Stroke Foundation response to the Australian Commission on Safety and Quality in Health Care Clinical Quality Registries (CQRs) Stakeholder Survey

Which of the following best describe your role(s) in the healthcare system?

- Academic / Researcher
- Consumer / Carer
- Healthcare funder / Insurer (e.g. private health insurer, government funder)
- Healthcare provider (e.g. clinician, nurse, allied health professional)
- Healthcare worker (e.g. administrative staff, support staff, health support staff)
- Industry representative (e.g. medical technology, pharmaceuticals)
- Policy maker / Government official
- **Other (please specify)**

  Charity/Peak Body/NGO

Please rate the importance of the following principles in guiding the prioritisation and investment in Clinical Quality Registries (CQRs).

	Not Important	Slightly important	Moderately important	Very important	Essential
Focus on safety and quality – prioritising registries that directly support improvements in clinical care, patient safety, and health outcomes.					✓
Target high-cost health areas – focusing on conditions or procedures (including surgical, drug or device) or healthcare resources that place a significant financial burden on the health system, where registries can help reduce inefficiencies or improve value.					✓
Established coordinated care pathways – supporting registry development in areas where care is already structured and data infrastructure exists, enabling more effective implementation and use.					✓
Equitable – ensuring that prioritisation decisions consider populations with greater unmet needs or health disparities, including First Nations communities.				✓	
Designed for continuous improvement – prioritising CQRs that include mechanisms for regular review, feedback, and adaptation to ensure they remain relevant, effective, and responsive to evolving health system needs and likely to lead to meaningful outcomes.				✓	
Feasibility and governance – focusing on registries with realistic, achievable goals that align with available resources and infrastructure, adhere to clinical standards, and that demonstrate strong governance, data quality, and oversight to ensure sustainability and credibility				✓	

Transparent and evidence-informed decision making – ensuring that the prioritisation process for CQR development is clearly defined, openly communicated, and based on sound, evidence-informed criteria that are understandable and justifiable to stakeholders					✓
Inclusive engagement – prioritising CQRs that actively involve clinicians and stakeholders to ensure relevance, ownership, and long-term sustainability of the registry.					✓

Please rate the importance of each criterion for prioritising CQR development and investment.

	Not Important	Slightly important	Moderately important	Very important	Essential
Burden of disease – the extent to which the condition, procedure or healthcare resource of the CQR/monitored by the CQR contributes to illness, disability, or death in the population					✓
Alignment with national priorities – whether the registry supports current national health strategies or policy goals (for example mental health initiatives)				✓	
Scientific and evidence building – prioritising registries that support high-quality, methodologically sound data collection and analysis, and have the potential to generate new insights in areas where evidence is currently limited				✓	
Ethical and moral considerations – the importance of addressing conditions or populations with unmet or inequitable care for example conditions disproportionately affecting First Nations People				✓	
Contribution to quality improvement - prioritising registries that have the potential to influence clinical practice, policy, and patient outcomes, and drive measurable improvements in care delivery and health system performance					✓
Feasibility and system readiness - prioritising registries that are realistic and achievable to implement, and that strengthen health system capabilities through workforce development, digital infrastructure, and alignment with existing resources and operational capacity				✓	
Relevance to healthcare system stakeholders – the degree to which the registry addresses questions that are important and relevant to clinicians, policymakers, and the community					✓

Value for money – whether the expected benefits of the registry justify the investment required				✓	

Please rate the importance of each criterion for prioritising CQR development and investment.

	Ranking
Clinical relevance – the seriousness or burden of the condition, or how often you encounter it in practice.	1
Emerging or urgent issues – the condition is rising in prevalence, newly recognised, or of growing public concern.	7
Equity or ethical concerns – the condition disproportionately affects certain populations or is under-recognised.	4
Evidence or momentum – there's growing research, policy interest, or community attention in this area.	6
Feasibility and readiness – there are practical elements in place to support implementation of a registry in this area (e.g. existing data systems, clinician interest or infrastructure)	5
Observed variation or unmet need – you've seen differences in care, gaps in services, or areas where better data could improve outcomes	3
Potential for real-world impact – a registry could meaningfully improve care, outcomes or decision-making	2
Personal or professional experience – you've been involved in clinical care, research, or service delivery in this area	8

Please rank the following clinical domains in order of priority for CQR improvement or investment, from highest to lowest.

	Ranking
Acute and emergency services (for example emergency care and rehabilitation medicine)	2
Aged care and end-of-life care (for example aged care, palliative care, advanced care planning)	7
Chronic and complex conditions (for example chronic disease management such as diabetes, cancer care, stroke care, pain management, genetic are rare disease	1
Infectious and immune conditions (for example infectious diseases such as COVID-19, HIV, immunology)	6
Maternal, child and family health (for example maternity and newborn care, child and adolescent health, men's health, women's health)	4
Mental and behavioural health (for example mental health, addiction and substance use)	5
Preventive and community health (for example preventive health, Aboriginal and Torres Strait slander Health, disability services, rural and remote health, oral health)	3

Do you have any additional comments or suggestions?

Variation in access to recommended evidence-based care remains a major area of concern across Australia. Coordinating change and improvement across the components of the healthcare system is often slow and difficult to sustain. Advances in research and digital health integration have immense promise to improve adherence to evidence-based care. Involvement in partnerships between consumers, researchers and health care providers, supported by a strong culture of innovation and adaption is needed to optimise care delivery, and patient experiences and outcomes.

The **Learning Health System (LHS**) approach, first proposed in the United States in 2007 by the Institute of Medicine, can be applied as a dynamic, multifaceted framework that integrates existing evidence and real-world data to inform clinical decision making. Important aspects of a LHS are that it can deliver continuous and near real-time data insights to support improvements in clinical care, it has governance and involvement of all relevant stakeholders, and it supports a culture of continuous review and adaption.

Knowledge of performance is critical to identify gaps in care and to help prioritise quality improvement activities. Review of local performance data by clinical teams is one important strategy to drive improvement in evidence-based care delivery; however, **the collection and monitoring of data, including CQR data, is only useful if acted on to improve care.** Implementation involves understanding local issues that both hinder (barriers) and enhance (enablers) care, and tailoring strategies to address these issues. Evidence-based implementation strategies include education, facilitated interdisciplinary workshops to develop tailored implementation plans, reminders, improvement collaboratives, consumer mediated strategies, or peer influence (key opinion leaders).

It is critical that funding and resources are in place to ensure that the health system (including health professionals) is able to take the practical steps required to utilise CQR data to improve clinical care and patient outcomes.