Privacy Management Plan for the Australia New Zealand Trauma Registry

Version

1.0 August 2023

Contents

Version control

Version	Comment / changes
2023	First version of the ATR Privacy Management Plan in line with The Privacy Act 1988 (Privacy Act)

Review of this Privacy Management Plan

Legal review, The Alfred. The Alfred is the legal entity for the ATR. Reviewed June 2023.

ATR Board: Endorsed August 2023

Contact:

Professor Mark Fitzgerald, Co-Chair ATR, Director of Trauma Services, Alfred Health.
M.fitzgerald@alfred.org.au

Siobhan Isles, Co-Chair ATR, National Programme Director, NZ Trauma Network,
siobhan.isles@majortrauma.nz

Introduction

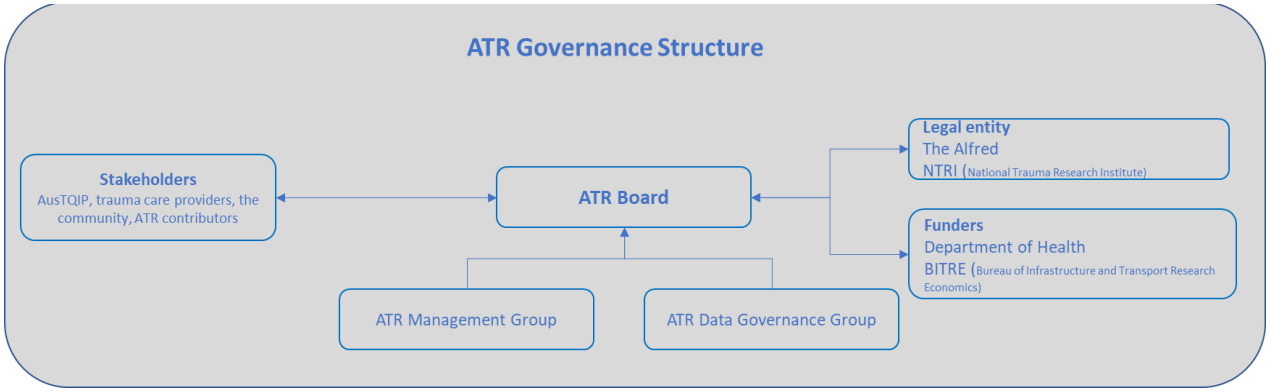
This document provides a comprehensive overview of the privacy considerations for the ATR. It describes the measures taken to protect the privacy of patient information from the point of collection through to storage, access and use. It also responds to each of the 13 principles outlined in the Privacy Act, 1988.

Part 1: Overview of the ATR

The ATR is a national clinical quality registry of all people admitted to hospital with trauma who meet the inclusion criteria since 2012. The minimum dataset includes demographic information about the individual injured, the circumstances surrounding how the injury occurred, and a sub-set of the patients' pre-hospital and hospital clinical record. The ATR is the foundation for a contemporary, data-driven trauma system in Australia.

The ATR is funded by and accountable to the federal Department of Health, the Bureau of Infrastructure and Transport Research Economics, and receives contribution by Accident Compensation Corporation (NZ) and in-kind resources from Monash University, the National Trauma Research Institute and The Alfred. The Alfred is the legal entity for the ATR.

The following diagram shows the various organisations and groups involved in data collection and management as they relate to this Privacy Management Plan.



Role of the ATR Board

The Board has oversight of all ATR activities and for defining and achieving the strategic goals of the ATR. All activities carried out by the ATR are to make data accessible to prevent and improve trauma care.

Role of the ATR Data Governance Group

The Data Governance Group reviews all requests to use ATR data to ensure they are ethical, appropriate, and contribute to knowledge of trauma in Australia.

Legal Framework for the ATR

The ATR will comply with ATR Privacy Management Plan for the collection, management and use of health information about individuals held within ATR. The 13 Privacy Principles articulated in the Privacy Act are used in this document as the framework of controls for the safe management of health information about identifiable individuals. The legal arrangements for the ATR are held by The Alfred.

