



**Te Rēhita Whētuki o Aotearoa**  
**New Zealand Trauma Registry**

**Te Whatu Ora**  
**Health New Zealand**

# **New Zealand Trauma Registry**

## **Data Use Policy**

**December 2023**

## 1. STATUS OF THIS POLICY

This Data Use Policy was formally endorsed by the NZ Trauma Registry –Data Governance Group in June 2020, and updated in September 2023 to reflect changes to the law and the reformed health system of Aotearoa New Zealand, including the establishment of Te Whatu Ora – Health New Zealand (“Te Whatu Ora”)and Te Aka Whai Ora – The Māori Health Authority.

## 2. PURPOSE OF THIS DATA USE POLICY

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

Data held in the NZTR is primarily intended to be used as a source of aggregate data for quality improvement, research and statistical purposes, and/or in ways in which individuals are not identified.

This Data Use Policy is a core policy document delivered by the NZTR Data Governance Group which is part of the broader –Te Hononga Whētuki ā-Motu - National Trauma Network (“the Network”). It is intended to be used in conjunction with the following documents:

- NZTR Privacy Framework (2020)
- Data Request Form
- 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
- Pae Ora (Healthy Futures) Act 2022
- Privacy Act 2020
- Public Records Act 2005
- Te Whatu Ora General Disposal Authority
- Health Information Privacy Code 2020 (HIPC)
- HISO 10064:2017 Health Information Governance Guidelines 2017
- HISO 10029:2022 Health Information Security Framework.

## 3. BACKGROUND

Te Whatu Ora leads the day-to-day running of the health system across New Zealand, with functions delivered at local, district, regional and national levels. In particular, Te Whatu Ora manages all health services, including hospital and specialist services, and primary and community care, which were previously managed by the 20 former District Health Boards.

Te Aka Whai Ora is an equal partner in the reformed health system of Aotearoa New Zealand, which provides a Te Tiriti o Waitangi lens on the delivery of all health services for Māori working together with Te Whatu Ora. Te Aka Whai Ora’s role is to lead and monitor transformational change in the way in which planning and service delivery responds to aspirations and needs of whānau Māori.

The role of the Network is to implement a contemporary formal trauma information 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 national NZ data supporting:

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

Since 1 July 2015, all public hospitals in New Zealand have collected the major trauma National Minimum Dataset on patients who have been admitted to hospital with an Injury Severity Score (ISS) greater than 12, or who have died in hospital following injury. The NZTR is the central repository of the national minimum dataset for major trauma collected on all major trauma patients.

Te Tāhū Hauora – the Health Quality and Safety Commission (“the Commission”) is contracted by Te Kaporeihana Āwhina Hunga Whara- Accident Compensation Corporation (the “CC”) 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.

#### **4. 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.

#### **5. PRINCIPLES OF DATA USE**

The NZTR contains patient identifiable information (National Health Index – NHI,, date of birth etc.) and individual institutions (Te Whatu Ora, Hospitals, and regions).

The custodianship of the Major Trauma Dataset includes:

- Te Whatu Ora hospitals for its 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
- Te Whatu Ora Waitaha Canterbury as the host of the NZTR
- The 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.

Te Whatu Ora 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. Tightly control access to and export of 'raw data' (e.g. in Excel). 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 agreed in the NZTR Data Request Form and to securely maintain the data as required only for audit and publication following its intended use (as required by the Health Information Privacy Code).
4. Enable Hospitals to use their own NZTR data for the purpose of local audit and quality improvement without prior national approval. The same applies to regions where there is a regional data sharing agreement in place.
5. Provide a transparent and efficient processes for managing data requests that support the appropriate use of NZTR data for research and publications.
6. Encourage trauma research and publications using NZTR data to contribute to NZ and international trauma knowledge.

## 6. SCOPE

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

## 7. BI-NATIONAL DATA USE

Alfred Health, through the National Trauma Research Institute with the support of the Federal Government of Australia, facilitates the Australia New Zealand Trauma Registry (**ANZTR**) under the auspices of Australian Trauma Quality Improvement Programme (**AusTQIP**).

Te Whatu Ora has entered into an agreement with Alfred Health for the provision and use of the NZTR data for the purpose of bi-national benchmarking. Between 1 October and 31 December of each year, the Commission will provide complete and accurate de-identified NZTR data from Auckland City Hospital, Starship Hospital, Middlemore Hospital, Waikato Hospital, Wellington Hospital, Christchurch Hospital and Dunedin Hospital to Alfred Health for inclusion in the ANZTR.

Alfred Health will not provide to, or allow the NZTR Data to be accessed by, any third party without the prior written consent of the NZTR Data Governance Group.

