ANZACS-QI
Aotearoa New Zealand All Cardiology
Services Quality Improvement

Terms of Reference

Aotearoa New Zealand All Cardiology Services Quality Improvement (ANZACS-QI)

Data Governance Group
November 2025
Version 13.0

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1. Introduction

This is a living document which captures the (consensus) views around data governance, formed through discussions in the ANZACS-QI Governance Group, the New Zealand Cardiac Network, the Māori-led equity-focussed Data Sovereignty Governance Group for Vascular Risk Equity for Aotearoa New Zealand (VAREANZ) and Health New Zealand | Te Whatu Ora. The document is progressively revised, and details of revisions are given in Appendix 5.

Versions: When ANZACS-QI was set up in 2012 there were two founding documents – the ‘ANZACS-QI Governance Structure and Data Governance Principles’ and the ‘ANZACS-QI Privacy Framework’. These underwent several modifications, which are outlined in Appendix 5. In 2023 these were combined in a single document, the ‘ANZACS-QI Governance Group Terms of Reference’.

1.1 The Terms of Reference (TOR) will be reviewed annually.

1.2 These terms of reference set out the:

- role and function of the ANZACS-QI Data Governance Group (the Group)
- composition of the Group
- responsibilities of Group members
- role and function of the chair and secretariat.

2. The ANZACS-QI Registry

The ANZACS-QI registry is an advanced, web-based registry system that was initially established to capture data on acute coronary syndrome (ACS) management in secondary care after a patient has experienced an ACS event. It was initially called the All New Zealand Acute Coronary Syndrome Quality Improvement (ANZACS-QI) programme. The registry has expanded and is now deployed nationally, collecting standardised data from 47 Participating Agencies including all 40 public and 7 private hospitals in New Zealand where adult patients are managed for acute coronary syndromes (contained in the ACS registry) and heart failure (contained in the Heart Failure registry) or undergo coronary angiography or intervention (contained in the Cath PCI registry) and cardiac implantable electronic device procedures (contained in the Device registry). To recognise this expanding role, it has been renamed the Aotearoa NZ All Cardiology Services Quality Improvement (ANZACS-QI) programme.

2.1 The registry aims to:

- support appropriate, evidence-based management of cardiac disease regardless of age, sex, ethnicity, socioeconomic status, or rurality
- drive improvements in the quality of cardiac care delivered in New Zealand’s hospitals
- reduce regional variation in regard to the assessment, investigation and treatment of cardiac patients.

To support this goal, the Ministry of Health (MoH), and since 2022, Health New Zealand | Te Whatu Ora have introduced national cardiology targets as follows:

3. Aotearoa NZ All Cardiology Services Quality Improvement (ANZACS-QI) National Indicators

The ANZACS-QI National Indicators have been endorsed by the National Cardiac Network and MOH/ Health New Zealand | Te Whatu Ora. They are nationwide key performance indicators (KPIs) for the purpose of quality improvement of cardiac service delivery. These indicators are revised and updated regularly, and the latest version can be found on the ANZACS-QI website.

4. Role and Function of the ANZACS-QI Data Governance Group

4.1 The Group will report and provide recommendations to the New Zealand Cardiac Network.

4.2 The Group will seek and be guided by advice which honours the principles of Te Tiriti o Waitangi via its relationship with the Māori-led equity-focussed data sovereignty governance group for Vascular Risk Equity for Aotearoa New Zealand (VAREANZ).

4.3 The role and function of the Group will be to:

- ensure that the data being collected through the ANZACS-QI registry supports *Health New Zealand | Te Whatu Ora's strategic priorities for cardiology management in New Zealand*
- oversee the consistent application of the ANZACS-QI registry's data governance principles which incorporate Te Tiriti o Waitangi principles (see Appendix 1 and 2)
- develop standard data definitions for the ANZACS-QI registry and disseminate them across the country
- make recommendations or provide advice on data quality issues affecting the registry
- make recommendations on new quality indicators
- make recommendations on the content and results of hospital-level clinical audits, with a particular focus on supporting hospitals' quality improvement activities
- make recommendations on the content, frequency, and outcomes of any new quality improvement reports
- make recommendations on the content of user access reports
- make recommendations on and endorse any new change requests or data access requests received by the Human Health Research Services Platform (HHRSP) at the University of Auckland or Enigma Solutions Ltd. (Enigma).

4.4 The relationship between the ANZACS-QI Data Governance Group and other key stakeholders is shown below.

The ANZACS-QI programme is governed by a Data Governance Group, who volunteer their time, alongside the **VAREANZ Data Sovereignty Group** and **The NZ Cardiac Network**.

The Human Health Research Services Platform (University of Auckland), **Enigma Solutions** and the ANZACS-QI Operations Group manage the operational delivery of the programme.

The NZ Cardiac Network, **Health New Zealand Long Term Conditions** team, and the **Health Quality and Safety Commission** are responsible for quality improvement.

Composition of the ANZACS-QI Data Governance Group

4.5 Members will include:

- Cardiac Society nominated Co-Chair
- VAREANZ nominated Equity Co-Chair
- Māori representative/s
- Clinical Leaders of the four Regional Cardiac Networks (Northern, Midland, Central and Southern)
- Chair of the New Zealand branch of the Cardiac Society
- Second committee member of the New Zealand branch of the Cardiac Society
- Chair of the Interventional Group
- Chair of Heart Rhythm New Zealand
- Cardiac nurse representative
- Consumer representative
- Heart Failure representative
- Cardiac Society nominated ACS expert
- Chair of the New Zealand Cardiac Network
- Health New Zealand | Te Whatu Ora representative/s
- University of Auckland advisor (secretariat)
- Enigma Solutions advisor.

5. Responsibilities of ANZACS-QI Data Governance Group Members

5.1 Members must first and foremost be committed to working for the public of New Zealand.

5.2 There is an expectation that members attend all meetings and devote sufficient time to becoming familiar with the Group’s affairs and completing any actions they have been assigned.

5.3 Members will be responsible for keeping their respective organisations, networks or groups informed of the Group’s work, as well as any changes that have been recommended by the Group and agreed by the New Zealand Cardiac Registry Governance Group.

6. Role of the Co-Chairs

The Clinical Co-Chair is proposed and endorsed by the NZ regional committee of the Cardiac Society of Australia and New Zealand. The appointment is reviewed by the NZ committee every three years.

The Equity Co-Chair and Māori representative are proposed and endorsed by the Māori-led equity-focussed data sovereignty governance group for Vascular Risk Equity for Aotearoa New Zealand (VAREANZ). The appointments are reviewed every three years.

6.1 The role of the Chairs are to:
- facilitate orderly and constructive discussions between members on matters relating to the role and function of the ANZACS-QI Data Governance Group
- assist members to work together as a group, ensuring that all members have equal opportunity to contribute ideas, opinions and concerns, and drawing participation from all members
- ensure that any actions are appropriately assigned
- liaise with the secretariat to develop meeting agendas and ensure the progression of actions arising from meetings
- report the Group’s recommendations to the New Zealand Cardiac Network.

7. Role of the Secretariat

7.1 Secretariat support will be provided by HHRSP at the University of Auckland.

7.2 The role of the Secretariat is to:
- develop meeting agendas in consultation with the Chair
- distribute the agenda and meeting papers
- take minutes at meetings, send them out to members for feedback and revise them as needed
- produce a progress report on the status of actions since the last meeting.

8. Meetings

8.1 The Group will meet every three months via teleconference for approximately one hour.

8.2 Members will receive a copy of the agenda, previous meeting minutes and any meeting papers at least five working days before the meeting, so that they have time to review the information and follow up on any outstanding actions.

8.3 Minutes will be taken at each meeting recording all decisions made and any actions or recommendations agreed. A copy of the minutes will be circulated to members within 10 working days for review.

8.4 For recommendations to be agreed at meetings, there needs to be a quorum of no less than half the total number of members plus one.

8.5 Members should attend the teleconferences. If they are unable to attend, they are responsible for delegating their responsibilities to another appropriate person.

9. Removal from the ANZACS-QI Data Governance Group

9.1 The Chair may, at any time and entirely at the Chair’s discretion, remove any member from the Group.

10. Conflicts of Interest

10.1 Members should perform their functions in good faith, honestly and impartially and avoid situations that might compromise their integrity or otherwise lead to conflicts of interest.

10.2 When members believe they have a conflict of interest on a subject, they must declare this. This must be done at the earliest possible opportunity in the regular agenda item around conflicts of interest and when the relevant item of business comes up in the meeting, the Chair will decide what action needs to be taken.

11. Liability

11.1 Members are not liable for any act or omission done or omitted in their capacity as a member, if they acted in good faith, and with reasonable care, in pursuance of the role and function of the Group.

12. Confidentiality

12.1 Meetings, including agendas, meeting papers and minutes, are confidential. Members must ensure that the confidentiality of the Group’s business is maintained.

12.2 Members are free to, and are expected to, express their own views during meetings, or the general business of the Group. However, members must publicly support any recommendation made by the Group, or if unable to do that, must not publicly comment on recommendations.

12.3 At no time shall members divulge Group matters or recommendations to people who are not members or Health New Zealand | Te Whatu Ora employees. Disclosure of Group business to anyone outside the Group must be the decision of the Chair.

12.4 Members must ensure that documents are kept securely to ensure that confidentiality is maintained. Release of correspondence or papers can only be made with the approval of the Chair. At the end of a member's term, all ANZACS-QI Data Governance Group information must be returned to the Chair.

13. Remuneration

13.1 There is no payment for meeting preparation or participation in teleconferences.

14. Review of Terms of Reference

14.1 The Group’s Terms of Reference will be reviewed each year alongside the ANZACS-QI Data Governance Principles (Appendix 1) and the ANZACS-QI Data Access Process and Publishing Guides (Appendix 3).

Appendix 1

ANZACS-QI Data Governance Principles

1. Document Purpose

This document focuses on data governance – principles around (security of) data, access to data, and guidelines for processes around data access requests and publications using ANZACS-QI data.

2. Data Governance Principles

Te Tiriti o Waitangi principles: The Te Mana Raraunga - Māori Data Sovereignty Network Charter enables Māori data sovereignty and advances Māori aspirations and individual wellbeing. The Group will seek advice and guidance from the Māori-led equity-focussed data sovereignty governance group for Vascular Risk Equity for Aotearoa New Zealand (VAREANZ) to ensure that the ANZACS-QI programme complies with and respects that:

- Data is a living tāonga and is of strategic value to Māori
- Māori data refers to data produced by Māori or that is about Māori and the environments they have relationships with
- Māori data is subject to the rights articulated in Te Tiriti o Waitangi and the United Nation's Declaration on the Rights of Indigenous People, to which Aotearoa New Zealand is a signatory
- Data sovereignty typically refers to the understanding that data is subject to the laws of the nation within which it is stored
- Indigenous data sovereignty perceives data as subject to the laws of the nation from which it is collected
- Māori data sovereignty recognises that Māori data should be subject to Māori governance
- Māori data sovereignty supports tribal sovereignty and the realisation of Māori and Iwi aspirations.

