



National Data Analysis and Reporting Centre

Approved interRAI Data Access Protocols

Last updated: September 2016

Purpose

1. This paper outlines the approved guiding principles that the National interRAI Data Analysis and Reporting Centre (the Centre) will follow in making decisions about granting unit record interRAI data access to any party. These guiding principles were approved by the interRAI New Zealand Governance Board, the Joint Aged Residential Care (ARC) Steering Group and the Health of Older People (HOP) Steering Group in March 2016.
2. Unit record level data requests refer to data requests at the client/resident, 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, therefore, involve greater risks for both clients and organisations to be identified from a privacy and security perspective.
3. In particular, the interRAI data access protocols set out:
 - 3.1 The guiding principles that will govern the interRAI data use and access.
 - 3.2 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.
 - 3.2 Provisions for the publication and release of reports using interRAI data.
 - 3.4 The application process to access, store and use interRAI data.

Scope

4. The scope of the interRAI data access protocols includes:
 - 4.1 All unit record interRAI data requests made by any requesting party to the Centre.
 - 4.2 Data on all interRAI assessment types from the suite of interRAI assessments held in the Centre's database, i.e. Contact assessments, Home Care assessments, Long Term Care Facilities (LTCF) assessments and any other assessment types under development in New Zealand.
5. ARC facilities, ARC providers and District Health Boards (DHBs) are able to 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 in a particular way that makes it easier for them to use, they can seek this service from the Centre.

Guiding principles to process data requests

6. The following outlines the approved principles that the Centre 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

7. All interRAI data collected in New Zealand on individual clients/residents, ARC facilities, and home and community support providers remains the property of the participating clients/residents. The interRAI New Zealand Governance Board acts as guardian of the interRAI data on behalf of interRAI New Zealand.

Principle 2: Kaitiaki/Guardianship of the data

8. Once the requesting party receives access to interRAI data, it will act as guardian of the interRAI data collected from clients/residents, ARC facilities, home and community support providers and will ensure:
 - 8.1 that the data is held and used in accordance with the principles and provisions of the proposed protocols.
 - 8.2 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

9. The data collected from and about interRAI clients/residents, ARC facilities, home and community support providers is used for purposes of quality improvement, research purposes, strategic service planning and development and ultimately to improve the health outcomes of older people.
10. The privacy of individual clients/residents, ARC facilities, and home and community support providers must be preserved at all times.
11. Any interRAI client/resident who has not consented for his/her personal information to be used for analytical or research purposes must be excluded when making unit record data available to any party.
12. Once a requesting party receives access to interRAI data, it must comply with the Privacy Act 1993, Section 22 of the Health Act 1956, the Health Information Privacy Code 1994, the Statistics Act 1973 (section 37) and any other relevant legislation.

Principle 4: Security of interRAI data

13. Once the Centre approves the data access, interRAI data will be transferred by secured transmission processes to the requesting party.
14. Once interRAI data is received, the requesting party must keep the data safe by using a secure data network. 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.
15. When the study is completed, the requesting party will take the necessary steps to destroy the data from their network in a timely fashion. The requesting party will inform the Centre once this is done within 12 months of the completion of the study.

Principle 5: Confidentiality when disseminating interRAI data

16. When the requesting party publishes any analysis or reports¹ from the use of interRAI data, no individual client/resident, ARC facility, and home and community support provider should be able to be identified. The requesting party must ensure that release of interRAI data complies with the Official Information Act 1982, Privacy Act 1993, Health Information Privacy Code 1994, and any other relevant legislation.
17. The requesting party must acknowledge the use of interRAI data by quoting the source as agreed by interRAI New Zealand and the Ministry of Health (MoH).

Principle 6: Linking interRAI data with other datasets

18. interRAI data can be linked at various levels to a number of other health datasets such as Pharmacy, National Minimum Dataset (NMDS), mortality, hospitalisation to name a few.
19. The requesting party must explicitly state the data sources he/she intends to link interRAI data to in his/her application for data request. Data linkages are encouraged as long as the provisions in Principles 3, 4 and 5 are maintained.

How to process data requests

Applying to get access to interRAI dataset(s)

20. To apply for data access to the interRAI dataset(s), a requesting party must contact the National interRAI Data Analysis and Reporting Centre by emailing interRAI_Data@CentralTAS.co.nz for an application form (see Appendix 1) and information on the supporting documentation that must be attached to the application form. The supporting documentation required is as follows:
 - 20.1 A project proposal outlining the study the requesting party intends to carry out using the data. The project proposal should highlight any data linkages intended with other health datasets.

¹ Analysis and reporting may include tables of data, data cubes, journal articles, conference abstracts and presentations, theses or dissertations.

- 20.2 A Health and Disability Ethics Committee (HDEC) approval².
 - 20.3 A list of interRAI assessment variables required for the study.
 - 20.4 Contact details for the requesting party. The Centre expects that the requesting party has the skills and experience to use interRAI data and are aware of the principles and provisions of the data access protocols.
 - 20.5 Name and contact details of two referees for first time data requestors. The purpose is to enable the National interRAI Data Analysis and Reporting Centre to verify the identity of the requesting party (section 45, Privacy Act 1993).
 - 20.6 A statement setting out where and when it is proposed that the results of the study will be published (the Dissemination Plan).
 - 20.7 A copy of all papers and reports that have been produced and disseminated as part of the Dissemination Plan.
21. Aside from the above, the following processes must also be followed:
- 21.1 The Centre will contact the requesting party 6-12 months after the data release for a progress report (either via a written report or a presentation).
 - 21.2 At the end of the study, the requesting party is required to destroy all copies of the data and communicate that this has been done to the Centre.

When a data request application form is received

22. Once a data request application is received, the Centre will review the application subject to the guiding principles and make a recommendation to the General Manager, interRAI Services for a decision.
23. The Centre expects that the time frame to process a unit record data request will be approximately a month, assuming all documentation has been submitted.

When there is a breach of data access protocols

24. Once a breach of the data access protocol is identified, the Centre will immediately carry out a risk assessment of the breach and will take necessary steps to minimise the identified risks. The Centre will inform all parties of the breach including informing the interRAI New Zealand Governance Board and the MoH.
25. As a result, the Centre may recommend to the General Manager interRAI Services to grant no further access to interRAI data to the requesting party.

² The Health and Disability Ethics Committee (HDEC) provides protection for participants in study in the health and disability sector. A study is likely to require HDEC ethics approval if it involves the use of human tissue samples, human participants or disclosure of health information. Institutional ethics committees are established by tertiary educational institutions. Most study reviewed by university-led ethics committees are not health related. See <https://www.auckland.ac.nz/en/about/study/re-ethics/health-and-disability-studyethics-committees.html#e67fac2ab6efbd3e939ee6d6ec2bb408> for more information on whether a study requires HDEC ethics approval.

26. If the breach is not resolvable from within TAS, the General Manager interRAI Services will raise the matter with the interRAI New Zealand Governance Board Chair and where appropriate Board members. The interRAI New Zealand Governance Board will take the necessary steps to minimise risks and issue instructions for actions to be taken accordingly.

What is the cost for processing data requests

27. The Centre is in the process of developing a pricing policy for charging a requesting party for data requests, depending on the level of the requests and the analytical time required in producing the information. This process will be in line with other agencies such as the MoH, Statistics New Zealand and the Canadian Institute of Health Information (CIHI).