Te Rēhita Whētuki o Aotearoa
New Zealand Trauma Registry

New Zealand Trauma Registry

Data Use Policy

12 June 2020

FINAL

Status of this policy

This Data Use Policy was formally endorsed by the NZ Trauma Registry Data Governance Group in June 2020.

Purpose of this Data Use Policy

The purpose of this Policy is to articulate the governance and use of major trauma data contained in the New Zealand Trauma Registry (NZTR).

This Data Use Policy is a core policy document delivered by the NZTR Data Governance Group which is part of the broader National trauma Network (the Network). It is intended to be used in conjunction with the following documents:

- NZTR Privacy Framework (2020)
- Data Request From
- Acknowledgement and Authorship Form
- Fees and guidelines for data requests

In addition, the following Acts and Guidelines govern the use of NZTR data:

- Health Act 1956,
- New Zealand Public Health and Disability Act 2000,
- Privacy Act 1993,
- Public Records Act 2005
- DHB General Disposal Authority
- Health Information Privacy Code 1994 (HIPC)
- Health Information Governance Guidelines 2017
- HISO 10029:2015 Health Information Security Framework

Background

The role of the Network is to implement a contemporary formal trauma system across New Zealand to improve outcomes for major trauma patients. The availability of consistent, accurate and timely data is a key initiative of this work to provide:

- Measures for trauma quality improvement,
- Trauma systems performance
- Risk-adjusted benchmarking
- A valuable resource for research to build an understanding of trauma and ultimately improve patient outcomes

Since 1 July 2015 all 20 DHBs have been required to collect the major trauma National Minimum Dataset on all patients who have an ISS score greater than 12 or died in hospital from injury. The NZTR is the central repository of the national minimum dataset for major trauma collected on all major trauma patients.

The Health Quality and Safety Commission (the 'Commission) is contracted by ACC on behalf of the Network to provide a range of functions, including analysis of the NZTR data for reporting and quality improvement initiatives across the trauma system.

NZTR Data Governance Group

The NZTR Data Governance Group is an independent group accountable to the National Trauma Network Governance Group. The Group has a Terms of Reference which outlines the parameters for decisions and has an independent Chair.   The intent of the NZTR Data Governance Group is to provide governance of the NZTR data and assure its use is appropriate and ethical. In its decisions to release data to external parties, the Group considers the privacy of patients, New Zealand law under the relevant provisions, and contribution to the field of knowledge in trauma.

Principles of Data Use

The NZTR contains patient identifiable information (NHI, date of birth etc.) and individual institutions (DHBs, Hospitals, and regions).

The custodianship of Major Trauma Dataset includes:
- DHBs for their own data submitted to the NZTR
- Regions, where there is a regional agreement in place, for the region's data
- The NZTR Data Governance Group as the entity accountable for how NZTR data is used
- Canterbury DHB as the host of the NZTR
- Network and the Commission as the primary user of the NZTR to drive quality improvement in the trauma system

Each custodian has the right and responsibility to approve use of the data according to this policy and in alignment with the NZTR Privacy Framework and the relevant legal and ethical Acts and guidelines. DHBs and regions have the right to receive reports on how the data is being used, disclosed and protected from the NZTR Data Governance Group and Network, at least annually.

The core principles underpinning trauma data governance are to:

1. Keep NZTR data secure and protected from access by any unauthorised person(s) and ensure it is used for authorised purposes only. The NZTR is not publicly accessible, and access to NZTR data is tightly controlled.

2. Enable quality improvement across the trauma system to

    - Understand the patterns of major trauma

    - Report on key performance indicators

    - Provide data for clinical audit

    - Assess performance against NZ and international benchmarks

3. Access to and export of 'raw data' (e.g. in Excel) will be tightly controlled. This includes but is not limited to password protection of the exported file, email to a nominated email address using a secure network (such as Connected Health Network).   Researchers will be asked to commit to use the data only for the purpose proposed and to destroy it after use.

4. Hospitals can use their own NZTR data for the purpose of local audit and quality improvement without prior national approval. Similarly, for regions where there is a regional data sharing agreement in place.

5. Transparent and efficient processes for managing data requests will be developed to support the use of NZTR data for research and publications.

6. Trauma research and publications using NZTR data will be encouraged to contribute to NZ and international trauma research.

Scope

The scope of the NZTR Data Use Policy includes the national minimum dataset for major trauma data collected on all major trauma patients submitted to the Registry. It also includes data collected during the patient reported outcome measures.