Ethical approval of the ATR

The ATR has received ethics approval from Monash University Human Research Ethics Committee CF12/2577 – 20120011386.

The primary ethical and privacy consideration of the ATR is that of maintaining patient confidentiality across all steps in the gathering, storage and use of information. The remainder of this paper describes the measures taken to assure the privacy of personal information.

Collection

What information will be collected?

The ATR Bi-National Minimum Dataset details the data set being collected. Eligibility for entry to the Registry includes patients admitted to hospital after trauma and whose injuries are severe enough to meet the criteria that are set. Injuries are assessed using the Injury Severity Score (ISS) which is based on scoring the severity of each anatomical injury, and the higher the ISS, the greater the threat to life. This score is used in contemporary trauma systems worldwide and allows risk adjusted performance measures to be benchmarked across different jurisdictions.

All patients who have an ISS score of 13 or more, or ISS under 13 and die after admission to hospital, are entered to the ATR.

The data collected broadly includes:

Demographic data including date of birth, ethnicity, and sex. No patient identifiable information is included. Codes are included which can reference back to the registry in the state/territory the data was submitted from.

Incident details including the time and date of the injury, what the person was doing when they were injured, location, and description.

Pre-hospital information including vital signs such as heart rate, blood pressure, and Glasgow Coma Score. Information about how the patient was transported to hospital is also included.

Hospital information including the date and time of admission to hospitals the patient was taken to, vital signs, emergency procedures, diagnostic imaging, adverse events, whether there were any serious missed injuries, and where the patient was discharged to.

How will information be collected?

Information is collected by trauma nurses and trauma data managers in the contributing sites. The information is gathered from the patient's clinical record, which includes hospital and pre-hospital information.

Why is this information collected?

Using the information collected will help us to understand the patterns of injury, the processes of care, and the outcomes for those injured. This will:

- Enable the ATR Board to monitor and evaluate the effectiveness of the trauma system with the goal of reducing mortality, minimising disability for those that survive, and improving effectiveness of the trauma system as a whole
- Support audit and quality improvement activities to change the parts of the trauma system that could be improved
- Identify the issues that impact on recovery and chronic health impacts which result from injury.
- Support research into the understanding of the patterns of injury, processes of care and outcomes

How will individuals be informed that information is being collected?

Personal information is collected for clinical care and covered by existing collection statements within each contributing site.

Who handles this information?

The institutions responsible for handling of the ATR dataset include:

- Contributing sites for the data they submit to the ATR
- States and territories for data held in their registries, of which a set or sub-set is sent to the ATR
- Alfred Health as the legal entity for the ATR, and the entity contracted by the Commonwealth to manage the ATR.
- Monash University as the entity subcontracted by Alfred Health to host and manage the data on its systems as well as to deliver the analytics and reporting functions

The ATR Data Governance Group is the entity accountable for ATR data to ensure the use of data is ethical and appropriate. The DGG will consist of:

- Independent Chair
- Aboriginal or Torres Strait Island representative to provide data sovereignty expertise
- Clinical representative from AusTQIP
- Biostatistician
- ATR Board representative
- Consumer representative

Security

All data related to the ATR is collected and stored in Australia. Data storage and management is subcontracted to Monash University.

Collection at DHBs and input to the ATR

Security at Monash University

All authorised users are required to sign confidentiality statements and are Monash University employees with individual username and password. All staff also carry out regular cyber security awareness training.