The full terms of reference for Māori-led equity-focussed data sovereignty governance group for Vascular Risk Equity for Aotearoa New Zealand (VAREANZ) are shown in Appendix 2.

- All data must be kept secure and protected from access by any unauthorised person(s) and used for authorised purposes only.

- The primary purpose of the ANZACS-QI registry is to support clinical audit and local, regional, and national quality improvement initiatives by:
  - enabling reporting of nationally agreed key performance indicators across NZ hospitals and cardiac catheterisation labs
  - providing data for hospital-level clinical audit
  - standardising risk stratification and data definitions across the country
  - providing clinical decision support

  - assessing performance against NZ and international guidelines.

- The secondary purpose of the registry is to provide data that can be used:

  - by individual hospitals, districts, the New Zealand Cardiac Network and the New Zealand branch of the Australian New Zealand Cardiac Society for strategy and policy development, and
  - for research and publications that will support the public good and are not for private commercial gain.

ANZACS-QI data is not publicly accessible.

Access to data is defined in the ANZACS-QI Privacy Framework. Access to and export of 'raw data' (e.g. to Excel) will be tightly controlled, according to the service level agreement, as outlined in the Health New Zealand | Te Whatu Ora, HHRSP (University of Auckland) and Enigma Solutions Ltd Agreement, for the provision of acute coronary syndrome registry and associated support services.

- Quality of the data is paramount. ANZACS-QI will promote data quality through a range of initiatives including:
  - validation checking on the electronic forms
  - effective training of relevant hospital staff
  - formalised clinical leadership at each participating unit
  - national audit of data
  - feedback loops through relevant local reporting – providing an incentive for local staff to complete the datasets to a high standard.

- ANZACS-QI users at all levels will be able to run and/or access reports that are relevant to their responsibilities for quality improvement and clinical audit.

- A role-based model for (system) access will be implemented to allow all parties (e.g. cardiac care units, hospitals, regional cardiac clinical networks) to have access to their 'own patient's data'.

- Hospitals can use their own ANZACS-QI data for the purpose of local audit and quality improvement without prior national approval. In these cases, the source data may be acknowledged, but it must be clear for the audience that ANZACS-QI has not provided oversight or quality control for the interpretation and analysis of the data.

- Transparent and efficient processes for managing data requests will be developed, to support the use of ANZACS-QI data for research and publications.

3. Data Access Guidelines and Requirements

- A number of guidelines to managing access to data have been captured below – consistent with the Data Governance Principles. These guidelines are expected to be implemented through a mix of technology (such as system access controls) and processes.

- The below guidelines apply to *users* of the ANZACS-QI system. A user has access to (parts of) the system as part of their day-to-day responsibilities (e.g. data entry; data quality assurance, run audit reports, etc). Users will be authorised to access and use the system by their individual hospital administrator and will be expected to adhere to standard patient confidentiality principles.

3.1 Role-Based Access to Data

- Access to run reports will be controlled through the user access profile (for details see Appendix 4(4). Access tiers include:
    - national level access e.g. national data administrator, national report developer, Chair (or designate) of the ANZACS-QI Data Governance Group
    - regional level access e.g. regional clinical leader (or designate), regional Network report developer
    - hospital access e.g. Clinical Director for Cardiology (or designate)
    - clinic access e.g. coronary care unit user access, Cath lab user access.

  Note that in addition to users having the ability to run reports, a select number of (KPI style) reports will be developed nationally and 'pushed out' to selected users and stakeholders. Email distribution lists are managed by Enigma and HHRSP.

- A user will have access to reports available to their level in the hierarchy (tier), plus all levels below.
    - Example: a user with Middlemore Hospital access will be able to run reports that display Middlemore data - but not Auckland Hospital data - plus any individual Middlemore clinic level reports.

- Reports may display detailed data (including patient IDs and staff IDs) up to the defined tier, plus include anonymised comparison stats from other units or regions.
    - Example: a Middlemore hospital user may run a report showing door to balloon times for Middlemore patients, plus comparison statistics for the Northern region and the national level.

- By default, all users at a certain level can run and/or access reports.

- At each level (e.g. hospital, region) a single data administrator role will be identified – for example, the regional clinical leader or designate.
    - This person is responsible for the data being managed in accordance with ANZACS-QI security guidelines as follows - data files are required to be password protected and stored/accessed only within the Health New Zealand hospital IT system. Files should not be shared outside the hospital system and cannot be transferred to memory sticks.

  - The ability to export (e.g. Excel) NHI-encrypted patient level data will be controlled using the same role-based access tiers (see Appendix 4(4). With approval from the ANZACS-QI co-chairs one user at each hospital and regional level can be given access to identifiable patient level data Excel extracts.

- All the above applies to public hospitals. Where private hospitals participate in ANZACS-QI, a streamlined user access hierarchy will be created with a private hospital administrator and clinic levels only. Patient data will be available at the ANZACS-QI steering group level and national data administrator level for national reporting and research purposes.

- Access to data identifying individual clinicians will only be available to the regional clinician user access role.

- Audit logs will be maintained within the electronic system to track all user access to individual patient information. This includes accessing individual registry forms, running 'Excel' data extracts and generating a list of individual patients using the "click through" function of reports. Any unauthorised access will be notified to the local hospital management and addressed according to hospital protocols.

3.2 Linkage of ANZACS-QI Data to National Datasets for Reporting and Research

- Encrypted ANZACS-QI data will be linked with national databases including the National Mortality and Hospitalisations and Pharmaceuticals data sets. This will support reporting of outcomes and medication dispensing post discharge. This linkage will be done at the School of Population Health (SOPH), University of Auckland under the auspices of the HRC funded Vascular Risk Equity for All New Zealanders (VAREANZ) programme. The VAREANZ programme has multi-region ethics approval for this activity under defined conditions. These include:
  1. That permission for encrypted data use be provided by each regional service.
  2. That the VAREANZ poster be displayed, and patient information be available in each setting ANZACS-QI is implemented in.
  3. VAREANZ ethics approved processes for data encryption, and linkage to national data are adhered to.

- Any data access requests, new report formats and publications should be approved as appropriate by both the ANZACS-QI Data Governance Group and the VAREANZ Governance Steering Group according to the processes defined for both groups (see Appendix 3, ANZACS-QI Data Access Process and Publishing Guide v7). The equity focussed VAREANZ Data Sovereignty Group will review and support the interpretation and reporting of data according to ethnicity. This process will be facilitated by having a SOPH representative on the ANZACS-QI Data Governance Group and an ANZACS-QI representative on the VAREANZ Steering Group.

  The VAREANZ Governance Group will be responsible for maintaining ethics approval for the ANZACS-QI linkage to national datasets.

3.3 Data Requests

- One off data requests may be submitted to the Governance Group:
  - A requestor may submit data access to a certain subset of the national data as part of a research project for example
  - Data requests will be made following the ANZACS-QI Data Access Process and Publishing Guides (see Appendix 3)
  - Data requests will be will processed on the basis of first come first served, as long as these requests fit within the funded time for data requests. Once the requests exceed the funded time, prioritisation order will be requested from the ANZACS-QI Data Governance Group
  - As a guideline, the data made available must only be used for the agreed purpose, and not permanently stored in other (hospital, national, or international) databases.

- If the data set that is required includes data from other data sets (such as Pharmacy), the Data Governance Group will facilitate the process of obtaining permission to access and use that data.

- Where ANZACS-QI registry data for a single service (e.g. district, hospital or cath lab) is being used for audit or research ANZACS-QI Governance Group approval is not required. Investigators must however adhere to their local ethics requirements.

  See Appendix 3: ANZACS-QI Data Access Process and Publishing Guides v7.

3.4 Publications Using ANZACS-QI Data

- Publications that include or reference ANZACS-QI data must follow a process of review and approval, to be outlined in the ANZACS-QI Data Access Process and Publishing Guides.

  See Appendix 3: ANZACS-QI Data Access Process and Publishing Guides v7.

Appendix 2

Māori-led Equity-Focussed Data Sovereignty Governance Group for Vascular Risk Equity for Aotearoa New Zealand (VAREANZ) 2022 – 2026: Terms of Reference

Approved for and on behalf of VAREANZ Steering Group
Date: 24/11/2022

1. Introduction

Vascular Risk Equity for Aotearoa New Zealand (VAREANZ) is a University of Auckland-led research programme (2022-2026) funded by Health Research Council. It aims to close cardiovascular and metabolic (CVM) risk-equity gaps by creating, interrogating, and utilising a CVM collection and condition-specific sub-collections.

Specific aims for the programme are to:

1. Create the updatable VAREANZ collection and specific condition sub-collections that will include an up-to-date cardiovascular-metabolic risk factor profile on every adult in NZ.
2. Assess cardiovascular-metabolic risks and risk-management-equity gaps for all adults in NZ.
3. Establish a Māori-led, equity-focussed data sovereignty governance group to provide formal stewardship over every stage of the programme.
4. Establish a health data science expert group to provide the expertise to create, manage, curate, and protect the data, while making it accessible and providing advanced analytical support.
5. Establish a Research Impact Group to be responsible for sharing anonymised findings with end users and investigating mechanisms for sharing identifiable patient information to support optimal care.

These terms of reference establish the Māori-led data sovereignty governance group described in point 3 above.

2. Background

The VAREANZ programme is designed to have a direct impact on Māori health by tackling the major preventable causes of health expectancy gaps.

Māori hold ethical and governance concerns about health registers/data collections and their use in research. Specific issues include the deficit-framing of health conditions for Indigenous peoples including Māori, lack of data sovereignty, the unsafe analysis and dissemination of research results, and race-adjusted algorithms that can perpetuate or even amplify health inequities. Further, such research often fails to understand the complex interactions between ancestry, race, racism, socioeconomic status, and environment.

Advice and guidance on these issues is required. In consultation with hauora Māori, big data, CVD, equity and ethics experts from across Aotearoa, VAREANZ will establish Indigenous-led and equity focussed structures of oversight and regulation of data. Two groups of experts, Māori and non-Māori, noting that half are Māori in line with a Te Tiriti partnership, have been invited to the VAREANZ Data Governance Group. The Group will provide advice and guidance to the Programme so that the research is safe, effective, and will benefit all equitably.

Of note, all research streams in the programme are co-led by Māori, with support for upskilling the next generation of Māori big health data researchers.

3. Purpose of the Governance Group

The purpose of the Group is to provide the Programme and its partners with guidance and advice. This includes:

- Providing clinical, ethical, and cultural guidance and advice
- Guiding and advising VAREANZ on engagement with Māori, Pacific, and others to ensure that Māori legal rights and local laws are upheld
- Providing advice and guidance on Project compliance with principles of Te Tiriti o Waitangi (see below)
- Guiding the project team to remain focused on providing equitable health outcomes for all New Zealanders with a focus on Māori and Pacific peoples
- Formulate policies for the governance of data
- Develop and maintain a risk register and report key risks to the Steering Group
- Support research that meets the aims of VAREANZ
- Develop and implement systems for reviewing and approving or declining all requests for data for the purpose of research, guided principally by Tiriti o Waitangi principles, Māori data sovereignty and Māori ethical frameworks.

4. Te Tiriti o Waitangi

The Group will provide advice which honours the principles of Te Tiriti o Waitangi as expressed by the Waitangi Tribunal[1] and the Courts as outlined here:

Tino Rangatiratanga

Tino Rangatiratanga supports Māori self-determination and leadership. This means that the Governance Group will support Māori in the decision-making process and their part in the implementation of such decisions.

Equity

The principle of equity requires the Crown to commit to achieving equitable health outcomes for Māori. This requires appropriate resourcing to undertake, share and disseminate the research and its findings to have a positive impact for Māori and their whānau.

Active Protection

The principle of active protection requires the Crown to act, to the fullest extent practicable, to protect Māori data, knowledge, methodologies and outcomes. Māori will be involved in decisions about the collection of and access to Māori data, analysis, and interpretation. The use of data for research should also be consistent with frameworks for Māori research ethics[2] and contribute to achieving equitable outcomes.

Options

The principle of options support the Governance Group to provide for and properly resource kaupapa Māori options including those which are culturally safe and/or are an expression of kaupapa Māori models.

Partnership

Māori and non-Māori members will work in partnership in the governance, design, delivery, and monitoring of the research programme.

5. Māori Data Sovereignty3

The Te Mana Raraunga - Māori Data Sovereignty Network Charter enables Māori Data Sovereignty and advances Māori aspirations and individual wellbeing. The Group will therefore ensure that the Project complies with and respects that:

- Data is a living tāonga and is of strategic value to Māori.

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[1] Waitangi Tribunal. Report on stage one of the Health Services and Outcomes Kaupapa Inquiry. Wellington: Waitangi Tribunal; 2019. pp. 163–164.

[2] Te Mana Raraunga - Māori Data Sovereignty Network. Te Mana Raraunga - Māori Data Sovereignty Network Charter. 2016 [cited 2022 July 1]. p3. Available from: https://www.temanararaunga.maori.nz/tutohinga

[3] Te Mana Raraunga - Māori Data Sovereignty Network. Te Mana Raraunga - Māori Data Sovereignty Network Charter. 2016 [cited 2022 July 1]. p1.
Available from: https://www.temanararaunga.maori.nz/tutohinga

- Māori data refers to data produced by Māori or that is about Māori and the environments they have relationships with.
- Māori data is subject to the rights articulated in the Te Tiriti o Waitangi and the United Nation’s Declaration on the Rights of Indigenous People, to which Aotearoa New Zealand is a signatory.
- Data sovereignty typically refers to the understanding that data is subject to the laws of the nation within which it is stored.
- Indigenous data sovereignty perceives data as subject to the laws of the nation from which it is collected.
- Māori data sovereignty recognises that Māori data should be subject to Māori governance.
- Māori data sovereignty supports tribal sovereignty and the realisation of Māori and Iwi aspirations.

6. Governance Committee Membership

Māori (Ono)

- Professor Sue Crengle, Co-chair (Kāi Tahu) Co-director VAREANZ
- Associate Professor Matire Harwood, Co-chair (Ngāpuhi) Co-director VAREANZ
- Dr Anna Rolleston (Ngāti Ranginui, Ngāi te Rangi), Co-director Healthy Hearts for Aotearoa NZ – Manaaki Mānawa CoRE, Kaupapa Māori researcher & clinician
- Dr Andrew Sporle (Ngāti Apa, Rangitane, Te Rarawa), Member Te Mana Raraunga, biostatistician
- Dr Jamie-Lee Rahiri (Ngāti Porou, Ngāti Whātua ki Kaipara me Te Atihaunui-a-Pāpārangi.), co-lead metabolic conditions, new & emerging research leader
- Dr Wil Harrison (Ngāti Porou), cardiologist, current member Māori advisory group VAREANZ 2020

Equity (Six)

- Associate Professor Sue Wells, Co-director VAREANZ
- Dr Corina Grey (Samoan), Public Health Physician
- Dr Suneela Mehta (Indian)
- Julie Winter-Smith (Tongan), emerging, PhD on classification Pacific ethnicity & CVD
- Dr Monique Jonas, Ethical Theorist
- Dr Vanessa Selak, Epidemiologist & Public Health Physician

A quorum is one Co-Chair and three others.

The term for appointed members will be five years. Replacements will be approved by the Steering Group.

Other experts can be co-opted onto the group as required.

7. Expectations of Committee Members

Members of the Group are expected to:

- Provide advice and guidance as experts in their respective fields.
- Act in a professional and exemplary manner.
- Uphold and ensure that the principles of Te Tiriti o Waitangi are respected and embedded in the Project.
- Commit to guiding and advising the Programme and its partners who will be working to ensure that the research is actively contributing to equitable health outcomes for all New Zealanders with the focus on Māori and Pacific groups.

- Prepare for, attend, and actively contribute to all Committee meetings.
- Confidentiality - keep sensitive information confidential and not directly or indirectly publish, disseminate, or otherwise disclose, deliver, or make available to any third party any sensitive information.
- Declare conflicts of interest. If a declaration of conflict of interest is required (competing professional or personal interest such as services that can only be provided by a member), the member will take advice from the Chair.
- Meet as required including by teleconference or videoconference.

8. Governance and Accountability

The Group is accountable to the VAREANZ Steering Group.

The Group will report to the Steering Group via the Chairs.

9. Amendment or Variation of Terms of Reference

These Terms of Reference may be amended, varied, or modified in writing after consultation and agreement by the rōpū.

Appendix 3

ANZACS-QI Data Access Process and Publishing Guides

1. ANZACS-QI Data Access Process Guide (v7):

1.1 Preamble:

Clinicians in each region will have access to data on patients in their region. This data will be used for local audit and quality improvement activity. Local process will be developed in each region to manage access.

Approval of a Data Access proposal by the ANZACS-QI Data Governance Group and University of Auckland Vascular Risk Equity for All New Zealanders (VAREANZ) Governance Group will be required for any use of multi-region ANZACS-QI data and/or linked national administrative data for reporting or with a view to use for presentation/publication.

1.2 Requesting Access to ANZACS-QI Data

1. The clinician/researcher completes a Data Access Proposal (DAP) outlining the nature of the project and the type of data requested and sends this to the ANZACS-QI Project Manager and ANZACS-QI Governance Group Co-Chairs. This may be for the purpose of research or for national reporting/audit activity.

2. The Co-Chairs assess the DAP and advise on feasibility and appropriateness of the study. After appropriate revision by the applicants, they forward the DAP to the ANZACS-QI Data Governance and VAREANZ Steering Groups via the ANZACS-QI Project Manager.

3. Both Governance Groups discuss the DAP at the next meeting. Discussion will include: the feasibility of the project, potential overlap with other projects, which datasets are required, and which ethics approval the project will come under.

4. The ANZACS-QI Data Governance Group identifies other members of the Cardiology community who may be interested in being involved. The ANZACS-QI Project Manager sends the DAP to the relevant parties and collates any comments. In the case of research projects, the lead researcher should be copied into any emails regarding interest in co-authorship and comments on the DAP and is responsible for liaising with and acknowledging contributing authors. The VAREANZ Steering Group decides whether to send the DAP to the equity focussed Data Sovereignty Group for review.

5. The Governance Groups discuss any comments from their teams and the governance and advisory groups at the next meeting (face to face or by email consensus) and finally approve or decline the DAP.

6. Once approved by both ANZACS-QI and VAREANZ the lead researcher completes and signs the Data Release Agreement and sends it to the Project Manager to be authorised by

a member of the ANZACS-QI Data Governance Group (one copy to be kept by the researcher, another by the Project Manager).

7. The Project Manager creates a new folder for the project, files the DAP and Data Access Agreement and sends the data request to the Data Manager.
8. The Data Manager extracts the data and makes it available for a defined period via a secure virtual machine portal.
9. The Project Manager contacts the researcher six to 12 months after the Data Access Agreement is signed to request a progress report (either via written report or presentation at the ANZACS-QI team meeting).

2. Data Access Proposal (DAP) Guide and Application Form

ANZACS-QI has supported over 70 research projects since its conception, advancing understanding and improvement of cardiology services in New Zealand.

Clinicians will have access to data on patients in their region. However, if they require multi-region ANZACS-QI data for reporting or for presentation/publication, a Data Access Proposal will need to be approved by the ANZACS-QI Data Governance Group and University of Auckland Vascular Risk Equity for All New Zealanders (VAREANZ) Governance Group.

The latest version of the DAP form and guide can be found on the ANZACS-QI website.

3. Publishing Outputs Using ANZACS-QI Data (v7):

This includes conference presentations, journal articles, theses, dissertations, and external reports.

- A Data Access Proposal for the relevant research/project must have been submitted and approved by the ANZACS-QI and the VAREANZ Steering Group prior to this stage.
- All analyses must be verified independently before any results are made public – this includes having someone check the thought process and steps in the analysis, checking the logic of the command files and making sure that there are no transcription or data entry errors when the commands are run. A copy of command files with a clear description of the steps in the analysis should be saved in the relevant project folder.
- All relevant external sources of data and funding should be acknowledged such as: the Ministry of Health, PHARMAC, PHOs, The Heart Foundation, HRC, AMRF etc.
- Any output using data from the Ministry of Health or PHARMAC should be sent to the relevant person in that organisation before submission.

3.1 Journal Articles

1. The lead author sends the manuscript to the ANZACS-QI Programme Manager before submission indicating which journal it is being submitted to (if known).
2. The Programme Manager sends the manuscript to the ANZACS-QI Steering Group Chairs (and VAREANZ Steering Group as appropriate) and anyone else who indicated at the DAP stage that they wish to be authors on the paper. Co-authors have 10 working days to provide comments.
3. The lead author is responsible for making sure any comments are followed-up and appropriate changes made to the manuscript. He/she is also responsible for liaising with and acknowledging contributing authors and sending them a final copy of the manuscript prior to publication.
4. The VAREANZ Steering Group discusses the manuscript at the next meeting or via email and decides whether it should be sent to the VAREANZ Data Sovereignty Group or any other VAREANZ partner for the opportunity to provide final comments before submission.
5. All papers using data from ANZACS-QI should include an ANZACS-QI number in brackets at the end of the title. The lead author should contact the Project Manager or Clinical Co-chair at the time of submission to be assigned an ANZACS-QI number.
6. The lead author alerts the Project Manager when the paper has been (or will be) published and sends a final copy to be saved on the shared ANZACS-QI drive.

3.2 Conference Abstracts and Presentations

1. The lead author sends the conference abstract to at least one (other) ANZACS-QI named investigator for approval before submission.
2. The lead author sends a copy of the abstract and the presentation (when available) to the Project Manager to be circulated to the ANZACS-QI Steering Group and saved on the shared VAREANZ drive.

3.3 Theses and Dissertations

1. All theses and dissertations must be supervised by at least one ANZACS-QI Steering Group member and must be approved by them before being submitted.
2. The lead author sends a full copy of the thesis/dissertation to the Project Manager (once submitted) to be circulated to the ANZACS-QI and VAREANZ Steering Group and saved on the ANZACS-QI drive.

Appendix 4

ANZACS–QI Privacy Framework

1. About this Document

The purpose of this Privacy Framework is to explain how ANZACS-QI complies with the requirements of the Privacy Act 2020 and the HIPC, along with how data complaints and breaches will be handled. It has been approved by the Privacy Commission and the ANZACS-QI Data Governance Group on behalf of the Participating Agencies. This document forms part of the body of documents that have been developed and approved by the VAREANZ Programme and ANZACS-QI Data Governance Group around data handling practices relating to research.

The Privacy Framework is a living document that will be updated prior to any changes being made to the architecture or processes that have an impact on data handling practices. Any subsequent versions of this document must also be approved by the ANZACS-QI Data Governance Group prior to the changes being implemented.

2. ANZACS-QI Data Governance Group

The ANZACS-QI Data Governance Group has been established to ensure that identifiable data collected within ANZACS-QI is gathered, managed and used appropriately so as to ensure patient privacy whilst undertaking necessary national research to better understand the burden of cardiovascular disease (CVD) in New Zealand.

3. The Vascular Risk Equity for Aotearoa New Zealand (VAREANZ) Programme

Previously named the Vascular Informatics Using Epidemiology and the Web (VIEW) Programme, VAREANZ is a Health Research Council funded programme run from the School of Population Health at the University of Auckland. The purpose of VAREANZ is to develop a greater understanding of heart disease and stroke in New Zealand and to improve the ways they are assessed and treated. ANZACS-QI is the in-hospital part of this study.

Via VAREANZ, the ANZACS-QI database is anonymously linked to other national and research databases to report on outcomes and medication dispensing after patients have left their hospital care. This data is also available to the New Zealand Cardiology community for research purposes.

This linkage of anonymised patient data for VAREANZ-ANZACS-QI has been approved by the New Zealand Health and Disability Ethics Committee (Reference MEC/07/19/EXP/AM28).

4. Data Collection and Obligations

ANZACS-QI, under the auspices of this contract, comprises of 4 forms: the ACS, CathPCI, Device and Heart Failure forms. All suspected ACS patients who present at a Participating Agency will have an ACS form completed on their behalf and any patient who is seen in a Catheter Laboratory will have a CathPCI (coronary angiograms and PCI) or Device (pacemakers and ICDs) form completed. It is possible therefore, for a patient to have more than one form completed during an episode of care (EoC).

An EoC is an encounter with the health system, typically an admission to hospital or visit to out-patient clinic. The EoC is started at the beginning of that encounter e.g. date of admission to hospital or date of visit to the out-patient clinic. For an in-patient, a single EoC continues from admission to final discharge from hospital - a patient may be transferred between wards and hospitals within a single EoC. Once the patient is finally discharged from hospital the EoC can be considered to end. A re-admission after that would be a new EoC and the user should create a new EoC when prompted. For out-patient clinic visits, each visit is a new EoC.

Other modules have been developed which utilise the ANZACS-QI electronic platform. There is an additional CT/MRI module which is a research/audit enabled reporting template for clinical reporting of computer tomography coronary angiogram (CTCA) and cardiac magnetic resonance imaging (MRI) studies performed to investigate suspected cardiac disease. The CTCA/MRI module generates a clinical report and stores key structured variables in the ANZACS-QI dataset for audit and research purposes. Use of the data captured in all these modules is not currently covered under the VAREANZ ethics approval and governance is separate from the ANZACS-QI Data Governance Group.

The framework for the collection, management and use of health information about identifiable individuals held within ANZACS-QI falls within the provisions of the Health Act 1956, the New Zealand Public Health and Disability Act 2000, the Privacy Act 2020, the Public Records Act 2005 and the Health Information Privacy Code 1994 (HIPC). The HIPC, in particular, provides a broad framework of controls for the safe management of information about identifiable individuals. Additionally, the University of Auckland has its own policies, statutes, regulations, rules and legislations that will be upheld as necessary (Appendix 4(8)).

5. Versions

This document has undergone several modifications, and in 2023 was combined with the ‘ANZACS-QI Governance Structure and Data Governance Principles’ in a single document, the ‘ANZACS-QI Governance Group Terms of Reference’. All modifications are outlined in Appendix 5.

6. Privacy Principles

The following are the privacy principles under which ANZACS-QI data is managed:

6.1 Collection

What information will be collected, from whom, and how?
Information about the patient and their treatment in hospital is collected by clinicians within Participating Agencies to populate the form/s in ANZACS-QI. The required information is either gathered during the patient's EoC, from the paper medical record or from a hospital system. Data dictionaries which detail the full data set being captured are maintained and available on request from the ANZACS-QI Data Governance Group.

Why is this information collected?
Information on the patient's EoC is captured to:

1. Ensure the care they receive is appropriate, and improve upon it where a review or audit of the information shows it is not i.e. clinical quality improvement
2. Ensure the data being captured is an accurate account of the patient's EoC, and improve upon it where a review or audit of the information shows it is not i.e. data quality improvement
3. Report performance against the national cardiology targets set by Health New Zealand | Te Whatu Ora
4. Enable national research initiatives using anonymised patient data to:
    a. develop NZ risk prediction tools to identify patients at high risk of CVD;
    b. quantify disparities in appropriate treatment;
    c. model the impact of treatment disparities on CVD burden.
5. Provide patient tailored clinical management, advice and support.

How will individuals be informed that information is being collected?

Participants are not required by the New Zealand Health and Disability Ethics Committee (Reference MEC/07/19/EXP/AM28) to consent to having their data collected. Data is collected at a national level for quality improvement purposes, for the Ministry of Health). Information is collected as part of routine clinical care. In June 2014, however, several copies of a poster (Appendix 4(1)), approved by the ethics committee, explaining what happens with patient data collected in ANZACS-QI were issued to each Participating Agency to hang in view of their patients. Additionally, Participant Information Sheets (PIS) (Appendix 4(2)), also approved by the ethics committee, have been made available to Participating Agencies.

Who owns this information?
The information in ANZACS-QI is held (not owned) for privacy purposes by the Participating Agency that has care of the patient at that point in time during their EoC. They will be referred to as the Data Holder.

Wholesale transfer of patient information
The Participating Agency, who is the Data Holder, may change during the course of the EoC if the patient is transferred from one hospital to another. In this instance, patient information entered into ANZACS-QI by any earlier Participating Agencies for that EoC, and any prior EoC data for that patient (should there be any) will be transferred in ANZACS-QI, along with the

physical transfer of the patient, to the receiving Participating Agency, who is now deemed the lead care provider for that patient and therefore, the Data Holder.

Enigma acts as the Participating Agency's agent as far as holding information is concerned.

The system architecture (Appendix 4(3)) for ANZACS-QI has been captured pictorially.

6.2 Security

Connected Health Network

As per the contract, ANZACS-QI is run over the Connected Health Network (CHN). Connected Health is a standards-based, commercial model for the delivery of universal connectivity across the New Zealand health sector.

The CHN is a 'network of networks' delivered by multiple telecommunication service providers on a competitive basis, using industry standard, commodity capability. It is overseen by the Ministry of Health.

Connected Health aims to improve reliability, safety, and security of transferring health information as only products or services certified against approved network connectivity standards, such as ANZACS-QI, will be allowed to connect to the network.

Passwords

All authorised users have individual usernames and passwords allocated by a system administrator. Password checks are applied when user accounts are created and whenever a password is changed. These checks ensue complexity and avoid lists of reserved disallowed words and phrases.

Authentication

Access to ANZACS-QI is through individual username and password authentication. The authentication process is a two-pronged process. Before system access is granted, checks are done in the back end of ANZACS-QI to ensure there is a matching username and password for the User, and that they have a level object associated with their account. A level object, in the instance of ANZACS-QI, is the User's hospital, DHB, region or national account level access. If these criteria are met, the User is authenticated and access to ANZACS-QI is granted.

Encryption – General

ANZACS-QI data is used for national reporting and audit purposes. Ethics approval is granted to researchers on the basis that data linkage is conducted in an anonymised manner. Encrypting the patient identifiers and ensuring that only the encrypted versions are made available outside of the core hosted environment ensures that the data used for research purposes is always anonymised. Enigma facilitates this portion of work by managing the provision of data to external settings, including the data warehouse housed within HHRSP.

Encryption - VAREANZ Programme Use and Linkage to other National Datasets

The patient NHI is encrypted in such a way that an encrypted string can be used to link the various national datasets. For each source of data, a unique encryption key is used rendering a unique eNHI. This means that the version of the eNHI returned to each source of data is unique and does not directly match that of any other agency. The readable NHI values will never be passed onto the VAREANZ researchers but rather, their own eNHIs. VAREANZ researchers can use these eNHIs to link records between datasets.

Encryption - External Researchers

Any encrypted data extract released to authorised external researchers will also contain eNHIs rather than readable NHIs. Data is provided to researchers within a virtual machine environment, which restricts the downloading of data. This virtual machine is managed by the VAREANZ team.

External researchers will need to sign a Data Release Agreement, which is part of the Data Access Proposal (DAP) form, further safeguarding the data. (See the section '6.6 Use' below on for further details about the DAP process).

Testing

All new release content and functionality for ANZACS-QI is approved by the ANZACS-QI Data Governance Group. Testing of releases is conducted initially by Enigma, followed by formal user acceptance testing by members of the cardiology teams within the Participating Agencies.

Server Location

Information gathered within ANZACS-QI is held on Enigma's production hosting network. This was established within Vocus Communications Ltd (7A Parkhead Pl, Albany) in 2005.

Physical access is restricted using biometric access gates, the equipment is located within commercial grade, locked metal cabinets.

Network access is secured using a Juniper firewall.

Systems Maintenance

Enigma undertakes regular routine system maintenance on their production hosting environment; however, the majority of the environment has been built to provide high availability, through redundancy, which means it can often be performed without any outage.

Enigma infrequently has to undertake maintenance of some core elements of their network where a brief outage is unavoidable e.g. patching of our SQL servers. All work of this nature is limited to low usage times (late at night, after 11pm, or during the weekends at the same time). These outages are always kept to a minimum period to limit impact on users. Where the impact is expected to be more than 15 minutes, a planned outage notification will be sent to each Participating Agency.

Very infrequently some more singular areas of the network might experience difficulties (unscheduled). Where this occurs during normal working hours (8am- 7:30pm) and where production hosting is affected in this manner, Enigma will make contact with their primary points of contact under each of their SLAs. Enigma will endeavour to proactively communicate status updates, and estimated resolution timeframes.

6.3 Access

There is a user roles matrix (Appendix 4(4)) that details the permissions of the various user roles. Access to ANZACS-QI is role and location based. The issuing of District Health Board (DHB), Regional, Steering Committee and National Support access is governed by the ANZACS-QI Data Governance Group and its permission must be sought, and approval granted, before any user can be granted these roles. Additionally, the limited user set who can access identifiable patient data in order to perform their duties (as noted in the Clinical Access section below), must be authorised by the ANZACS-QI Data Governance Group prior to this permission being granted.

Users granted National Support access must sign either the Enigma (Appendix 4(6)) or NIHI/UniServices (Appendix 4(7)) Data Confidentiality Agreement. Note: A new HHRSP/University of Auckland Data Confidentiality Agreement is currently being drafted.

Patients cannot be searched for by their name in ANZACS-QI to ensure patient privacy is upheld. Access to patient data within ANZACS-QI is by NHI number only and can be accessed by any authorised user (with the appropriate permissions).

Data Governance Group Access
All the ANZACS-QI Data Governance Group members have Steering Committee access to ANZACS-QI to allow them to perform their governance function. Aggregated data only is displayed. This level of access may be in addition to their clinical access at a hospital level.

Clinical Access
Clinical and hospital staff are granted Clinic, Clinic +, Hospital or Hospital Admin access as required to perform their role and determined by the ANZACS-QI Administrators within their Participating Agency. These roles only allow access to patient data at an identifiable level at the hospital of their employment.

Regional Liaison Officers (there is one in each Northern, Midlands, Central and Southern regions) have regional access and can see all identifiable patient data from hospitals within their region in order to perform their oversight function for their region.

Those staff granted district access have access to all patient data for hospitals within that district at a non-identifiable level in order for them to perform their oversight function for their district. Staff with this level of access must adhere with the confidentially clauses specified in their employment contract with their district.

Additionally, a user at each hospital may be granted access to unencrypted patient data for audit purposes. This permission is restricted to one user per district.

System Support Access

Both HHRSP and Enigma provide support services for ANZACS-QI and therefore, these staff require National Support access to ANZACS-QI to be able to provide this service.

Enigma has two primary documents - the Data Handling and Privacy Policy (Appendix 4(5)), and a confidentiality agreement that all staff with access to the ANZACS-QI system must sign (Appendix 4(6)).

Enigma enforces the data handling and privacy policy which expressly prohibits staff access into products for any reason other than bona-fide support incidents, each of which are logged in their support ticketing system.

HHRSP personnel are bound to a similar data confidentiality agreement.

Patient Access

All patients have the right to access information about them collected in ANZACS-QI and can request this information directly from their health professional who will follow their existing process to provide access to their medical record.

If a patient decides at any time that they do not wish to have their data collected or provide unidentifiable information about their heart health for research purposes, they can opt out by contacting their health professional and their information will not be recorded in ANZACS-QI. Additionally, previous data that may have been recorded against the patient will be deleted.

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. Initially, the request will be given to the patient's healthcare professional who will decide whether the request should be actioned.

If deemed the change should be made, the healthcare professional can then refer the request to the Hospital Administrator at the particular participating agency to update the EoC. If the Administrator is unable to make the change as they do not have the ability to update certain fields due to system constraints, it will be referred to Enigma so that they can enact the change in the system's backend. The person who requested the change will be advised when the update has been made by their healthcare professional or their delegate.

If approval is not granted to correct the information, this will be worked through with the person who requested the change and their health care professional. If resolution is unable to be reached, the matter will be referred to the ANZACS-QI Data Governance Group for resolution.

Audit Log

All submissions of data into ANZACS-QI contain full details of who submitted that data. All patient movements and reassignments of EoCs (as care is transferred) are also logged through core registry data submissions.

In addition to this, various activities conducted through ANZACS-QI interfaces are tracked and logged within audit tables. These tracked activities have been established through discussion with the ANZACS-QI Data Governance Group and have been in place since the CHN release of ANZACS-QI.

Access to view audit logs is available to users with Administrator access, which enables them to generate reports of auditable activity, relating to individual user access to ANZACS-QI and the patient data it holds.

6.4 Retention

Health regulations require that health information be retained for 10 years from the date of last contact; however, the information and associated retention obligation can be transferred to another provider.

6.5 Disposal

The Public Records Act 2005 formally covers all records (patient and other). This Act makes it illegal to destroy any records, including health information, made or received by DHBs without the permission of the Chief Archivist at Archives New Zealand.

Disposal (or disposition) is a decision. It does not mean destruction - it is the final decision made by the ANZACS-QI Data Governance Group, districts and Archives New Zealand about the permanent preservation or otherwise of the record.

The processes outlined in this Act will be adhered with for ANZACS-QI patient data.

6.6 Use

The patient data within ANZACS-QI will be used for patient stratification and management, and national research. It will also be used for audit and quality improvement purposes. This information will also form a basis (ethics dependent) for discrete pieces of research. Such requests for access to the data are made via a Data Access Proposal (DAP) which must be approved by the ANZACS-QI Data Governance Group and the VAREANZ Group before data is released. The DAP process has its own body of documents associated with it to ensure the secure handling of patient data and are available on request from the ANZACS-QI Data Governance Group.

At no time in the future will any data be provided from ANZACS-QI to any external research group which could ever identify patients i.e. all future data requests will only ever be serviced using unidentifiable patient level, or aggregate data (also non-identifiable).

6.7 Disclosure

Patient information is disclosed as part of routine medical care within or between the Participating Agencies.

Neither Enigma nor HHRSP will be disclosing patient information to third parties. Only the ANZACS-QI Data Governance Group has this authority.

No third parties have access to the data within ANZACS-QI directly.

The Official Information Act 1982 makes official information more freely available, to provide for proper access by each person to official information relating to that person, to protect official information to the extent consistent with the public interest and the preservation of personal privacy, and to establish procedures for the achievement of those purposes.

Official Information Act 1982 requests may be made by members of the public from time to time in relation to ANZACS-QI. Any data released under this Act will be patient anonymised (unless requested by the patient themselves). The ANZACS-QI Data Governance Group will review all requests made under this Act, along with the Ministry of Health, and approve material to be released.

Official Information Act 1982 requests regarding individual clinicians can only be obtained from reporting capability provided at the district user level, rather than the National level.

6.8 Unique Identifier

ANZACS-QI uses the NHI number assigned to each patient as an identifier. This is consistent with current sector standards and is necessary for the purposes of the programme.

The Ministry of Health's Health Identity Team provides the ability within ANZACS-QI for users to perform a search on an NHI to find the demographic data for their patient. The Ministry of Health has stipulated that only users with the required user credentials, which include a Provider Organisation Identifier Code, can have access to this function i.e. authenticated ANZACS-QI users.

7. Complaints and Breaches

Any privacy related complaints relating to ANZACS-QI should be directed to the relevant district Privacy Officer in the first instance, who will then refer the complaint to the appropriate healthcare professional or that provider's employer, depending on where the breach occurred.

Where the complaint relates to Enigma or HHRSP personnel, it should be directed to the ANZACS-QI Data Governance Group Chair who will approach management within either organisation to work through their complaint process.

7.1 Acknowledgement

The Privacy Officer or ANZACS-QI Data Governance Group Chair (as relevant), on receiving a complaint or breach must:

1. Contact the person making the complaint in writing, within 10 working days of learning about the complaint or breach,
2. Inform the complainant of any relevant internal and external complaint procedures, and of the action that will be taken within 10 working days.

7.2 Investigation

As soon as practicable after a complaint is accepted, the Privacy Officer or ANZACS-QI Data Governance Group Chair (as relevant), must inform the complainee of the alleged complaint or breach. The Privacy Officer or ANZACS-QI Data Governance Group Chair (as relevant) must also inform the complainant of the steps being proposed to resolve the issue, and also that they have the right to contact the Privacy Commissioner. If the privacy breach has either caused or is likely to cause anyone serious harm (as defined by Section 113 of the Privacy Act 2020), the Privacy Officer or ANZACS-QI Data Governance Group Chair (as relevant) must also notify the Privacy Commissioner and any affected people as soon as practically able.

