

Learning Health System

# Learning together for better health,

Our Partners





















Our Associate Partners







## **Executive summary**

This summary is for partners, researchers, clinicians, managers and the community across Monash Partners Academic Health Science Centre (Monash Partners) as well as for other stakeholders. It outlines an important framework for evolving our health centres into a Learning Health System to capture, identify and address health service and community priorities and emergent challenges. The vision is 'Learning together for better health'. In 2019 we used a multi-step co-design process to synthesize the available evidence including a National Advisory Committee, Monash Partners Steering Committee, extensive consultations, a systematic review, qualitative research project, and stakeholder consultation workshop to build the Monash Partners Learning Health System Framework. The framework contains the key elements for healthcare performance to data, data analysis to knowledge, and knowledge implementation to healthcare. It takes routine healthcare data, into iterative cycles of knowledge generation and improvement in healthcare, with the Learning Health System enabled by partnerships across multidisciplinary stakeholders (academic, clinician, community and industry stakeholders).

#### **About Monash Partners**

Established in 2011, Monash Partners is a partnership between leading health service, teaching and research organisations focused on innovating for better health (monashpartners.org.au). Our partners include: Alfred Health, Monash Health, Monash University, Peninsula Health, Eastern Health, Cabrini Health, Epworth HealthCare, Burnet Institute, Hudson Institute and Baker Heart and Diabetes Institute. Our associate partners are La Trobe University and Latrobe Regional Hospital.

The purpose of Monash Partners is to connect researchers, clinicians and the community to innovate for better health for around three million Australians, and beyond.

Monash Partners is one of seven National Health and Medical Research Council (NHMRC) accredited Advanced Health Research Translation Centres (AHRTCs) whose aim it is to enable and support the translation of research and innovation into better health outcomes for the Australian community.

Monash Partners Clinical Themes and Enabling Platforms connect researchers, clinicians and the community across our Partners and stakeholders. Our Enabling Platforms support research, translation and evidence-based healthcare improvement, strengthen consumer and community involvement, build capacity and capability, drive clinical innovation and enhance integration across the translational research continuum and health care continuum including into primary care.

Monash Partners has prioritised Data-Driven Healthcare Improvement and created a Data Platform, leveraging the engagement of our health services and the strength in clinical registries across our network and in Monash University's Health Data Platform. The purpose of our Data Platform is to 'improve health outcomes across our community, through data-driven innovation and care'.

## Monash Partners Data-driven Healthcare Improvement Platform

The past decade has seen enormous advances in the amount of data routinely generated and collected as well as in our ability to harness technology to analyse and understand this data to improve the quality and efficiency of health care. Healthcare data enables clinicians, researchers, policy makers and the community to make informed decisions that improve healthcare and outcomes at the individual, organisation and population level. Current barriers to health data use include limited data literacy by health professionals; ad hoc data capture; poor data quality, and limited integration and linkage, with clinicians unable to use routine health data to improve care.

Our Data Platform aims to create a system to improve the use of data, taking practice to data, data to knowledge and knowledge to practice, to drive better health outcomes. The Platform steering committee comprising researchers, data specialists, clinicians and consumers is supported by a project manager, includes data fellows and PhD students and is funded by our partners and the Medical Research Future Fund. A key focus is development and implementation of the Learning Health System including exemplar projects across healthcare.



#### Collaborating nationally for impact: The Australian Health Research Alliance

Monash Partners is a member of the Australian Health Research Alliance (AHRA), comprising all ten NHMRC-accredited Research Translation Centres, with national reach and engagement across 95% of Australia's academic and research teams and 80% of its acute health services (ahra.org.au). AHRA facilitates the integration of healthcare, health and medical research, and health professional education to deliver better health outcomes for all Australians. AHRA Centres are working on wide ranging projects locally and are working together on key national system level initiatives and networks, funded by the Medical Research Future Fund (MRFF), aligned with national and government priorities.

Through AHRA, Monash Partners is co-leading a collaborative national system-level initiative to identify and address agreed priorities in data-driven healthcare improvement and progress previously intractable problems though large-scale collaboration, transcending silos and barriers to make tangible impact on health outcomes.