## 8. DATA USE POLICY

Data use	Detail	Is NZTR Data Governance approval required?
Te Whatu Ora access to data	<p>Te Whatu Ora and individual hospitals have access to all data submitted by them.</p> <p>Regions may be provided with identified data collected by Te Whatu Ora districts, if there is regional data sharing agreement in place.</p>	<p>No</p> <p>No</p>
Network reports	<p>The National Clinical Co- Leads for Trauma (or National Clinical Network 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 Te Whatu Ora and ambulance services.</p> <p>Reporting of results in publicly available form will be sensitive and respectful of identifying Te Whatu Ora districts or regions.</p> <p>Ad hoc reports may be requested by the National Clinical Network or Te Whatu Ora employees for investigative studies or for the purpose of quality improvement or audit purposes.</p> <p>The indicative Network reports are outlined in Appendix A.</p>	<p>No</p>
Research data requests	<p>NZ and international researchers may request national aggregate data for research purposes.</p> <p>In principle only non-identifiable patient data will be provided.</p> <p>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, including research requests which arise from the agreement with Alfred Health for the bi-national Australia New Zealand Trauma Registry ANZTR. The Group must provide written approval of any such requests</p> <p>Only where there is a valid reason for providing identifiable data to link with national or other collections, will identifiable data will be provided.</p>	<p>Yes</p>

Data use	Detail	Is NZTR Data Governance approval required?
	<p>Except where there is a valid reason for providing identifiable data link with national or other collections only the non-identifiable data will be provided. NZ Ethics approval is typically needed for patient or institution identifiable data. <a href="https://ethics.health.govt.nz/">https://ethics.health.govt.nz/</a></p>	
	<p>Researchers will agree that no report, publication, or other formats will contain information identifying individual patients and clinicians in their work. It may be possible for hospitals or district level information to be identified within research, and this will be confirmed by the NZTR Data Governance Group where it benefits the national trauma system. Release of data should be consistent with current national policies regarding locality approval for data use and ethics approval by HDEC.</p> <p>The NZTR Data Governance Group may decline to release data that could allow secondary identification of an individual or a cohort associated with unique circumstances such as: rare or high-profile injury events; geographic specificity; identifiable ethnic groups; or temporal factors;</p> <p>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.</p> <p>Fees may be payable as per the 'Fee for Provision of Data from The New Zealand Trauma Registry' in Appendix C.</p> <p>A data request form is to be completed outlining the proposal, in Appendix D.</p>	

## 9. ROLES AND RESPONSIBILITIES

<b>National Trauma Governance Group</b>	Over-arching accountability for the Network programme of work, including endorsement of the Data Use Policy and Privacy Framework.
<b>National Co-Leads</b>	Leads analysis of national data to inform policy and strategic direction. Manages publication of national data in line with this Data Use Policy.
<b>NZTR Data Governance Group</b>	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 NZTR NMDS from the perspective of ethics and appropriateness.
<b>Health Quality &amp; Safety Commission</b>	Analysis of trauma data to inform quality improvement and for reporting.
<b>Network Operational Group</b>	Endorses the NZTR NMDS from an operational perspective. Conduit between Te Whatu Ora, regions and the Network. Operationalises changes to the trauma system arising from research or policy etc.
<b>Dendrite and Te Whatu Ora Waitaha Canterbury</b>	Hosts the NZTR on behalf of Te Whatu Ora. Provides the data for reporting.
<b>Te Whatu Ora + Regional Trauma Networks</b>	Provides input to the NZTR Governance Group via regional representatives.
<b>Te Whatu Ora Privacy Team</b>	<p>Provides oversight for Te Whatu Ora on privacy matters whenever there is a substantive change to this Policy.</p> <p>For any difficult use cases, or significant privacy-relevant decisions the DDG need to take which are not covered by the policy, the Te Whatu Ora Privacy team can assist with advice. This may involve a Privacy Advisor attending a DDG meeting if the issue requires discussion, but may also cover written advice.</p>

## APPENDIX A: NETWORK REPORTING FRAMEWORK

Data report	Description	Frequency	Prepared for:
<b>Annual Report</b>	Annual report of regional and national aggregate data	Annually	Public release
<b>Ad hoc reports</b>	Up to five ad hoc reports per annum on agreement by the Network	Ad hoc	Network all groups Regions Te Whatu Ora
<b>Performance measures</b>	Reporting of nationally agreed performance measures	At least annually	Network all groups Regions Te Whatu Ora
<b>Business Intelligence tools to interrogate Te Whatu Ora district, region, and national aggregate data</b>	Business Intelligence to enable Te Whatu Ora, regions and the Network to interrogate their own data	At least annually	Network all groups Regions Te Whatu Ora
<b>Data extract of all NZTR NMDS elements</b>	Transfer of all data elements from the NZTR to:  Te Whatu Ora for its own data  Regions for regional data  Network for national data	As agreed	Network all groups Regions Te Whatu Ora



- 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 Te Whatu Ora and the Accident Compensation Corporation, 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 use the NZTR data provided. 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 NZTR as the source 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](mailto:help@majortrauma.nz)

- 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).
- Data summaries and analyses provided by NZTR may 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 +GST. Thus, a data analysis/report requiring one and a half hours of NZTR time will be charged at \$150 + GST
- The fee of \$100 + GST 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 modelling, etc.), this will need to be charged at a higher rate.
- 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 two 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](mailto:help@majortrauma.nz)