Data Use Policy

Data use	Detail	Is NZTR Data Governance approval required?
DHB and regional access to data	Individual DHBs or Hospitals have access to all data submitted by them. Regions may be provided with identified data collected by its DHBs, if there is regional data sharing agreement in place.	No No
Network reports	The National Clinical Lead for Trauma (or delegate) and the Commission has access to all national data for the purposes of preparing national reports, benchmarking, performance measures, and all other national aggregate reporting in collaboration with the DHBs, regions and ambulance services. Reporting of results in publicly available form will be sensitive and respectful of identifying DHBs or regions. This provision excludes special research projects which are led by the Network and the Commission The indicative Network reports are outlined in Appendix A.	No
Research data requests	NZ and international researchers may request national aggregate data for research purposes. The NZTR Data Governance Group has authority for release of patient level data. Such requests for access to the data are made using the NZTR Data Access Forms and other documentation submitted to the NZTR Data Governance Group for consideration. The Group approves proposals before data is released. In principle only non-identifiable patient data will be provided. Exception to this is where there is a valid reason for providing identifiable data such as cross-matching with national or other	Yes

	collections. HDEC approval is typically needed for patient or institution identifiable data. http://ethics.health.govt.nz/	
	Researchers will agree that no report, publication, or other formats will contain information identifying individual patients, clinicians, hospitals, DHBs in their work.	
	Researchers will acknowledge the NZTR data as per the instructions on the 'Guidelines for Provision of Data from The New Zealand Trauma Registry' Form. The form is in Appendix B	
	Fees may be payable as per the 'Fee for Provision of Data from The New Zealand r Trauma Registry' in Appendix C.	
	A data request form is to be completed outlining the proposal, in Appendix D.	

Roles and responsibilities

Network Governance Group   Over-arching accountability for the Network programme of work, including endorsement of the Data Use Policy and Privacy Framework.

National leadership   Leads analysis of national data to inform policy and strategic direction. Manages publication of national data in line with this Data Use Policy.

NZTR Data Governance Group   Develops and implements this policy. Manages stakeholder engagement on data use and privacy. Reviews requests for data to accept or decline, taking into account the need for ethics and any other approval which may be required. Endorses the NMDS from the perspective of ethics and appropriateness.

Commission   Analysis of trauma data to inform quality improvement and for reporting.

Network Operational Group   Endorses the NMDS from an operational perspective. Conduit between the DHBs, regions and the Network. Operationalises changes to the trauma system arising from research or policy etc.

Dendrite and Canterbury DHB   Hosts the NZTR on behalf of participating DHBs. Provides the data for reporting.

DHBs + Regional Trauma Networks   Provides input to the NZTR Governance Group via regional representatives.

Appendix A: Network Reporting Framework

Data report	Description	Frequency	Prepared for:
Volume report	Events entered ISS grouping CFR	Monthly	Network Ops
Annual Report	Annual report of regional and national aggregate data	Annually	Public release
Ad hoc reports	Up to fivead hoc reports per annum on agreement by the Network Operational Group	Ad hoc	Network all groups Regions DHBs
Performance measures	Reporting of nationally agreed performance measures	at least annually	Network all groups Regions DHBs
Business Intelligence tools to interrogate DHB, region, and national aggregate data	Business Intelligence to enable DHBs, regions and the Network to interrogate their own data	at least annually	Network all groups Regions DHBs
Data extract of all NMDS elements	Transfer of all data elements from the NZTR to: - DHBs for their own data - Regions for regional data - Network for national data	As agreed	Network all groups Regions DHBs

Appendix B: Authorship and Acknowledgement Form

Guidelines for Provision of Data from The New Zealand Trauma Registry

- The New Zealand Trauma Registry (NZTR) is a valuable source of data about major trauma patients in New Zealand. Access to the data, and requests for data from the NZTR database are subject to strict access guidelines (see Data Use Policy for The New Zealand Trauma Registry).

- Conditional to the provision of data from the NZTR, the NZTR must be acknowledged as the source of the data. The recommended reference is:

  "We wish to thank The New Zealand Trauma Registry (NZTR) group, which is sponsored by the Accident Compensation Corporation and the Ministry of Health, for the provision of NZTR data."

- Where the interpretation of NZTR data is central to the data request, it is expected that at least one member of the NZTR team is named as a co-author on any publication arising from use of data from this project. The actual NZTR contributor/s to be named will depend on the contribution to the particular data exercise.

- The capture rate applicable to the period/s of NZTR data provided must be quoted with any published data. This information will be provided to you with your completed data request.

- It would be appreciated if you could provide (via the email address below) the NZTR group with a copy of any document or presentation in which you quote these figures. A record is maintained of all requests for NZTR data and its subsequent use as a means of monitoring its use by those interested in trauma data.

- I agree to acknowledge The New Zealand Trauma Registry for the provision of data for reports, presentations, publications and documents as appropriate.

Signature: _____   Date: [   ]

Print: _____

Position [   ]   Organisation [   ]

Phone [   ]   Email [   ]

Please sign and email this form to help@majortrauma.nz

Appendix C: Fee for provision of NZTR data

Fee for Provision of Data from The New Zealand Major Trauma Registry

- The New Zealand Trauma Registry (NZTR) is a valuable source of data about major trauma patients in New Zealand. Access to the data, and requests for data from the NZTR database are subject to strict access guidelines (see Data Use Policy for The New Zealand Trauma Registry).

- All data summaries and analyses provided by NZTR will incur a fee to cover the costs for staff to undertake this work.

- The minimum charge per hour of work (or part thereof) is $100. Thus, a data analysis/report requiring 1 and a half hours of NZTR time will be charged at $150

- The fee of $100 per hour (or part thereof) is for basic tabulations and data extractions only. When more detailed analysis of data is required (e.g. statistical comparisons, statistical modeling, etc.), this will need to be charged at a high rate.