#### Establishing national data priorities

Monash Partners led a process across AHRA, to establish joint priorities using a modified Delphi process and nominal group technique. Stakeholders involved in the priority setting process included representatives from national health data organisations, government agencies, consumers and all AHRA centres (Teede et al. 2019).

Previous and current work in this field was captured through stakeholder input and an evidence-based literature review. Government priorities were captured along with other national bodies, to avoid duplication and optimise collaboration. The relevance of the priorities to AHRA objectives was also considered, including the potential for greatest measurable impact over time. This resulted in three agreed prioritised areas of focus:

- Creation of virtual or actual Learning Health System data hubs to stimulate partnerships across academic, clinician and industry stakeholders
- $\boldsymbol{\cdot}$  Building workforce capacity in data use for healthcare improvement through training
- · To integrate large-scale data sets to undertake research and quality improvement across the primary care, acute and sub-acute continuum.

The National priorities were ratified by the Monash Partners Data Committee, with the addition of:

- $\cdot$  Enhancing access to and presentation of registry data, and facilitating integration and linkage between other data sources and registry data
- $\cdot \ \, \text{Integrating the Monash University data platform-Helix, through strengthening and building of data infrastructure and systems.}$

"Monash Partners is co-leading a collaborative national system-level initiative to identify and address agreed priorities"

1. The AHRA Centres are: Melbourne Academic Centre for Health, Monash Partners Academic Health Science Centre, Health Translation SA, Sydney Health Partners, Brisbane Diamantina Health Partners, SPHERE Maridulu Budyari Gumal, Western Australian Health Translation Network, Central Australian Academic Health Science Network, NSW Regional Health Partners, Tropical Australian Academic Health Centre.



Across AHRA, Monash Partners has led the initiative on the Learning Health System with strong engagement from other Centres including Health Translation SA, Sydney Health Partners and more recently other centres. Monash Partners has dedicated internal and MRFF funding to developing an evidence-based framework for a Learning Health System. This approach aligns with the Australian Medical Research and Innovation Priorities and can inform the establishment of hubs across the Translation Centres nationally. This report summarises development of the Learning Health System to date.

#### Learning Health System data hubs

Data hubs commonly function as systems and structures that improve access to, and increase the use of data. They also provide analysis expertise so the data can inform decision making in the clinical setting (Teede et al. 2019). An initial systematic review of the academic and grey literature explored the evidence for different models

and systems that would enable better use of data in the healthcare setting. Publications targeted were those with clear evidence of impact of data on clinical decision-making and healthcare improvement.

The Learning Health System emerged from this work, providing an innovative systems level approach which aims to embed data-driven research within healthcare and community, and link the needed infrastructure and multidisciplinary expertise to focus on enhancing health impact (Budrionis and Bellika 2016; Institute of Medicine 2011; McLachlan et al. 2018; Menear et al. 2019).

Learning Health Systems use health-related data, analyse it to generate new knowledge, and provide this knowledge in an ongoing and timely manner to support near-time health care delivery and outcomes. Typically, a Learning Health System sits within an organisational partnership and comprises an integrated team of frontline clinicians, researchers, informaticians and community members, embedded in healthcare.

We define a Learning Health System as a system in which routine health practice data, from service delivery and patient care, can lead to iterative cycles of knowledge generation and improvement in healthcare,

and industry stakeholders.

whereby the whole Learning Health System is enabled by partnership across academic, clinician, community

However, little is known about how to create effective, sustainable and service-led Learning Health System environments that stimulate partnerships across academic, clinician, community, primary care and industry stakeholders to utilise data to iteratively achieve better health outcomes and service improvements. This report presents an evidence-based framework to support a sustainable Learning Health System in the Translation Centre context and to encourage a network of Learning Health Systems in Australia.