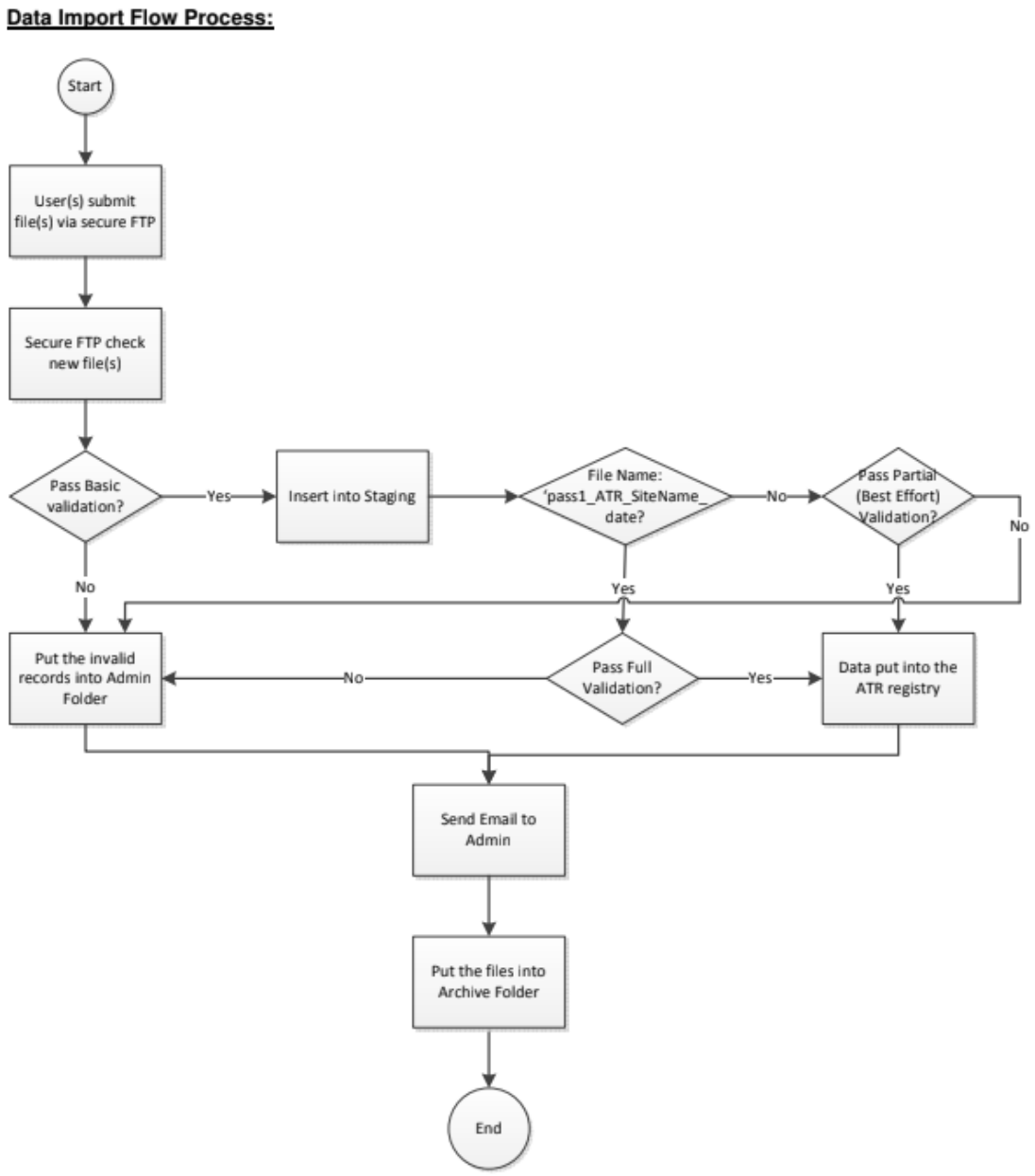
Backup

The data is stored on the Monash University high availability SQL cluster. Data is backed up twice daily. All data is stored across two geographically isolated sites in ISO27001 Certified data centres with standard eSolutions disaster recovery.

Data transfer

Contributing sites transfer their data to the ATR by uploading to the Helix SFTP server. This is a secure file transfer protocol.

Data sent to the ATR is ingested into the database using an automated process as outlined below:



Access

A small number of users need to access the ATR database via analytical tools. This includes the ATR Data Manager (contracted to Monash University), and Helix staff as required to support the system. All access to the database is via a bastion host server, accessed via Citrix Workspaces. All access to this server is logged and protected by username, password and multifactor authentication.

Patient Access

All patients have the right to access information about them collected in the ATR. Patients will not be able to access the ATR directly, however an extract of their information can be made available to them on request. If a patient wishes to access their information held in the ATR, the onus is on the relevant contributing site to inform the ATR Data Manager to extract that patient's information, using the unique code between the contributing site and the ATR.

Effort will be made to facilitate discussion between the patient and the hospital clinician to address any questions that may arise about their record.

Opting out

If a patient wishes to opt-out of the ATR they can do so. If a patient wishes to opt out of the ATR, the onus is on the relevant contributing site to inform the ATR Data Manager to delete that patient's information, using the unique code between the contributing site and the ATR.

Patient correction of information

If a patient wishes for their information to be corrected, depending on the nature of the request, the person making the request may be asked to put it in writing. If a patient wishes to change information held in the ATR, the onus is on the relevant contributing site to inform the ATR Data Manager to change that patient's information, using the unique code between the contributing site and the ATR.

Audit Log

All submissions of data into ATR are from authorised and named persons who submitted that data. The ATR also has the capability to audit who views a patient record. Audits will be undertaken on an as required basis and at minimum annually. Monash University will undertake the audit and report back summary findings to the ATR Board.

Inappropriate access

Inappropriate access to information on the ATR by any user is considered a serious breach of trust and would be a breach of the Confidentiality and Information Security Agreement that the user has signed with Monash University. Inappropriate access includes any access to a patient record which is not necessary for the normal function of the ATR. If inappropriate access does occur, Monash University, as the contracted provider to the ATR, will act in accordance with due process and natural justice. This may include informing the employee of their concerns, removal of access privileges, referral to a relevant professional authority and notification to the Office of the Australian Information Commissioner.

Data Breaches

The Notifiable Data Breach in Part IIIC of the Privacy Act requires the ATR to notify affected individuals and the Office of the Australian Information Commissioner under the following circumstances:

- There is unauthorised access to, or disclosure of personal information held by an entity (or information is lost in circumstances where unauthorised access or disclosure is likely to occur).
- This is likely to result in serious harm to any of the individuals to whom the information relates.
- The entity has been unable to prevent the likely risk of serious harm with remedial action.

The ATR has taken steps to mitigate the risk of a breach occurring. These steps have been outlined in this document. The primary onus is on Monash University as the sole entity which has access to the ATR dataset.

Retention

There is no provision within Australian law which requires the disposal of data held in the ATR. The ATR will hold data until such time as it is no longer required.

Use of data

The role of the ATR Data Governance Group is to ensure the use of ATR data is ethical and appropriate.

The ATR Data Use Policy describes how the data is used and the controls applied to ensure the use of data is ethical and appropriate.

Aggregate ATR is used for quality assurance and national reporting.

ATR is also available for researchers, and the ATR Data Governance Group will review all requests to ensure they have the appropriate ethics and other approvals, and are appropriate fields of research. All data released will be deidentified as the ATR does not hold identifiable data.

Data linkages may occur to leverage the information held in national collections, such as the admitted patient episode. Approval from the Data Governance group is required for each linkage. The likely process is to send the unique codes back to the contributing site to obtain patient identifiable information, sending that to the AIHW, and return to the ATR deidentified. Further work in this area is signalled as there are likely different processes depending on the data source.

Disclosure

No third parties have access to the data within ATR directly. Access to the ATR is only through authorised access and this is held solely by Monash University.

Official Information Act requests may be made by members of the public from time to time in relation to the ATR. Any data released under this Act will be patient anonymised (requests by the patient themselves will be dealt with under the Privacy Act). The ATR Data Governance Group and legal counsel at The Alfred will review all requests made under this Act and approve material to be released.

Unique Identifier

The ATR uses unique codes which enable a record to be linked back to the contributing site.

Part 2: Response to the 13 Privacy Principles

The Australian Privacy Principles are the cornerstone of the privacy protection framework in the Privacy Act 1988. They apply to the ATR as it holds personal information on individuals who have been seriously injured.

1. Open and transparent management of personal information

The information collected in the ATR are described in detail in the Bi-National Trauma Minimum Dataset for Australia and New Zealand. This is publicly available on the ATR website - here

Only information which is relevant to the activities of the ATR is collected.

2. Anonymity and pseudonymity

The ATR holds de-identified information only. It does contain a code which can be linked back to the trauma registry at the contributing site which is needed to fulfill other requirements of the Privacy Act, and to enable linkages with other collections such as the admitted patient episode. Only the contributing site holds the link to identify the patient.

3. Collection of solicited personal information

The ATR collects information solicited from contributing hospitals across Australia. These are subject to the relevant ethics approvals in each state/territory. The information solicited is limited to the Bi-National Minimum Dataset and is necessary to fulfill the function of the ATR to monitor the performance of the trauma system in Australia.

4. Dealing with unsolicited personal information

This principle is not applicable to the ATR. The ATR accepts data only with the mutual agreement of the contributing site, which has the required consent or waiver to collect it from the patient.

5. Notification of the collection of personal information

The onus is on contributing sites to inform individuals that their data is entered into the site's trauma registry.

6. Use or disclosure of personal information

The use of ATR data for reporting purposes and to monitor the performance of the trauma system in Australia depends on aggregate data. These are presented in documents such as the Annual Reports found here. Utmost care is taken to ensure no population group is stigmatised in the data presented, and results where low numbers exist are supressed to ensure no individual could potentially be identified.

The use of ATR for research purposes must have the relevant ethics approval plus approval from the Data Governance Group to ensure the research is ethical and appropriate. Researchers are required to state how they will use the data and the specific data points requested. Researchers are required to agree not to use the data beyond the use requested for.

7. Direct marketing

The ATR does not undertake any marketing with any individual whose information is held in the ATR, direct or otherwise.

8. Cross-border disclosure of personal information

The only circumstance when ATR data is sent outside of Australia is for approved research purposes, in accordance with the approval processes set out in paragraph 6 above. It is expected that the country the researcher is from would have at least equivalent or stronger privacy laws in place than the Privacy Act of Australia. This may include New Zealand and the countries which fall within the European Union General Data Protection Regulation. The Data Governance Group has the ability to seek legal advice on specific requests which involve sending personal information outside Australia.

The ATR does not hold identifiable information and thus any information sent cannot be identifiable.

9. Adoption, use of disclosure of government related identifiers

The ATR does not contain government related identifiers such as Medicare numbers, passport numbers, or other identifier. The ATR does contain unique codes common to the contributing site and the ATR, but these fall outside of the definition of a government related identifier.

10. Quality of personal information

The first step is at the time of information is collection. Information is collected by trauma nurses and data collectors in contributing hospitals using the patient's clinical record. All data collectors are expected to be trained in the use of the unique injury coding used in trauma systems worldwide (Abbreviated Injury Scale) and in the use of their trauma registry. All contributing sites are also expected to implement steps to assure the quality of data provided, such as cross-checking information and coding exercises.

The second step is at the time the information is used or disclosed. Extensive review of annual and other reports takes place prior to release to ensure the results are relevant and the statistical analysis is sound. A number of experts are involved in the review process, including biostatisticians, clinicians, and analysts.

11. Security of personal information

The ATR is hosted by Monash University and is subject to its Information Technology controls and measures. All staff who access the ATR are employed by Monash University. The detailed security arrangements are described earlier in this document.

12. Access to personal information

All patients have the right to access information about them collected in the ATR. Patients will not be able to access the ATR directly, however an extract of their information can be made available to them on request. If a patient wishes to access their information held in the ATR, the onus is on the relevant contributing site to inform the ATR Data Manager to extract that patient's information, using the unique code between the contributing site and the ATR.

If a patient wishes to opt-out of the ATR they can do so. If a patient wishes to opt out of the ATR, the onus is on the relevant contributing site to inform the ATR Data Manager to delete that patients information, using the unique code between the contributing site and the ATR.

13. Correction of personal information

If a patient wishes for their information to be corrected, depending on the nature of the request, the person making the request may be asked to put it in writing. If a patient wishes to change information held in the ATR,

the onus is on the relevant contributing site to inform the ATR Data Manager to change that patient's information, using the unique code between the contributing site and the ATR.