- GST (15%) is also payable and the overall charge per hour (or part thereof) is therefore $115 for a standard analysis

- Upon receipt of a data analysis request, NZTR will send the data requester a cost estimate to undertake the work. This will normally be within 2 weeks of receipt of the request. All data requesters must agree to these costs (in writing) before any data request can be met.

- See also Acknowledgment and Authorship (Guidelines for Provision of Data from The New Zealand Trauma Registry).

Signature: _____ Date: _____

Print: _____

Position _____ Organisation _____

Phone _____ Email _____

Please sign and email this form to help@majortrauma.nz

Appendix D: Data Request Form

Data Request Form

Te Rēhita Whētuki o Aotearoa
New Zealand Trauma Registry

Date of request

Requestor Details

First name   Last name

Phone   Email

Position   Organisation

Are you a student?   Yes   No   If yes, what degree

Supervisor name and contact number

Project Details

Short title of data request

Please provide a short description of your project below, and please attach a comprehensive protocol to your application.

Who are your collaborating researchers?

What are you intending to do with this research? If you are intending to publish, which journal or other format?

I understand this data cannot be shared to other parties. I agree that any distribution of data or publications resulting from this data will not be released without prior written approval by the NZTR Data Governance Group.

Data Request Form

Te Rēhita Whētuki o Aotearoa
New Zealand Trauma Registry

Data Required:

Date Range   From: [   ]   To: [   ]

Please tick the data points that you require for your study

Definitive Care Hospital

Incident number

Encrypted National Health Index

Non-encrypted National Health Index

Patient first and last name

Date of birth

Age

Sex

Ethnicity

Weight

Date & Time of Injury

Injury Cause

Dominant Injury Type

Place of Injury (Domicile) Code

Injury Intent

Place of Injury Occurrence

Activity Engaged in when Injured

Injury Event Description

Safety Devices Used

Date & Time of Observations at Scene

Scene Pulse

Scene Systolic BP

Scene Spontaneous Respiratory Rate

Scene GCS Eye

Scene GCS Voice

Scene GCS Motor

Scene Total GCS

Mode of Transport from Scene

Referring Hospitals

Referring Hospital Pulse

Referring Hospital Systolic BP

Referring Hospital Respiratory Rate

Referring Hospital Temperature

Referring Hospital GCS Eye

Referring Hospital GCS Voice

Referring Hospital GCS Motor

Referring Hospital Total GCS

Referring Hospital Vital Sign Qualifiers

Date & Time of Observations at Referring Hospital

Date & Time of Departure from Referring Hospital

Mode of Transport to Definitive Care Hospital

Date & Time of Observations at Definitive Care Hospital

Definitive Care Hospital Pulse

Definitive Care Hospital Systolic BP

Definitive Care Hospital Respiratory Rate

Definitive Care Hospital Temperature

Definitive Care Hospital GCS Eye

Definitive Care Hospital GCS Voice

Definitive Care Hospital GCS Motor

Definitive Care Hospital Total GCS

Definitive Hospital Vital Sign Qualifiers

Trauma Call on arrival

Blood Alcohol Concentration on Arrival

First Measured Venous Base Excess

First Measured INR

Date & Time Index CT Performed

Discharge Date & Time

Disposition After ED

Patient Intubated?

Date & Time Patient Intubated

Emergency Operative Procedures

Date & Time for Each Emergency Procedure

AIS Injury Codes

Injury Severity Score

Number of Hours on Ventilator

Total Length of Stay

Length of ICU Stay

Tertiary survey at Definitive Care

Hospital Diagnosis Made >48 hours After Arrival?

Discharge Destination from Acute Care

Date & Time of Discharge from Definitive Care

Type of Death

Te Rēhita Whētuki o Aotearoa
New Zealand Trauma Registry

Data Request Form

Data required from all Hospitals?   Yes ☐
If no, please specify the region(s)/hospital(s) required:

Is this research funded?   Yes ☐   No ☐
If yes, who has funded this?

Have you received ethics approval for this research?   Yes ☐   No ☐
If yes, please attach copy of ethics application and approval. If no, please state why approval was not/will not be obtained.

Security of Data Extracts
Please provide details of the storage of data, including details on location and security of data. And the destruction schedule of the data (anticipated date and method of destruction)

Please advise the method or format you would like the data to be transferred to you securely? (eg. external hard drive, cloud storage)

Privacy
I confirm that I have read and understood the NZTR Data Use Policy and will adhere to its conditions. I confirm I will use the data only for the specific purpose agreed to by the NZTR Data Governance Group:

Signature: _____   Date: _____

Upon completion of this form please forward it by email to the below address, you will receive an email of receipt and your request will be logged. Once your application has been processed you will receive notification via email regarding the outcome.
help@majortrauma.nz

Approval for Data Release (office use only)

The NZTR Governance Group authorise the use of this data based on the data use policy and Term of Use.

Signature of the CD: _____   Date: _____