subject to the guiding principles and make a recommendation to the interRAI Services Group Manager (Data Steward). The form is used internally for managing sign-off and other administrative procedures that record the number and status of applications.

12 interRAI Services, Health NZ expects that the time to process a unit record data request will be twenty-one working days assuming all documentation has been submitted.

Processing costs for data requests

13 The aim is to make interRAI assessment data freely available as much as possible to support evidence-based planning and research. Use of assessment data maximises the value of the interRAI assessment for New Zealand and acknowledges the contribution of the assessed community who provided their consent for their data to be used for public good.

14 Health NZ retains the right to enact a pricing policy for charging a requesting party for data requests. Reimbursement costs will depend upon:

14.1 services covered by the Health NZ Outcome Agreements (district or national level agreements with NGO's)

14.2 the level of the request and the analytical time required in producing the information. This process will be in line with other agencies such as the Ministry of Health and Statistics New Zealand.

Appendix Two

Summary of requester type and associated security and privacy required.

Requestor Category	Requester Description	Security – managing data	Privacy requirements
A	A Health NZ organisation or provider requesting their own data	May keep their data under their own organisation's security protocols and used for multiple data activities.	Managed under Health NZ privacy requirements
B	Recognised repeat requesters attached to recognised institutions engaged in research or planning e.g., University of Auckland	May keep their data set under their own institution's security protocols for multiple data use activities, provided data is not transferred elsewhere.	Managed under their institution's privacy requirements
C	Requesters of data related to formal research or planning	Manage data under their own institution's security protocols and take the necessary steps to destroy the data within 12 months of the completion of the study. Inform Health NZ once this is done by written email and failure to comply may impact on future requests.	Managed under their institution's privacy requirements. Project proposal and Ethics approval required (or state why none is required)
D	Ad hoc request for data related to a specific topic	Manage data under their own institution's privacy and security protocols and take the necessary steps to destroy the data within 12 months of the completion of the study. Inform Health NZ once this is done and failure to comply may impact on future requests.	Managed under their institution's privacy requirements. Project proposal and Ethics approval required (or state why none is required)
E	Requesters of data for commercial purposes	Provide evidence about how data will be managed securely, to meet the standards set out in this protocol. Take the necessary steps to destroy data within 12 months of the completion of its use. Inform Health NZ once this is done and failure to comply may impact on future requests	Mitigation of Privacy Act 2020 requirements explicitly described. Project proposal and Ethics approval required (or state why none is required)