# Data Request Form

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

**Data Required:**

**Date Range:**

From:  To:

*Note: Please tick the following variables that you require for your study*

<input type="checkbox"/>	Definitive Care Hospital	<input type="checkbox"/>	Referring Hospital Vital Sign Qualifiers
<input type="checkbox"/>	Incident number	<input type="checkbox"/>	Mode of Transport from Scene Referring Hospital
<input type="checkbox"/>	Encrypted National Health Index	<input type="checkbox"/>	Date & Time of Observations at Referring Hospital
<input type="checkbox"/>	Non-encrypted National Health Index	<input type="checkbox"/>	Date & Time of Departure from Referring Hospital
<input type="checkbox"/>	Patient first and last name	<input type="checkbox"/>	Mode of Transport to Definitive Care Hospital
<input type="checkbox"/>	Date of birth	<input type="checkbox"/>	Date & Time of Observations at Definitive Care Hospital
<input type="checkbox"/>	Age	<input type="checkbox"/>	Definitive Care Hospital Pulse
<input type="checkbox"/>	Sex	<input type="checkbox"/>	Definitive Care Hospital Systolic BP
<input type="checkbox"/>	Ethnicity	<input type="checkbox"/>	Definitive Care Hospital Respiratory Rate
<input type="checkbox"/>	Weight	<input type="checkbox"/>	Definitive Care Hospital Temperature
<input type="checkbox"/>	Date & Time of Injury	<input type="checkbox"/>	Definitive Care Hospital GCS Eye
<input type="checkbox"/>	Injury Cause	<input type="checkbox"/>	Definitive Care Hospital GCS Voice
<input type="checkbox"/>	Dominant Injury Type	<input type="checkbox"/>	Definitive Care Hospital GCS Motor
<input type="checkbox"/>	Place of Injury (domicile) Code	<input type="checkbox"/>	Definitive Care Hospital Total GCS
<input type="checkbox"/>	Injury Intent	<input type="checkbox"/>	Definitive Hospital Vital Sign Qualifiers
<input type="checkbox"/>	Place of Injury Occurrence	<input type="checkbox"/>	Trauma Call on Arrival
<input type="checkbox"/>	Activity Engaged in when Injured	<input type="checkbox"/>	Blood Alcohol Concentration on Arrival
<input type="checkbox"/>	Injury Event Description	<input type="checkbox"/>	First Measured Venous Base Excess
<input type="checkbox"/>	Safety Devices Used	<input type="checkbox"/>	First Measured INR
<input type="checkbox"/>	Date & Time of Observations at Scene	<input type="checkbox"/>	Date & Time Index CT Performed
<input type="checkbox"/>	Scene Pulse	<input type="checkbox"/>	Discharge Date & Time Disposition After ED
<input type="checkbox"/>	Scene Systolic BP	<input type="checkbox"/>	Patient Intubated?
<input type="checkbox"/>	Scene Spontaneous Respiratory Rate	<input type="checkbox"/>	Date & Time Patient Intubated
<input type="checkbox"/>	Scene GCS Eye	<input type="checkbox"/>	Emergency Operative Procedures
<input type="checkbox"/>	Scene GCS Voice	<input type="checkbox"/>	Date & Time for Each Emergency Procedure
<input type="checkbox"/>	Scene GCS Motor	<input type="checkbox"/>	AIS Injury Codes
<input type="checkbox"/>	Scene Total GCS	<input type="checkbox"/>	Injury Severity Score
<input type="checkbox"/>	Mode of Transport from Scene	<input type="checkbox"/>	Number of Hours on Ventilator
<input type="checkbox"/>	Referring Hospitals	<input type="checkbox"/>	Total Length of Stay
<input type="checkbox"/>	Referring Hospital Pulse	<input type="checkbox"/>	Length of ICU Stay
<input type="checkbox"/>	Referring Hospital Systolic BP	<input type="checkbox"/>	Tertiary Survey at Definitive Care
<input type="checkbox"/>	Referring Hospital Respiratory Rate	<input type="checkbox"/>	Hospital Diagnosis Made >48 Hours After Arrival?
<input type="checkbox"/>	Referring Hospital Temperature	<input type="checkbox"/>	Post-Traumatic Amnesia (PTA) Screening
<input type="checkbox"/>	Referring Hospital GCS Eye	<input type="checkbox"/>	Discharge Destination from Acute Care
<input type="checkbox"/>	Referring Hospital GCS Voice	<input type="checkbox"/>	Date & Time of Discharge from Definitive Care
<input type="checkbox"/>	Referring Hospital GCS Motor	<input type="checkbox"/>	Type of Death
<input type="checkbox"/>	Referring Hospital Total GCS		



# 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?

Is this project exempt from ethics review as required by HDEC? Yes  No

Has this project been authorised by the appropriate local or regional locality research committee? Yes  No

*Please attach a copy of all ethics applications and approvals. 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)

# Data Request Form

**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](mailto: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 (Governance Group Representative):

Date: