APRIL 2023

TOWARDS A (NEAR) REAL-TIME CLINICAL DATA DASHBOARD FOR TASMANIA WORKSHOP

RATIONALE, BARRIERS, NEEDS AND OPPORTUNITIES

ACvA
Australian Cardiovascular Alliance

Australian Cardiovascular Alliance

Acknowledgements

The participants in the workshop, which was facilitated by the Australian Cardiovascular Alliance (ACvA), acknowledge the Traditional Custodians of Country throughout Australia where the participants at the workshop work, live, and meet to improve cardiovascular and stroke outcomes for the whole community. Participants would like to specifically acknowledge the traditional owners of the lands of Tasmania and the Muwinina peoples of Nipaluna, where the in person aspects of the workshop were held. Collectively, we recognise the Traditional Custodians' continuing connection to land, waters and community and pay our respects to them and their cultures, and to Elders past, present and emerging.

The ACvA would also like to recognise the support provided by the Menzies Institute for Medical Research and the Tasmanian Department of Health.

We would also like to recognise Mr Mike Whittle and thank him for sharing his story as a stroke survivor, re-enforcing the need for all patients to have access to best practice care and for our health system to be continuously improving and advancing patient outcomes.

Our thanks also go to Associate Professor Seana Gall, Professor James Sharman and Professor Matthew Jose for their significant input and advice that brought the workshop to fruition.

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Definitions

For the purposes of this report, the following terms are defined below:

Cardiovascular Health Leadership Research Forum (CV HLRF) – A strategic forum held at both state and national levels to bring together data/evidence and expertise to allow health system leadership to identify gaps and inequities, and prioritise areas for research investment, translation and implementation into the health system. The work of the CV HLRFs is underpinned by efforts to progress development and agreement on CV clinical quality indicators.

Clinical Quality Indicators– a minimum set of clinically meaningful data to assist health professionals and health services to understand, interrogate and monitor patient care, health structures, processes, and specific outcomes, providing a quantitative basis for quality improvement and addressing inequities.

Data Dashboards –Near real-time presentations of clinical quality indicators to be used by health services, researchers and clinicians, including General Practitioners, health providers and patients to aide clinical decision making and identify gaps and inequities.

Electronic Medical Record System (eMR) – These systems provide clinicians with digital access to patient reports and documents, manage and store relevant health information and clinical assessments.

Government Health Data Assets – Routinely collected administrative data assets. These data assets are national in scale and can be linked to multiple datasets through such mechanisms as the Australian Institute for Health and Welfare National Integrated Health Service Information Analysis Asset (NIHSI AA) and ABS Multi-Agency Data Integration Project (MADIP).

Primary Health Networks (PHNs) - Independent organisations, funded by the Commonwealth to coordinate primary health care in their region. PHNs assess the needs of their community and commission health services so that people in their region can get coordinated health care where and when they need it. They also support quality improvement in general practice.

About the Australian Cardiovascular Alliance (ACvA)

The ACvA is a not-for-profit, member-based organisation representing the interests of diverse members which spans individual researchers, research institutes, government agencies, peak bodies (advocacy groups/consumer groups), and industry members.

The vision of the ACvA is to deliver transformative change to cardiovascular research and health outcomes by building a thriving cardiovascular ecosystem serving health and the economy. This is done by bringing the cardiovascular research sector together to collaboratively develop solutions to the most pressing areas of need to make a measurable difference to cardiovascular health for communities.

The ACvA has devised seven strategic flagships that provide a platform of strengths in cardiovascular research and clinical care: 1) Implementation and Policy; 2) Clinical Trials; 3) Big Data; 4) Precision Medicine; 5) Drug Discovery; 6) Bioengineering and 7) Disease Mechanisms. These strengths are applied to the cross-cutting clinical themes of coronary artery disease, heart failure, stroke, arrythmias, hypertension, and to improving the health of Aboriginal and Torres Strait Islander Peoples. Importantly they are also applied to priorities identified by senior government officials (health), and data and clinical experts through biannual Cardiovascular Health Leadership Research Forums (CV HLRFs).

Introduction

The ACvA convened a workshop in Tasmania and brought together cardiovascular and stroke experts from the research and industry sectors and from State, Territory and the Federal governments across the country. This enabled a national discussion on what data is required for meaningful clinical quality indicators for cardiovascular disease and stroke, and how they can be used in near real time data dashboards to guide improvements in patient outcomes and identify investment needs.

This is important because the group of chronic diseases that includes CVD, stroke and renal disease remain the leading causes of death in Australia and globally. They are the largest burden of disease in terms of cost to the health care system and to our society through reduced life expectancy and quality of life. In fact, we face an increasing burden of chronic disease, but the current systems and use of health information are: i) not patient-centred, 2) not always aligned to health outcomes, 3) not directly connected to health systems and health practitioners 4) not available in timely fashion; and suboptimal in their ability to support quality improvements in health care and meaningfully guide research priorities.

Our solution is to support work that can achieve near real-time presentations of clinical quality indicators for cardiovascular disease and stroke. These indicators would be be used by health services, researchers and clinicians, including General Practitioners, health providers and patients. They would aid clinical decision making, identify gaps and inequities and guide research and implementation.

These data will provide critically important insights into the trends and impacts related to best-practice care (clinical quality indicators). They will also allow a granular understanding of the factors that underpin health inequities. The current data blackhole prevents population monitoring and evaluation of interventions being undertaken to improve outcomes for patients. It also severely limits the ability of health professionals to provide the best care for individual patients.

We believe that piloting work in a small island state will help develop learnings and support a nationally relevant system. Tasmania has a significant burden of disease from cardiovascular events and strokes. It is one of the nation's lowest socio-economic areas and has a high level of its population living in rural, regional and remote areas.

We recognise that the successful development and use of nationally harmonised clinical quality indicators will require governments, general practice, health services, clinicians, researchers and consumers to work together in a coordinated and collaborative fashion, with patient outcomes at the centre of all activity. There are currently many initiatives being undertaken across the country that aim to use data, including clinical quality indicators, to inform health policies, investment and improve patient outcomes. Few are near to real time. Moreover, projects have often focused on local areas and jurisdictions, and have limited scope for national expansion. This is because each project may: collect different data or indicators; use different definitions; not be deemed clinically useful; focus on procedures, rather than specific health outcomes; and use systems that do not 'talk' to one another.

Framework for the workshop

The workshop activity sits within the framework of the ACvA facilitated Cardiovascular Health Leadership Research Forum (CV HLRF). This model has been endorsed as important by health chief executives across the country (see Figure 1, below). The CV HLRF has achieved an unprecedented level of collaboration between State/Territory and Commonwealth health jurisdictions and clinical and research leaders. It is designed to provide a strategic forum for senior health and research leaders to use best available data to identify gaps and inequities in the delivery of health at state/territory and national levels. It helps prioritise those areas where research is central to providing solutions for cardiovascular disease and stroke.

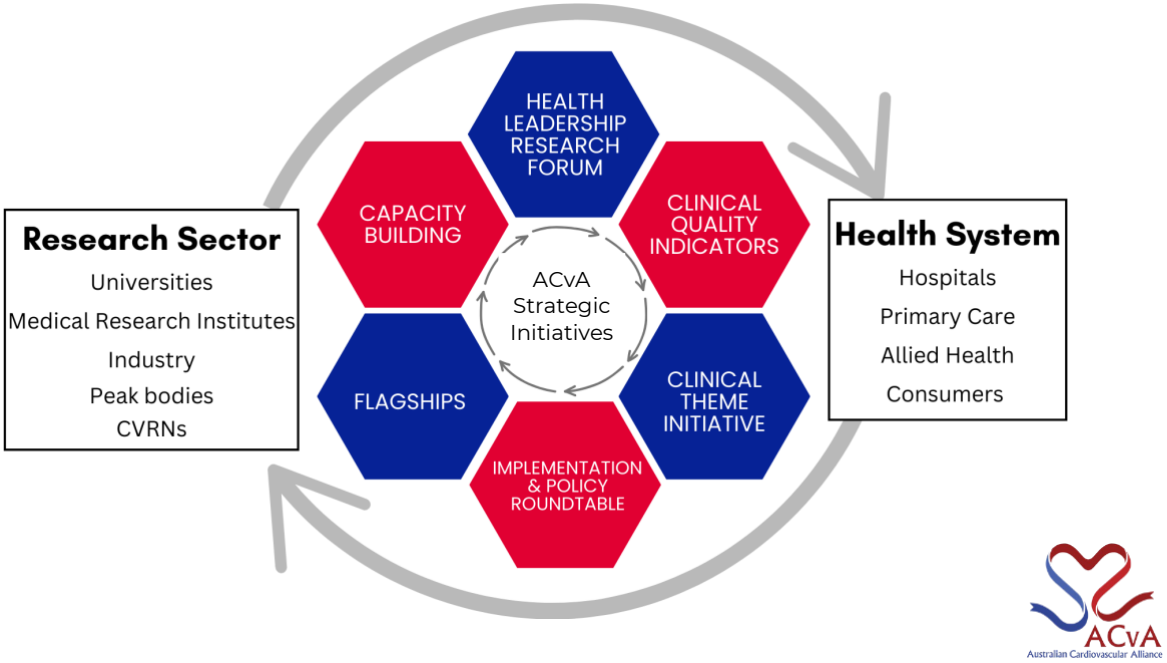


Figure 1. The Australian Cardiovascular Alliance model for connecting the research sector to the health system.

Tasmanian context

Tasmania has been identified as an ideal launch pad from which to initiate focussed work towards the development of a national roadmap for clinical quality indicators, available in near real time data dashboards. This will support continuous quality improvement in health care and the prioritisation of research activity to address gaps and inequities and recommend implementable solutions to the most pressing health care problems related to cardiovascular disease and stroke.

Tasmania was selected due to:

- Strong engagement between researchers, clinicians, consumers and the Tasmanian Department of Health and Menzies Institute for Medical Research leadership
- Research strengths and focus of the Menzies Institute for Medical Research
- Development of a state-wide, health system-wide, digitally enabled health system, through the imminent rollout of an eMR in Tasmania
- Launch of the State's Digital Health Transformation Strategy
- The relevance of the Tasmanian population to this activity.

Long term outcomes for Tasmania

Harmonised clinical quality indicators, presented in a near real time data dashboards should enable:

- increased implementation of guideline-based care by clinicians and health professionals
- improvements in care and patient outcomes to be measured, including the efficacy of guideline based care
- a locally relevant data platform, guiding efficient and effective research collaborations in priority areas
- increased ability to conduct pragmatic clinical trials
- strategic evidence-based investment in research priorities related to CV, stroke and renal diseases
- increased innovation, continuous quality improvement and evidence-informed policy decision-making.

The Workshop

Workshop aims

1. To commence work that will lead to the development of near real time data dashboards that are clinically relevant and drive prioritisation of collaborative research activities.
2. To develop a shared understanding of current and planned work associated with the collection and use of clinical quality indicators both locally and nationally.
3. To determine the steps necessary to develop a roadmap that will result in:
    - the collection of a minimum set of clinical quality indicators that is meaningful and relevant to clinicians, patients, health systems and governments
    - identification of infrastructure and infrastructure gaps related to indicator collection and presentation
    - identification and agreement on frameworks and governance arrangements for collection of clinical quality indicators
    - agreement on an initial clinical area to test the impact of clinical quality indicators on patient outcomes.
4. Facilitate greater alignment and reduce duplication of effort both locally and nationally

Workshop preparation

In preparation for the workshop, a preliminary survey was circulated to invitees, who were asked to provide information on:

- Key clinical quality indicators being collected for CVD and stroke.
- How these data are being collected.
- How these data are being used.
- Critical data gaps.

In summary, survey respondents indicated:

- Data is predominantly collected via Primary Health Networks (PHNs) and eMRs/ digitally scanned medical records.
- Strategies are being developed both locally and nationally to improve data accessibility.
- Further investment (incl. FTE) is required to review data and support quality improvements.
- Infrastructure and resources are required to link datasets and enable near real time presentation.
- Mechanisms are required that feed identified care/treatment gaps back to the clinics/practices and provide support to drive improvements in identified issues.

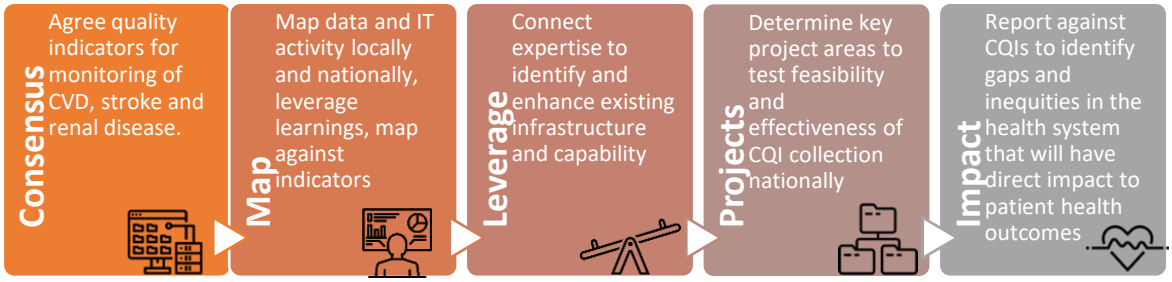
Workshop format

The workshop was a hybrid event. Participants were invited to attend in-person at the Menzies Institute for Medical Research in Hobart or virtually, with participants attending from across Australia. The workshop was facilitated by Associate Professor Seana Gall and Professor James Sharman. Further details and a full list of participating organisations and attendees can be found in Appendix 1.

Discussion traversed national and local activities related to the definition, collection and use of clinical quality indicators, currently available infrastructure and technologies in acute and primary care settings. Speakers presented key projects that could be leveraged and discussed the barriers and solutions to harmonising indicators and enabling their collection in near real-time to create the data dashboard(s).

Approach

1. **Consensus:** bring members of the local CVD, stroke and renal research ecosystem together in a structured workshop to test and agree on a roadmap to advance evidence-based care in Tasmania.
2. **Map:** establish a shared understanding of current and planned clinical quality indicator collection and use, gaps and barriers; enable a shared understanding of available infrastructure capable of monitoring, auditing and reporting on the delivery of evidence-based care in a clinically relevant manner.
3. **Leverage:** connect expertise that can help enhance existing infrastructure and capability that could support the goal of developing a near real-time data dashboard.
4. **Projects:** using identified locally relevant and nationally scalable priorities, agree on an initial project to facilitate clinical quality indicator collection and test the model.
5. **Impact:** work within the CV HLRF Framework to ensure that the data collected supports identification of and devlopment of solutions to health system priorities



Emerging themes from discussions (see Appendix 2 for additional information)

Value proposition

The value proposition associated with near real time reporting of high-quality, aligned datasets in a dashboard is significant, including:

- Improving individual patient outcomes.
- Reducing costs (including by helping define things NOT to be done, and high value care).
- Allocating resources and deploying infrastructure where it is most needed.
- Integrating primary and acute care data to lift performance in primary and secondary prevention.
- Tackling things that are important to consumers.

Data Capture and Accessibility

- There are significant national data assets already available and an urgent need to increase accessibility for research purposes to ensure research investment and effort is enabled to provide relevant solutions.
- Private hospital data is generally not available; however, it is held by the Commonwealth Government. Access to this data is important because a large percentage of elective treatments occur in private hospital settings. Accessibility needs to be prioritised.
- There is a strong appetite from governments to develop and make available the data assets that can help the research sector and partners delve into the critical questions and inform policy and practice. For example, does guideline-based care make a difference and how does it impact individual patients?
- The current digital transformation of the Tasmanian Health Service is a prime opportunity to embed clinical quality indicators across CVD and stroke into eMR to facilitate the near real time data dashboard in the coming years.

Clinical quality indicators need to support the patient journey (primary care, acute care, secondary prevention and rehabilitation)

- Current registries predominantly hold procedural data not clinical quality indicator data. We need to expand the data elements that are currently being collected.
- Map current standards and indicators and test and report their utility in driving improvements.
- The clinical quality indicators need to cover acute care, as well as primary/community care and help bridge the current disconnect between these sectors.
- General Practice must be involved in co-design (indicator selection, systems, feedback mechanisms – needs to work with not against the current GP business model).
- Patient Reported Outcome Measures and Patient Reported Experience Measures must be part of/inform indicator choices.

Resources and Education

- There are significant issues with the resourcing (time, money and expertise) associated with maintaining registries and quality. Automation of data collection and reporting will help overcome many of the issues and must be a top priority for expenditure. The concept of 'collect once, use many times' needs to be central to work going forward.
- Education, awareness and support for General Practice is critical to ensure they are able to fully participate in and contribute to data collection, reporting and interpretation in the dashboards.
- There is a desire to have a continuously learning health system encompassing acute and primary care with the data dashboard for CVD and stroke to underpin quality improvement activities across sectors

Flagship project

An exemplar flagship project needs to be identified to ensure indicators are meaningful and usable. Tasmania has nominated to be a test bed for a project in an agreed clinical area.

Roadmap and flagship project in Tasmania: Next steps

Based on breakout sessions and post workshop analysis, the following steps are proposed.

1. Establish a steering group to:
    - Clearly articulate the value proposition for the development of the clinical quality indicators and near real time data dashboard presentation, and the principles that will guide the work.
    - Formalise the governance structure for the proposed work.
    - Identify and agree on a clinical area/issue.
    - Agree on a flagship project and governance to provide a test case for clinical quality indicators and near real time presentation, identify gaps, and issues arising and embed economic evaluation in the process.
    - Ensure inclusion of an appropriate implementation plan for the agreed flagship project, including expertise and skills sets required.
    - Support and help steer project and working group activities.
    - In the Tasmanian context, advise on commissioning a separate body of work on improving clinical documentation/clinical coding for CVD across acute and primary care/ensure it is a part of the digital health strategy but CVD specific training will be required.
    - Engage with the CV HLRF to continue the national discussion on existing clinical standards and clinical quality indicators and assess feasibility and align for national collection.

2. Establish working groups to:
    - map the current state of play in the collection, use and presentation of clinical quality indicators
    - map the patient journey and put forward measures (determine how the patient journey can be disaggregated, e.g., by sex, cultural background, rural and regional status) and advise on specific indicators that have patient and practitioner support
    - map projects and technologies being advanced to collect indicators, and share learnings and report on opportunities for alignment
    - identify existing governance arrangements and gaps.

Appendix 1

Name	Organisation
Adina Hamilton	Safer care Victoria
Allyson Essex	Commonwealth Department of Health and Aged Care
Andrew Black	Tasmanian Department of Health
Angela Brennan	Monash University
Bianca Heron	NT Health
Catherine Francis	NSW Health
Catherine Shang	Australian Cardiovascular Alliance
Charmaine Tam	Telstra Health
Christian Verdicchio	Heart Support Australia
Daniela Vanvuuren	Novartis
David Thomson	Amgen
Dean Picone	University of Tasmania
Debbie Schofield-Gavin	University of Tasmania
Ella Van Tienen	Pharmaceutical Society of Australia
Ellie Paige	Australian National University
Faline Howes	Tasmanian Department of Health
Frederick Carl Couldwell	Northern Territory Government
Gemma Figtree	University of Sydney
Geoff Strange	National ECHO Database of Australia
Glen Wiesner	National Heart Foundation of Australia
Helen Castley	Tasmanian Department of Health
Jan Radford	University of Tasmania
Jim Sharman	University of Tasmania
Jo-Anne Manski-Nankervis	University of Melbourne
Jodi Glading	Tasmanian Department Health
John Elkerton	Snug Health
Julian Ellis	Victorian Agency for Health Information
Kate White	National Heart Foundation of Australia
Keith McNeil	Queensland Health
Kerry Doyle	Australian Cardiovascular Alliance
Kim Greaves	Queensland Health
Lee Nedkoff	University of Western Australia
Louisa Jorm	University of New South Wales
Louise Gates	NSW Health
Marie Hartley	Amgen
Mark Nelson	University of Tasmania
Mark Upton	Tasmanian Department of Health
Matthew Gorringe	Sax Institute
Matthew Jose	University of Tasmania
Melita Stirling	Stroke Foundation
Meng Hsu	Australian Cardiovascular Alliance
Michelle Cretikos	NSW Health

Mike Whittle	Consumer advisor
Miriam Lum On	Australian Institute for Health and Welfare
Monica Trujillo	Telstra Health
Monique Mackrill	Pharmacy Guild of Australia
Naomi Mermod	Global Alliance for Patient Access
Natalie Raffoul	National Heart Foundation of Australia
Niamh Chapman	University of Tasmania
Olivia Pantelidis	VIC Health
Olivia Toune	NT Health
Paul Davis	Abbott
Peter Maree	Tasmania Health
Peter Thomas	National Heart Foundation of Australia
Rachel Climie	University of Tasmania
Sam Brodribb	Tasmanian Department of Health
Saman Farahangiz	Primary Health Tasmania
Sanjeev Patel	Northern Territory Government
Seana Gall	University of Tasmania
Suchit Handa	Safety and Quality Commission
Sze Yuan Ooi	University of New South Wales
Tanya Hall	Hearts4heart
Tracey Dickson	University of Tasmania

Appendix 2

The workshop sought to engender discussion that would be both local and national in scope, with the goal to develop a shared understanding that leads to aligning activities. With this in mind, the workshop sessions covered:

The patient perspective

- The importance of patient participation and co-design in research studies to ensure relevance to the end-user.
- The need to ensure that patient-reported measures are collected and drive improvements in the quality of care.

National policy context and current initiatives

- The availability of major data assets such as Multi-Agency Data Integration Project (MADIP) and National Integrated Health Service Information Analysis Asset (NHISI AA), noting the NHISI will be open to researchers in 2023 (will need local ethics and will have cost recovery elements)
- The AIHW is using case studies to test the way data can be used and what the gaps and barriers are, for example coronary artery disease and adherence to medication
- The National quality standards for registries
- An outline of existing clinical care standards and indicators, for stroke, ACS and Heart Failure
- Work and opportunities for integrating Patient Reported Outcome Measures (PROMS) and Patient Reported Experience Measures (PREMS).
- The significant need to reframe the 'why' of data collection/registries to the original vision as change agents.
- Planning how to embed PHDs and postdocs in Commonwealth Health.
- Enabling a comprehensive understanding of the types of data currently used to inform the health spend

The local Tasmanian policy context and current initiatives

- The Health Department has brought research, safety and quality together in its current structure, to allow the research sector to collaborate with the health department on the problems that matter. Substantial governance work undertaken helps to support this coming together in an appropriate fashion.
- Work is being undertaken to embed PROMS and PREMS in local registries/data collection activities.
- The Tasmanian Research Strategy was released in 2022.
- Tasmania's data strategy development has been commissioned.
- The Australian Stroke Clinical Registry (AUSCR) is a successful Australian example of a clinical quality registry being used for research and quality improvement activities. Tasmania has contributed data for many years with all public hospitals now contributing data. AUSCR provides an exemplar and a potential roadmap to drive near-real time data to permit contemporary quality of care insights for clinicians.
- The current data dashboard approach in Tasmanian is not near real time but nevertheless holds important information and can not only support the system but also patient choices in relation to care.
- There is a need and an opportunity with the commissioning of an eMR and the implementation of the digital strategy to move to more automated and integrated approaches.
- Data availability needs to catch up with local clinician need.

The current data environment – from data to decisions

- The core goal of all this work must be to improve patient outcomes (from descriptive to prescriptive)
- The development and reporting on data must be seen as a positive tool by all stakeholders. We need to create incentives that will drive consistent, high quality patient outcomes.
- Around 10% of all clinical interventions actually cause harm (administering penicillin to someone with allergy as a clear example). This occurs predominantly because there is a lack of quality, contemporary information available to the clinician at the point of care/clinical decision-making. There is an urgent imperative to change this.
    - Getting to near real time data reporting can be done, using cloud based technologies.

    - Precision medicine approaches are driven by data.
- QLD provides an exemplar in terms of what can be done using a single eMR.
- We need to prioritise the development of agreed clinical standards and indicators, which will help define what data is needed and allow measurement, benchmarking and improvement.

National approaches (Projects being undertaken across the country), including:

- National Echo Database Australia (NEDA)
- Next generation approaches (AI, Cloud computing)
- Linked Data Asset for Australian Health Research (LINDAHR)
- The Sax Institute's Secure Unified Research Environment (SURE) platform and SURE sandbox
- The Cardiac AI Project
- Australian Stroke Clinical Registry (AUSCR)
- Preventing Heart Attack and Stroke through Electronic Surveillance (PHASES)

Opportunities, barriers and challenges, impacting on data dashboard development and data quality and consistency, in both primary and acute care settings, including:

- Jurisdictional boundaries and internal complexities.
- Data quality (including definitional issues)
- Resourcing demands/constraints
- Skills and Experience gaps
- Impost on those collecting/inputting, reporting and using the data
- The gap between acute and primary care
- The divide between primary and secondary prevention
- Risk aversion/privacy concerns.
- Governance, including ensuring the Five Safes Framework is used.

Breakout sessions that focussed on solutions and a high level road map to accelerate dashboard development, key points include the need to:

- produce a comprehensive map of current data being collected, collection mechanisms and infrastructure and identify key points of intersection with the health system
- define one clinical area to commence work
- define end users
- clearly define the value proposition (frame as a safety and quality issue, articulate efficiencies to the system, private sector benefits, agreed measures of success)
- develop the patient journey (starting with prevention) and use to identify key data points and gaps
- engage consumers throughout the process
- ensure broad stakeholder engagement (priority populations)
- develop co-design framework/principles
- set parameters for risk appetite
- define parameters for research accessibility (ideally generalisable)
- ensure linkage to and alignment with guidelines (which should have a regular update cycle and include KPIs)
- ensure that approaches recognise that the e-MR is central to success, noting that Tasmania is commissioning an eMR, will benefit from the experience of other jurisdictions, and can potentially build a new model for consideration at the interjurisdictional forums (including the CV HLRFs)
- urgently move towards automation of data collection
- pilot inclusion of patient-generated data (eg wearables).