No Investigation

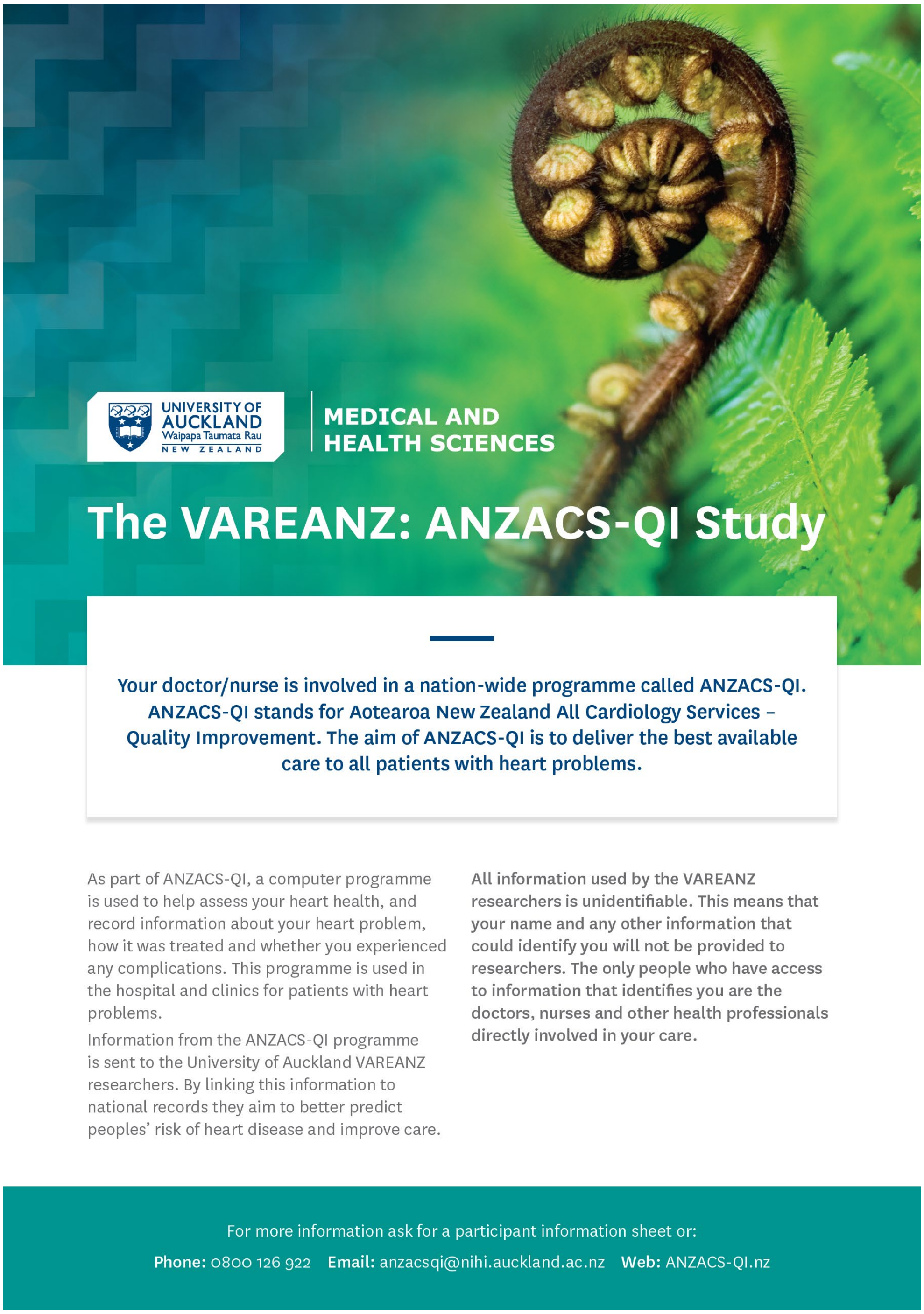
If the Privacy Officer or ANZACS-QI Data Governance Group Chair (as relevant) decide a complaint or breach has not occurred on the basis that none of the terms of the HIPC or Privacy Framework have been breached, then as soon as practicably possible they must inform the complainant of the reasons for the decision, and their right to contact the Privacy Commissioner regarding their decision. The Privacy Officer must also inform the ANZACS-QI Data Governance Group Chair.

Inappropriate Access

Inappropriate access to information on ANZACS-QI by any user is considered a serious breach of trust. The Privacy Officer or ANZACS-QI Data Governance Group Chair (as relevant) will take action, in accordance with due process and natural justice, which may include disciplinary action, removal of access privileges, and/or referral to a relevant professional authority.

Appendix 4 (Continued)
ANZACS–QI Privacy Framework

Appendix 4(1): ANZACS-QI Poster for Hospital Settings



UNIVERSITY OF AUCKLAND
Waipapa Taumata Rau
NEW ZEALAND

MEDICAL AND HEALTH SCIENCES

The VAREANZ: ANZACS-QI Study

Your doctor/nurse is involved in a nation-wide programme called ANZACS-QI. ANZACS-QI stands for Aotearoa New Zealand All Cardiology Services – Quality Improvement. The aim of ANZACS-QI is to deliver the best available care to all patients with heart problems.

As part of ANZACS-QI, a computer programme is used to help assess your heart health, and record information about your heart problem, how it was treated and whether you experienced any complications. This programme is used in the hospital and clinics for patients with heart problems.

Information from the ANZACS-QI programme is sent to the University of Auckland VAREANZ researchers. By linking this information to national records they aim to better predict peoples' risk of heart disease and improve care.

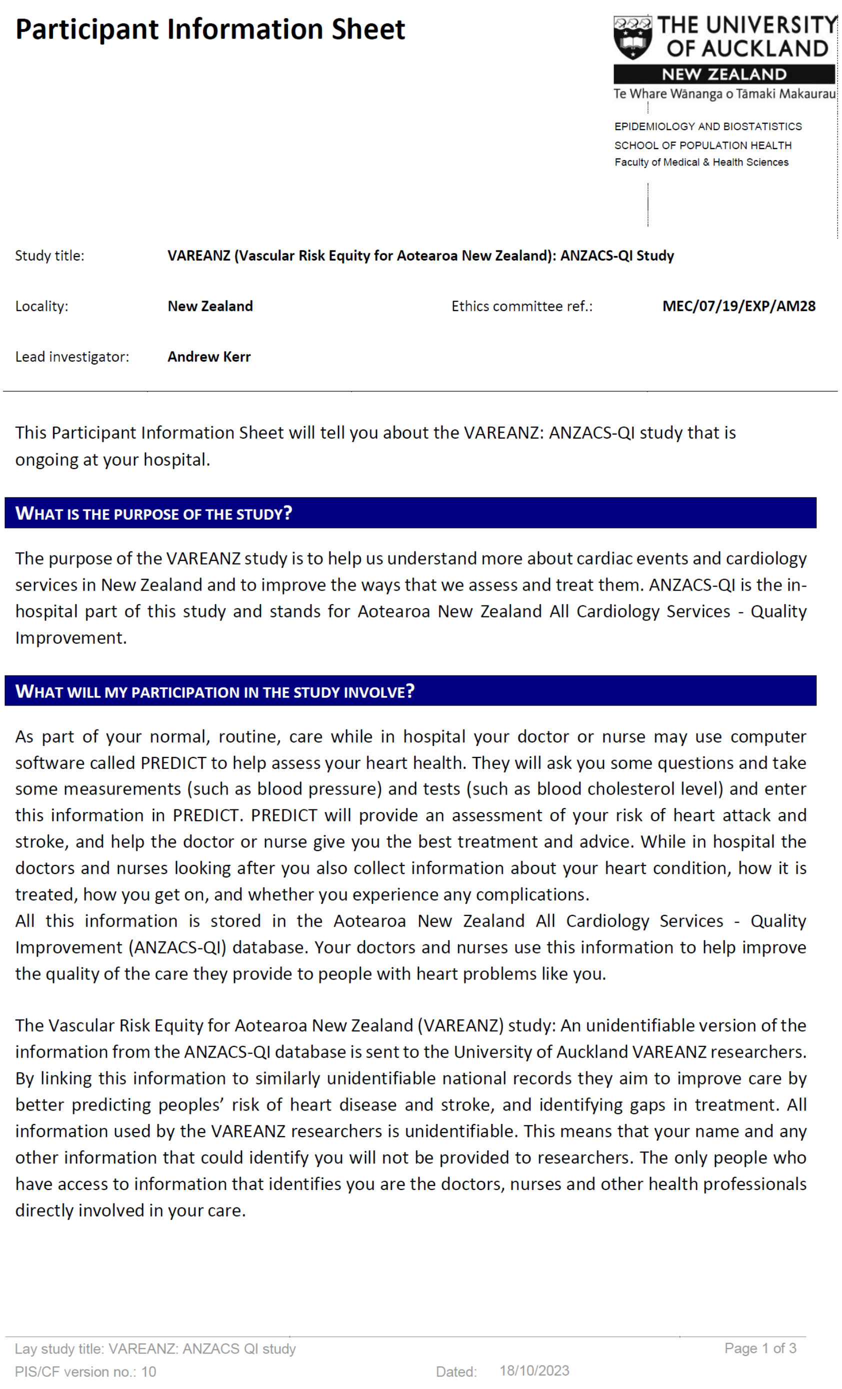
All information used by the VAREANZ researchers is unidentifiable. This means that your name and any other information that could identify you will not be provided to researchers. The only people who have access to information that identifies you are the doctors, nurses and other health professionals directly involved in your care.

For more information ask for a participant information sheet or:

Phone: 0800 126 922 **Email:** anzacsqi@nihi.auckland.ac.nz **Web:** ANZACS-QI.nz

Appendix 4 (Continued)
ANZACS–QI Privacy Framework

Appendix 4(2): ANZACS-QI Participant Information Sheet (v10)



Participant Information Sheet

THE UNIVERSITY OF AUCKLAND
NEW ZEALAND
Te Whare Wānanga o Tāmaki Makaurau

EPIDEMIOLOGY AND BIOSTATISTICS
SCHOOL OF POPULATION HEALTH
Faculty of Medical & Health Sciences

Study title:	**VAREANZ (Vascular Risk Equity for Aotearoa New Zealand): ANZACS-QI Study**		
Locality:	**New Zealand**	Ethics committee ref.:	**MEC/07/19/EXP/AM28**
Lead investigator:	**Andrew Kerr**		

This Participant Information Sheet will tell you about the VAREANZ: ANZACS-QI study that is ongoing at your hospital.

WHAT IS THE PURPOSE OF THE STUDY?

The purpose of the VAREANZ study is to help us understand more about cardiac events and cardiology services in New Zealand and to improve the ways that we assess and treat them. ANZACS-QI is the in-hospital part of this study and stands for Aotearoa New Zealand All Cardiology Services - Quality Improvement.

WHAT WILL MY PARTICIPATION IN THE STUDY INVOLVE?

As part of your normal, routine, care while in hospital your doctor or nurse may use computer software called PREDICT to help assess your heart health. They will ask you some questions and take some measurements (such as blood pressure) and tests (such as blood cholesterol level) and enter this information in PREDICT. PREDICT will provide an assessment of your risk of heart attack and stroke, and help the doctor or nurse give you the best treatment and advice. While in hospital the doctors and nurses looking after you also collect information about your heart condition, how it is treated, how you get on, and whether you experience any complications.
All this information is stored in the Aotearoa New Zealand All Cardiology Services - Quality Improvement (ANZACS-QI) database. Your doctors and nurses use this information to help improve the quality of the care they provide to people with heart problems like you.

The Vascular Risk Equity for Aotearoa New Zealand (VAREANZ) study: An unidentifiable version of the information from the ANZACS-QI database is sent to the University of Auckland VAREANZ researchers. By linking this information to similarly unidentifiable national records they aim to improve care by better predicting peoples' risk of heart disease and stroke, and identifying gaps in treatment. All information used by the VAREANZ researchers is unidentifiable. This means that your name and any other information that could identify you will not be provided to researchers. The only people who have access to information that identifies you are the doctors, nurses and other health professionals directly involved in your care.

Lay study title: VAREANZ: ANZACS QI study Page 1 of 3
PIS/CF version no.: 10 Dated: 18/10/2023

WHAT ARE THE POSSIBLE BENEFITS AND RISKS OF THIS STUDY?

The Aotearoa New Zealand All Cardiology Services - Quality Improvement (ANZACS-QI) database (using PREDICT software) will help your doctor or nurse to assess your risk of heart disease and stroke and talk to you about things you can do and treatments that can reduce your risk.

The benefit of the VAREANZ: ANZACS-QI study is to be able to study heart and diabetes risk factors and provide better ways for your doctor to assess and treat you. The study also investigates the quality of care received by patients, whether there are groups of people missing out and whether this is improving over time.

There are no immediate risks to you being involved in the study as all data is unidentifiable. This means that your name and any other information that could identify you will never be provided to researchers. The only people who have access to information that identifies you are the doctors, nurses and other health professionals directly involved in your care.

This research has received ethical approval from the Northern A Health and Disability Ethics Committee. The unidentifiable information will only be given to VAREANZ researchers if the District Health Board that your doctor or nurse belongs to has given permission.

WHO PAYS FOR THE STUDY?

This study is funded by the Health Research Council of New Zealand.

WHAT ARE MY RIGHTS?

All participants have the right to access information about them collected in the ANZACS-QI database and can request this information directly from their hospital doctor or nurse. The data sent to VAREANZ researchers has no identifying information so neither you nor the researchers could tell which information belongs to you.

If you decide at any time that you do not wish to participate by providing unidentifiable information about your heart health, you can withdraw without experiencing any disadvantage. Please contact your doctor or nurse and your unidentifiable information will not be sent to the VAREANZ researchers.

WHAT HAPPENS AFTER THE STUDY?

This is an ongoing, long-term study. An unidentifiable version of the information collected in the ANZACS-QI database will be stored securely on University of Auckland computers for this research project and possible future use.

Findings from this study have been and continue to be published in health care journals and presented at conferences. They will also help to inform New Zealand guidelines for doctors and nurses about assessing and managing risk of heart disease and stroke.

WHO DO I CONTACT FOR MORE INFORMATION OR IF I HAVE CONCERNS?

If you have any questions, concerns or complaints about the study at any stage, you can contact:

ANZACS-QI
Phone: 0800 126 922
Email: anzacsqi@nihi.auckland.ac.nz

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

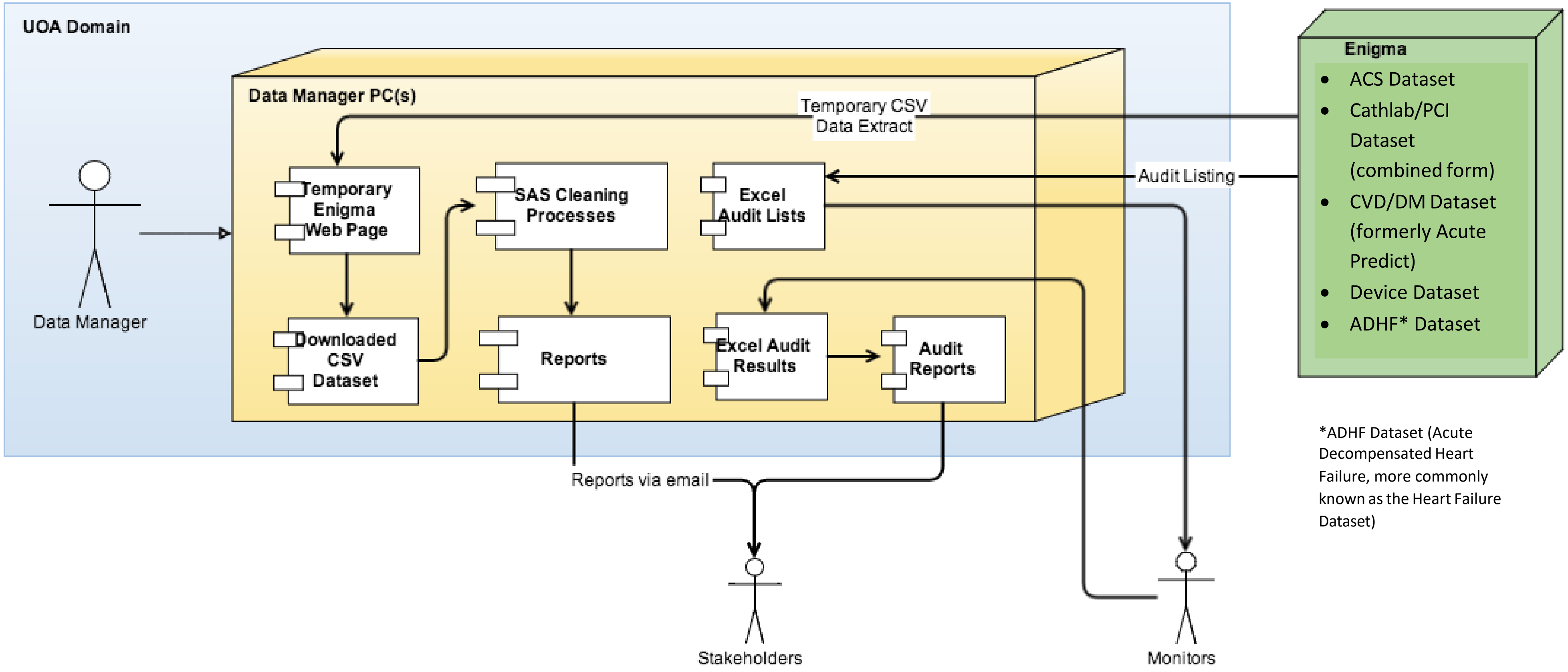
Phone: 0800 555 050
Fax: 0800 2 SUPPORT (0800 2787 7678)
Email: advocacy@hdc.org.nz

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone: 0800 4 ETHICS
Email: hdecs@health.govt.nz

Appendix 4 (Continued)
ANZACS–QI Privacy Framework

Appendix 4(3): ANZACS-QI System Architecture



*ADHF Dataset (Acute Decompensated Heart Failure, more commonly known as the Heart Failure Dataset)

Appendix 4 (Continued)

ANZACS–QI Privacy Framework

Appendix 4(4): User Access Roles and Permissions as at July 2016 v 1.1

	Clinic Access	**Finalise**	**Edit EoC Start Date**	**Generate Reports ie ACS, Cath**	**Access KPI Reports ie Quarterly, Weekly**	**Data Extract (Encrypted Only – No NIHI [1&3]**	**Redundant EOC**	**Add/Edit User Clinic etc**	**Filter Cath/PCI Report by Clinician**	**Resources**	Notes
Shared Service Agency	None	N	N	N	Y	Y	N	N	N	View, not edit	Can drill down to hospital overview but NO to clinic overviews. No patient identifiable data to be viewed
Registry Trial Group PM	None	N	N	N	Y	N	N	N	N	View, not edit	Can drill down to hospital overview but NO to clinic overviews. No patient identifiable data to be viewed
Clinic	Single	Y	Y	Y	Y	N	N	N	N	View, **and** edit	Single clinic access, no admin functions
Clinic +	Single	Y	Y	Y	Y	Y	Y	N	N	View, **and** edit	Single clinic access, limited admin functions
Hospital	All	Y	Y	Y	Y	N	N	N	N	View, not edit	Multiple clinic access, no admin functions
Hospital Admin	All	Y	Y	Y	Y	Y	Y	Y	N	View **and** edit	Multiple clinic access, plus admin functions
DHB	All	Y	Y	Y	Y	N	N	Y	N	View, not edit	Multiple clinic access, multiple hospital access, no admin functions
Regional Admin	All	Y	Y	Y	Y	Y	Y	Y	N	View, **and** edit	Multiple clinic, hospital and patient level access, plus admin functions
Regional Clinician[2]	All	Y	Y	Y	Y	Y	Y	Y	Y	View, not edit	Multiple clinic, hospital and patient level access, plus admin functions
Steering Committee[2]	None	N	N	Y	Y	N	N	N	N	View, not edit	Can drill down to hospital overview but NO to clinic overviews. No patient identifiable data to be viewed
National Support[2]	All	Y	Y	Y	Y	Y	Y	Y	N	View **and** edit	Can access patient level data and all function

Note 1 Unencrypted extracts with NHIs are available to only one user per region, selected by the regional liaison officer, and one user per hospital, selected by the hospital liaison officer. All requests must be authorised by the Chair of the ANZACS-QI Governance Group. Further requests may be granted on a case by case basis.

Note 2 Can only be given if approved by the Chair of the ANZACS-QI Governance Group .

Note 3 Clinician name removed from all extracts except Regional Clinician

Appendix 4 (Continued)

ANZACS–QI Privacy Framework

Appendix 4(5): Enigma Data Handling Policy

1. Security

Encryption of sensitive data

All normal access controls apply to databases which hold sensitive data, but in addition to those basic protections, the data itself is encrypted before being written into any database. In terms of our production products, Enigma routinely applies this practice to all data which is considered to be 'identifiable patient' data, or similar data relating to workplace-based usage.

Enigma has purchased a Java and a .COM based extension of their ColdFusion-based development platform which provides AES256bit ECB mode encryption. This is used to encrypt identifiable fields. This means that the data needs to flow through that same application layer (with application authorisation controls being satisfied) before those fields can be decrypted to readable content.

How is data accessed?

All parts of the product require access through a secured online interface using username and password authentication. If accessed by Enigma staff, a support ticket reference or reason for accessing the service is required, which is audited.

Password policy for accessing production data:

- Passwords must be a minimum of eight (8) characters in length.
- Users are prevented from using any of their last eight (8) passwords when changing password.
- Six incorrect login attempts will block a user's password for two (2) hours. If the user resets their password and enters the correct password in the meantime, it will unlock the account.
- Accounts are blocked after three months of inactivity and deactivated after six months of inactivity.
- Passwords are masked on screen so that the password cannot be observed by others as it is entered.
- When Enigma resets a user's password no password details will be sent by email. A time-based, one-time-usage link will be sent to the user's email account which will enable them to set a new password. Nothing will be made available by email which, when stored in an inbox, could present a lasting security issue for any account.
- When initially setting passwords for new user accounts, Support personnel will use randomly-generated passwords for each user account that is being set up and this will not be shared with the user. Users will be advised to reset their password to set a password in the first instance before they can access any of our systems.
- Log files will be held which capture account creation, user-initiated passwords changes and logging on.

2. Access to Sensitive and Identifiable Data

Who owns the data?

Enigma is a custodian of data relating to individuals. The data belongs to the individual. Enigma acts as an agent, under contract to the customer.

Who can access stored data?

Users with login credentials that provide access to a specific collection, or collections, of data. As custodians of data relating to individuals, Enigma may release data to entitled parties contained within the stated use and purpose at the time of the data collection. The general / default stance of Enigma to is to allow access only to the group who made the submission of data to our services. Special arrangements to exceed this stance would be made on a product by product / contract by contract basis. Where extensions of this arrangement are considered to require informed consent by the individual and where individual identifiable data is requested to be released beyond the scope of any previously made arrangement with the group collecting the data, individual consent will be obtained at the time of making the submission.

This consent may be collected electronically.