"It's a system where routine health practice data can lead to iterative cycles of knowledge generation and improvement"



## **Methods**

We adopted a multi-step co-design process in the development of the Learning Health System data hubs framework, which valued knowledge co-production through genuine engagement with key stakeholders. Co-design is a process that values the skills and experience of all stakeholders or end users and is important in the development of complex systems and services.

The steps have included:

- · Stakeholder input, including expert opinion
- · Systematic review
- · Qualitative research including national and international research and partnership scoping
- · Stakeholder consultation workshop.

#### Stakeholder input, expert opinion

Stakeholders consulted during development of the framework include:

- · Monash Partners and Data Committee
- · Monash Partners Executive comprising leading clinical academics
- · Monash Partners Council comprising senior leaders of Monash Partners partner organisations
- · Monash University Helix and data platform experts
- · AHRA centres and AHRA National Data Committee
- · Consumers
- · Digital Health Collaborative Research Centre
- · State Government of Victoria
- · Australian Digital Health Agency
- · Public Health Research Network
- $\boldsymbol{\cdot}$  International experts from both the UK and Canada.





#### Systematic review

A systematic academic and grey literature review aimed to gather evidence on effective Learning Health Systems (or similar entities with alternative names) that stimulated partnerships across multiple stakeholders and increased the translation of data and research in healthcare provision with explicit evidence of health impact. Best practice systematic review methods were followed (see Appendix one).

Forty-three articles were identified, which described research translation leading to impact in twenty-three Learning Health System environments. Learning Health System environments included were: United States (n=18), Canada (n=2), and one each in the UK, Sweden and Australia/New Zealand. Five (21.7%) of the Learning Health System environments produced medium-high level evidence. The key themes are captured in Figure 1.

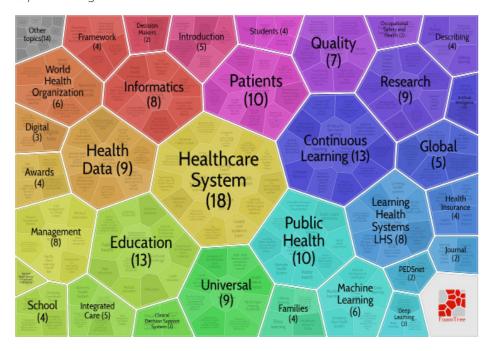


Figure 1; A pictorial representation of key themes from literature on Learning Health System data hubs.

Key findings included:

- · Learning Health System environments are system level initiatives with effective examples demonstrating translation from practice data to data analysis and new knowledge back to clinical practice
- · An integrated multidisciplinary team of frontline clinicians, researchers and community members, embedded in healthcare settings, is key to success
- $\cdot$  To have direct health impact, a Learning Health System must provide timely access to data, as well as analysis of that data with feedback
- Effective Learning Health Systems require people with a broad range of workforce capabilities to make sense of the data arising from complex healthcare environments.



# Qualitative research including national and international research and partnership scoping

We purposively identified and conducted semi-structured qualitative interviews with national and international leaders, experienced in supporting or developing data-driven innovations in healthcare. Representatives from all AHRA centres, Monash Partners member organisations, the Digital Health Collaborative Research Centre, State Government, Australian Digital Health Agency, Public Health Research Network, consumers and international experts from both the UK and Canada, were included.

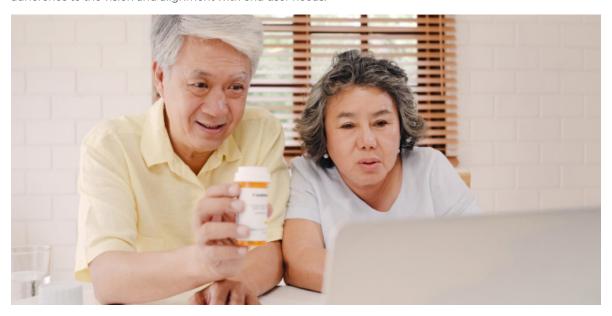
Analysis of twenty-six interviews revealed five themes, integral to an effective, sustainable Learning Health System:

- Broad stakeholder, clinician and academic engagement, with collective vision, leadership, governance and a culture of trust, transparency and co-design
- · Resourcing with sustained investment over time
- $\cdot$  Skilled workforce, capability and capacity building
- · Data access, systems and processes
- Systematic approaches and iterative, continuous learning with implementation into healthcare contributing to new best-practice care.

Fundamentally, a Learning Health System requires continuous learning with implementation of new evidence back into frontline care to improve outcomes. Structure, governance, trust, culture, vision and leadership were all seen as important along with a skilled workforce and sustained investment. Processes and systems to optimise access to quality data were also seen as vital in an effective, sustainable Learning Health System.

## Stakeholder consultation workshop

Stakeholder input, a systematic review and qualitative research informed the development of a preliminary Learning Health System framework. A stakeholder consultation workshop was then held with 60 representatives from Monash Partners organisations, government, national data agencies, AHRA centres and consumers. The purpose of the workshop was to seek input from stakeholders and refine the proposed model, ensuring adherence to the vision and alignment with end user needs.





## Monash Partners Learning Health System Framework

The vision of the Monash Partners Learning Health System is 'learning together for better health'. In line with the findings of our systematic review and qualitative research, and co-design processes, four principles underpin all aspects of the Learning Health System: People, Culture, Standards, and Resources/Infrastructure.

#### **Principles**

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PEOPLE
All those who contribute to a healthy LHS

CULTURE
Trust, transparency,
partnership and
co-design

STANDARDS
Guides to
processes and
governance
frameworks

RESOURCES / INFRASTRUCTURE Access, linkage, storage, analysis and application

People: a healthy Learning Health System requires people with a broad range of capabilities including:

- · Frontline clinical and non-clinical staff
- · Patients, consumers and carers
- · Health information experts
- · Technologists
- · Researchers
- · Health service leaders and executives.

Culture: a culture of trust, transparency, partnership and co-design, underpin the Learning Health System with:

- · The commitment, or buy in, of clinicians and senior management
- Senior management support to integrate new approaches into standard care processes, and achieve sustainable, scalable change.

Standards: transparent and agreed processes and governance, including:

- $\cdot \ \mathsf{Compliance} \ \mathsf{with} \ \mathsf{legal} \ \mathsf{and} \ \mathsf{legislative} \ \mathsf{requirements} \ \mathsf{for} \ \mathsf{sharing} \ \mathsf{and} \ \mathsf{linkage} \ \mathsf{of} \ \mathsf{data}$
- $\cdot$  Transparent processes for consent to use healthcare data
- · Robust data governance systems and processes.

## Resources and infrastructure: including:

- · Systems and processes to enable timely access, linkage and analysis of data
- · Agreed terminology/algorithms to link data terms
- · Information technology infrastructure and support
- · Single entry data systems wherever possible
- · Linkage of differing software programs with the electronic medical record
- · Meaningful interpretations and visualisations readily available at point of care
- $\boldsymbol{\cdot}$  Access to data that is as close to live as is accurately and logistically possible
- · Provision of meaningful end-user targeted reports (routine, scheduled, or ad hoc).

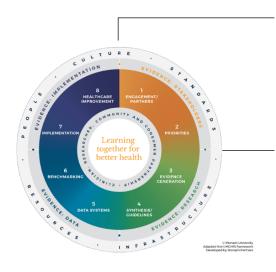


## The evidence quadrants

The Monash Partners Learning Health System encompasses four different sources of evidence, with each represented diagrammatically in a quadrant of the wheel (see below):

- · Stakeholder's evidence
- · Research evidence
- · Data evidence
- · Implementation evidence

Each is essential to capture, identify and address health service and community priorities and emergent challenges and need to be integrated to create the systems level intervention needed for a Learning Health System to deliver health impact.



#### Stakeholder's evidence

Stakeholder's evidence in the Learning Health System is generated through engagement with end users, understanding of front-line health problems and identification of priorities. To achieve this the following is required:

- End-user engagement, partnership and transparent governance
- · Genuine and ongoing engagement of all stakeholders at all stages
- Stakeholder engagement from the very beginning to understand the problem/issue from all perspectives; including front-line clinicians, patients and consumers with lived experience of the health condition and system
- Robust priority setting in partnership with all stakeholders including policy makers so that research and healthcare improvement efforts address what is most important.



#### Research evidence

In the Learning Health System, research evidence includes:

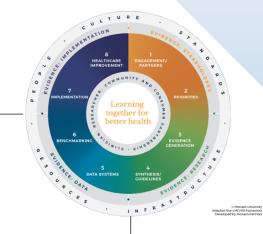
- · Randomised clinical trials, systematic reviews and meta analyses
- $\cdot$  Evidence based guidelines
- Data and relevant information from research/ academic sources, reports and grey literature
- · Economic and policy data
- · Standards and policies as sources of best practice.



### Data evidence

Data evidence is generated from real time health data and benchmarking, aspiring to the following:

- · Identifying existing data relevant to the problem/issue
- · Identifying what, if any, additional data is needed
- · Accessing quality, timely, meaningful and actionable data
- Compliance with FAIR data principles: Findable, Accessible, Interoperable and Reusable\*
- Governance data sharing systems to support appropriate management and sharing of data
- · Support for data linkage, data interpretation and data analysis
- · Application of big data analytics, Natural Language processing and artificial intelligence
- $\cdot$  Real time visual representation of data at individual, service and organisational levels
- · Mechanisms for ongoing audit and feedback
- Benchmarking of data to evaluate the quality of data, health care provision and health outcomes.
- \* (See Australian Research Data Commons website: https://ardc.edu.au/resources/working-with-data/fair-data/).



## Implementation evidence

In a Learning Health System, data generated knowledge must then be translated into clinical practice and healthcare improvement to improve patient outcomes. Implementation evidence around how to create change, is generated through implementation research and sustainable change through health care improvement. Key considerations include:

- $\boldsymbol{\cdot}$  Effective leadership to support and drive implementation
- Building rigour and capacity for improvement programs through theory driven, methodological, rigorous and economically sound approaches
- $\cdot$  Taking into account system level (external) and organisational (internal) perspectives
- · Identifying and addressing barriers and enablers to implementation
- Ensuring the change is relevant across stakeholders and settings
- $\cdot$  Capturing learnings on effective implementation and improvement practices
- $\cdot$  Monitoring, audit and feedback, assessment of impact, and refinement.





## Components

#### 1 ENGAGEMENT OF PEOPLE

- Consult
- Engage
- Involve
- Collaborate
- Empower
- Inform

## 2 IDENTIFYING PRIORITIES

- · Formal engagement
- Agreed priorities
- Ranked priorities
- Prioritised outcome measures

## 3 EVIDENCE BASED INFORMATION

- · Cohort trials
- Randomised and pragmatic clinical trials
- · Epidemiology based research
- · Economic analysis
- Qualitative and Quantitative research

## 4 EVIDENCE SYNTHESIS AND GUIDELINES

- · Systematic reviews
- Meta- analysis: aggregate and individual data
- Secondary research
- Consideration of stakeholder and evidence based priorities
- Guidelines, standards and policies

## 5 DATA AND INFORMATION SYSTEMS

- Quality, timely, harmonised, meaningful and actionable data
- Data from health care and other sources
- Patient reported experience and outcome measures
- Compliance with 5 safes\*, FAIR data principles\*\* and legislative and privacy requirements
- Governance, data sharing, linkage, analysis and interpretation
- Big data analytics, machine learning
- Technology and infrastructure

## 6 BENCHMARKING

- Transparency and equity
- Adjustments for service variation
- Real time visual representation at individual, service and organisational levels
- Measurement to iteratively and continuously drive improvement
- Evaluation
- Learning feedback

## 7 IMPLEMENTATION

- Leadership
- · Theory driven
- · Economically sound
- Methodologically rigorous
- Addressing barriers and enablers
- Capability in change management
- Consideration of the Burden of data collection
- Sustainable and scalable
- Demonstrating healthcare improvement

## 8 HEALTHCARE IMPROVEMENT

- Leadership
- Pragmatism
- Contextual/ local
- Outcome improvement
- Quality improvement
- Change management
- Evaluation

<sup>\*</sup>Five Safes: Safe Projects, People, Settings, Data and Outputs

<sup>\*\*</sup> FAIR data principles: Findable, Accessible, Interoperable and Reusable



## Stroke: A Learning Health System exemplar

The Australian Stroke Coalition (ASC) brings together clinical networks and professional associations/colleges in the stroke field to progress agreed priorities to improve stroke care, reduce duplication amongst groups and strengthen the voice for stroke care at a national and state level (www.australianstrokecoalition.com.au).

The activities of the Coalition align with the four types of evidence encompassed in the Monash Partners Learning Health System Framework:

**Stakeholder's evidence:** the Monash University Stroke and Ageing Research Group (STAR) engages all relevant partners with agreed priorities formed for data collection, analysis, and reporting.

**Research evidence:** STAR generates evidence-based guidelines, co-developed with stakeholders, that are evolving into living guidelines (https://informme.org.au/en/Guidelines/Clinical-Guidelines-for-Stroke-Management).

**Data evidence:** A stroke registry provides data evidence. Systems ensure the data is accurate, timely, consented and provided in a manner that is compliant with privacy requirements. These systems also provide for consistent and safe data collection, storage and analysis.

Benchmarking activities are guided by pre-agreed priorities and processes. These Australia-wide approaches to quality improvement include:

- · A national audit (every two years)
- $\cdot$  A national registry (ongoing) Australian Stroke Clinical Registry (AuSCR)
- · National Stroke Data Linkage Program
- $\cdot$  Australian Stroke Clinical Registry, established in 2009 for patients admitted with a diagnosis of acute stroke or transient ischaemic attack (TIA).

"The activities of the Australian Stroke Coalition align with the Monash Partners Learning Health System framework"

**Implementation evidence:** Implementation has achieved changes in practice that have resulted in measurable improvement in health outcomes, for example, a 70% reduction in hazard of death within 180 days of stroke (Cadilhac et al. 2017). The application of the Stroke exemplar can be found in Appendix two.





## Conclusion

As leading centres for collaboration, the NHMRC-accredited Translation Centres bring acute health services, primary care, universities, research institutes and government together to translate research into best practice to improve patient care and health outcomes. There is a commitment, and requirement, to transcend traditional silos across individual research, education and healthcare organisations and sectors and create a systems approach for effective healthcare improvement.

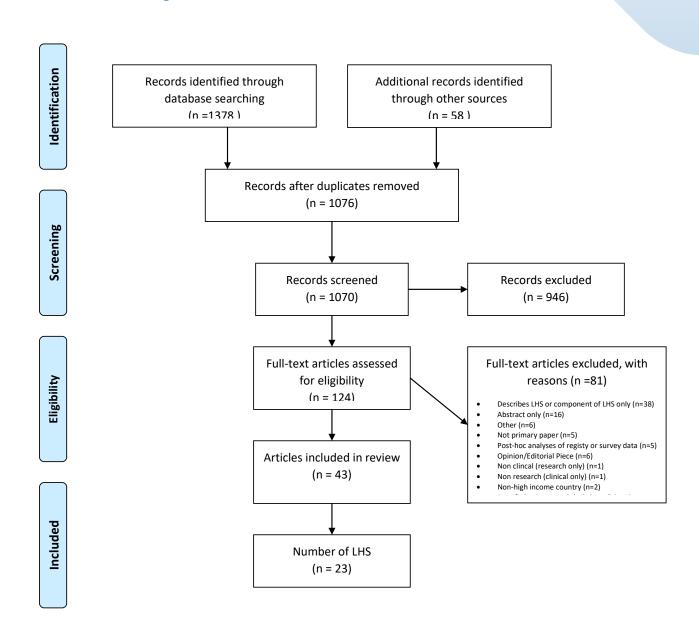
The Australian Health Research Alliance has prioritised the creation of virtual or actual Learning Health System data hubs to stimulate partnerships across academic, clinician and industry stakeholders. Monash Partners has led this work, engaging with other centres and applying robust methods across systematic literature review, qualitative research and stakeholder consultation workshops. The resultant Learning Health System aims to integrate stakeholder priorities, research and best practice evidence, data analysis and benchmarking, and implementation and improvement. The aim is to take a system level approach to take practice to data, data to new knowledge and knowledge to practice, embedded within healthcare, linked to needed infrastructure and multidisciplinary expertise with effective streamlined systems and processes.

Data alone does not result in change. An integrated approach is vital to enable use of data to improve healthcare delivery. The Learning Health System provides a system to continuously learn from successes and failures in innovation and accelerate the use of health data to iteratively produce new knowledge to improve clinical care and health outcomes. Monash Partners is now working across our partners and with the Victorian Government and other centres to pilot and iteratively learn together for better health.



## Appendix one

## **PRISMA Flow Diagram**



A systematic review in 2016 (Budrionis and Bellika 2016) identified only five papers where evidence that Learning Health System environments produced an impact was reported. The Monash Partners review found a further 23 papers, published since 2016, that provided evidence that Learning Health Systems improve health outcomes.



## Appendix two

## Stroke: A Learning Health System exemplar

With thanks to Associate Professor Dominique Cadilhac and Dr Monique Kilkenny for agreeing to share their Intellectual Property.

## 1 ENGAGEMENT OF PEOPLE

#### Stakeholders include:

- · Representatives from groups and organisations working in the stroke field
  - Clinical networks and professional associations/colleges
  - Stroke Foundation, Stroke Society of Australasia and the Australian Stroke

#### 2 IDENTIFYING

Methods for identifying priorities included:

- Survey
- Focus group
- Workshops

#### Agreed Priorities

- improve stroke care
- reduce duplication amongst groups
- strengthen the voice for stroke care at a national and state level





#### EVIDENCE BASED

 AuSDaT (Australian Stroke Data Tool) built to offer hospital clinicians in acute and rehab settings a single data collection tool for clinical monitoring in stroke care



## 4 EVIDENCE SYNTHESIS AND GUIDELINES

 Clinical guidelines for Stroke Management 2017 were developed (First-ever living guidelines being trialed in Australia for stroke, updated as new evidence emerges)



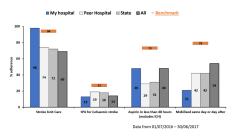
## Appendix two continued

#### DATA DERIVED EVIDENCE

## 5 DATA AND INFORMATION SYSTEMS

- National Audit and Registry developed
- Australia-wide, approaches to quality improvement
  - National Audit (every 2 years)
  - National Registry (ongoing) AuSCR
  - National Stroke Data Linkage Program







#### IMPLEMENTATION EVIDENCE

#### 7 IMPLEMENTATION

- Financial incentive for access to stroke units
- StrokeLink workshops
- National Stroke Data and Quality Improvement Workshop

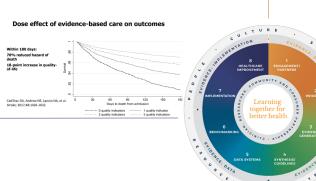
## 8 HEALTHCARE IMPROVEMENT



#### Multicenter, Prospective, Controlled, Before-and-After, Quality Improvement Study (Stroke123) of Acute Stroke Care

Dominique, A. Cadilhac, PhD\*; Rohan Grimley, MBBS\*; Monique; F. Kilkemy, PhD; Nadine E. Andrew, PhD; Nataba, A. Lamin, PhD; Keivin Hill, BApochès Brenda Grabsch, BSW; Christopher R. Levi, MBBS; Amanda G. Thrift, PhD; Steven G. Faux, MBBS; John Wakelridd, MPH; Ging Cadigan, BN; Geoffrey A. Doman, MD; Sandy Middleton, PhD; Craig S. Anderson, PhD; on behalf of the Stroke 123 Investigators and AuSCR Consortium

(Stroke, 2019;50:1525-1530. DOI: 10.1161/STROKEAHA.118.023075.



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