3. Use of Data for Aggregated Reporting

Aggregated, derived information may be distributed to entitled stakeholders or funding organisations who can demonstrate proper authority for access to this information. A declaration of the data which may be passed to these organisations will be made available to all users of the product upon request.

Production of Information for Stakeholders

From time to time, stakeholders may require a customised summary or ad-hoc report to be generated from the data held; this would constitute derived or aggregated information and would fall under the above provision.

National Benchmarking Information

Similarly, from time to time, benchmarking information may be required at a national level. This too would constitute derived or aggregated information. This information would not contain any details as to where the data was collected, or any details on any individuals. Agreement from stakeholders is always sought before performing any analysis or distribution of this nature.

4. Internal Access to Identifiable Data:

Internal Audit Processes

From time to time, Enigma’s staff may have a legitimate need to interact with individually identifiable data and are considered authorised to do so. Such legitimate needs would include providing support of Enigma products and services to their end users.

Providing QA / Oversight of Products.

Enigma and its staff undertake not to unnecessarily interact with any individually identifiable data; this would be considered unauthorised. Enigma undertakes periodic auditing of assigned user-rights for both clients and staff users. Enigma promptly removes credentials for staff members who leave the company; all staff within Enigma has their own personal login details to ensure that internal access is containable.

External Audit Processes

Enigma would make available information to a nominated and agreed third party organisation for the purposes of auditing the statements made herein should the need arise.

Any queries should be addressed to Chris Wiltshire, CIO of Enigma by email: chris.wiltshire@enigma.co.nz

Appendix 4(6): Enigma Solutions Data Confidentiality Agreement (Final Version: 1.7)

I, the undersigned, acknowledge and agree to the following which is aimed to constrain staff's interactions with patient level data and information:

All personally identifiable information and data shall be treated as strictly confidential and shall not be disclosed or provided to any Enigma Solutions Limited employee, contractor, or other third party who has not signed a Data Confidentiality Agreement.

In addition, access to such data shall be allowed only if necessary in the performance of that persons work responsibilities. All other access must be authorised in writing by the assigned data custodian.

In addition:

1. No attempt shall be made to identify any individual or other personally identifiable information contained in such records.
2. No data that identifies specific individuals or other personally identifiable information may be accessed or shared with any other party. Access to this data may be allowed in the course of an approved application development project and / or in the course of supporting a live production application.
3. Support of a live production application requires a support ticket to be lodged prior to access being permitted; access is permitted only to the owner of the ticket / engineer servicing the ticket. Access to production data should be noted against the support ticket by the supporting engineer. This may be cross referenced against access logs for audit purposes.
4. No aggregate data from such records shall be reported or published without written permission of the data custodian.
5. Data may not be copied or stored in any format outside of approved backup procedures.
6. Developers may not copy data for development and testing purposes without the written permission of the data custodian.
7. Access to production, acceptance test, and development data, shall be protected in accordance with the requirements of the data custodian.
8. Any breach, or suspected breach, of data confidentiality shall be reported immediately to the assigned data custodian.
9. No access to production products is permitted for the purposes of product demonstration, except where special access has been arranged in writing with the data owner / customer. Such special arrangements must be recorded as a referenceable support ticket. The special subject 'Demo Access Permission' will be used to enable searches for such consent.
10. I have read and understand the principals expressed within the Health Information Privacy Code 2020 and agree to operate within those principals.

https://www.privacy.org.nz/privacy-act-2020/codes-of-practice/hipc2020/

Violation of this agreement will constitute severe misconduct and may be the basis for immediate dismissal and other penalties as may be prescribed by law.

The data custodian is normally the General Manager of Enigma, except where this varies within the Register of Data and Products. The custodianship of a dataset may be allocated to an alternative position within Enigma as deemed appropriate by the General Manager.

____

(Signature)

____

(Date)

____

(Print Name)

Appendix 4 (Continued)
*Note: A new HHRSP/University of Auckland Confidentiality Agreement is currently being drafted.

ANZACS–QI Privacy Framework

Appendix 4(7): NIHI/UniServices Confidentiality Agreement

Data Confidentiality Agreement

Project: Aotearoa New Zealand All Cardiology Services – Quality Improvement Registry and Associated Support Services (ANZACS-QI).

I, the undersigned, acknowledge and agree to the following:

All personally identifiable information and data shall be treated as strictly confidential and shall not be disclosed or provided to any Auckland UniServices Limited or University of Auckland employee, contractor, or other third party who has not signed a Confidentiality Agreement.

In addition, access to such data shall be allowed only if necessary in the performance of that persons work responsibilities. All other access must be authorised in writing by the assigned data custodian.

The data custodian is the ANZACS-QI Data Governance Group. The custodianship of a dataset may be allocated to an alternative position as deemed appropriate by the Chair of this group.

In addition:

1. No attempt shall be made to identify any individual or other personally identifiable information contained within ANZACS-QI.
2. No ANZACS-QI data that identifies specific individuals or other personally identifiable information may be accessed unless it is necessary to provide legitimate support services to ANZACS-QI users. All support queries made to the ANZACS-QI support desk, managed by the National Institute for Health Innovation (NIHI) data management team, are logged at NIHI and access audit logs are available within ANZACS-QI itself from Enigma Solutions Limited.
3. No ANZACS-QI data in any form (unidentifiable or identifiable) shall be distributed, reported or published without written permission from the data custodian.
4. ANZACS-QI data may not be copied or stored in any format outside of approved procedures defined by the data custodian.
5. Developers may not copy ANZACS-QI data for development and testing purposes without the written permission of the data custodian.

6. Access to production, acceptance test, and development data within ANZACS-QI, shall be protected in accordance with the requirements of the data custodian.
7. Any breach, or suspected breach, of data confidentiality in relation to ANZACS-QI data shall be reported immediately to the data custodian.

Any breach of this agreement will be regarded seriously and could result in disciplinary action and other penalties as may be prescribed by law.

Dated this day of 20__

IN WITNESS WHEREOF, the parties have executed this Agreement as of this day and year.

____
(Signature)

____
(Print Name)

____
(Title)

In the presence of:

Witness Signature: ______________________________

Witness Name: ______________________________

Witness Address: ______________________________

____

____

____

ANZACS–QI Privacy Framework

Appendix 4(8): The University of Auckland Policies, Statutes, Regulations, Rules and Legislations

https://www.auckland.ac.nz/en/about-us/about-the-university/policy-hub.html

Welcome to the University's register for University policies, statutes, and related documents, which is augmented by links to key New Zealand legislation.

The register contains links to policies and statutes relating to the governance and management of the University. Documents available on this site are the official documents of the University and may be aligned with strategic objectives. They also facilitate compliance on the part of the University and individual staff and students. Staff of the University are able to view additional documents by signing in (top right).

The term 'statutes' refers here to University statutes, not government statutes.

To view the University's Policy Framework Policy, visit https://www.auckland.ac.nz/en/about-us/about-the-university/policy-hub/policy-development-review/policy-framework-policy.html.

The University's Legislative Compliance Policy and Procedures can be viewed at https://www.auckland.ac.nz/en/about-us/about-the-university/policy-hub/university-governance/legal/legislative-compliance-policy.html.

In the case where the content of a document kept in this register is in any way altered or misrepresented, the University takes no responsibility and cannot be liable to any person.

Appendix 5

Version Control

ANZACS-QI Governance Structure and Data Governance Principles

Initial draft collated by Arjan Schenk after discussions in the ANZACS-QI Working Group.

Version 4.1: includes revisions by Andrew Kerr, and further updates following review by the ANZACS-QI working group. References to the VIEW programme added. Governance group membership updated.

Version 5.0 (Dec 2012): changes to the proposed Governance structure, following review at the NZ Cardiac Network meeting (Sept 2012). Reviewed by Sebastian Lynch from the Privacy Commission.

Version 6.0 (2013): updated by Andrew Kerr (Chair) following review and incorporation of suggested changes by a) the ANZACS-QI Data Governance Group, b) feedback from Lucy Curtis, Senior Policy Advisor, Investment Systems and Planning, Information Strategy Group, NHB, and c) review in Oct 2013 at the National Cardiac Network meeting and Cardiac Registries Implementation Group.

Version 7.0: updated by Kristin Sutherland (Project Manager) to incorporate updates in the Data Access Application process.

Version 8.0 (2015): updated by Kristin Sutherland (Project Manager) to incorporate changes to the Governance Group structure, including a Consumer Representative and the Cardiac Society nominated ACS expert.

ANZACS-QI Privacy Framework

Version	Created By	Approved/In Effect On
1 (2014)	Programme Manager ANZACS-QI	Sebastian Morgan Lynch – Privacy Commission, and ANZACS-QI Governance Group 5 September 2014 (approvals held with Programme Manager ANZACS-QI)
2 (2016)	Chair ANZACS-QI Governance group	ANZACS-QI Governance Group Oct 2016: o Updated to encompass the CHF and CT/MRI modules o The consumer representative role has been added to the Governance Group membership o The User roles (Appendix 5) has been updated
3 (2022)	Programme Manager ANZACS-QI	o New indicators added o Privacy Act and HIPC updated o Governance Group members updated o Updated version of patient poster and patient information sheet added

In 2023 these were combined in a single document the ANZACS-QI Governance Group Terms of Reference.

ANZACS-QI Governance Group Terms of Reference

Version	Purpose/Change	Author	Date
10.0	• ANZACS-QI Governance Structure and Data Governance Principles and Privacy Framework combined • Equity and CSANZ Co-Chair introduced and Māori representative roles added • Link to the VAREANZ group for oversight introduced	Approved by MOH and ANZACS-QI Governance Group	2023
11.0	• Update ANZACS-QI name from 'All New Zealand Acute Coronary Syndrome – Quality Improvement' to 'Aotearoa New Zealand All Cardiology Services – Quality Improvement' and 'VIEW' to 'VAREANZ' • Updated Participant Information Sheet and Poster added • Old logo replaced with new • Update of Governance members list with roles only, removing current member names which will be stored within NIHI and on the ANZACS-QI website • Updated National Indicators moved from Appendix 4 to the beginning of the document • Minor spelling and formatting amendments • Addition of Appendix 5 and version control tracking, removing Version tables within the document which are replaced with a note that refers readers to Appendix 5	Jessica Collier, Programme Coordinator – NIHI	January 2024
12.0	• Update DAP Application Form and Guide • Updated National Indicators	Jessica Collier, Programme Coordinator – NIHI	October 2024
13.0	• Updated stakeholder name due to transition from NIHI at UniServices to HHRSP at the University of Auckland • Replaced stakeholder diagram with updated version • Updated to include links to National Indicators, and the DAP form and guide • Update to Appendix 4(8): The University of Auckland Policies, Statutes, Regulations, Rules and Legislations	Jessica Collier, Human Health Research Coordinator – HHRSP	November 2025