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Australian Catholic University

Clinical registry participation: Is it influencing quality improvement activities?

Ethics Exchange – October 2023

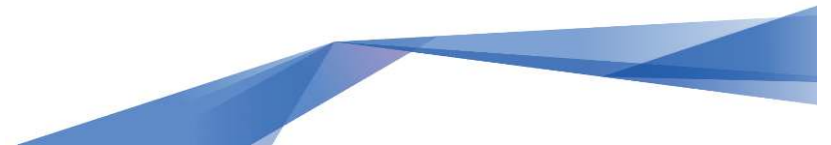
Professor Sandy Middleton

UNDER THE STEWARDSHIP OF MARY AIKENHEAD MINISTRIES

Disclosures



- Chair, Australian Stroke Clinical Registry (AuSCR) Steering Committee
- Chair, Australian Commission on Safety in Health Care, Clinical Quality Registries Framework Review Advisory Group



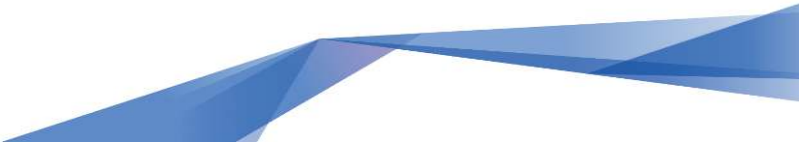
Background

Data are being collected across multiple speciality areas ... but:

Limited knowledge of -

- Who is contributing data to clinical registries
- Whether data from registries are being used to drive local clinical quality improvement initiatives

Lack of information regarding -

- Staff knowledge of implementation science methods
 - What training clinicians need to improve the use of data to drive practice change
- 

Economic evaluation



AUSTRALIAN COMMISSION
ON SAFETY AND QUALITY IN HEALTH CARE

November 2016

Economic evaluation of clinical quality registries

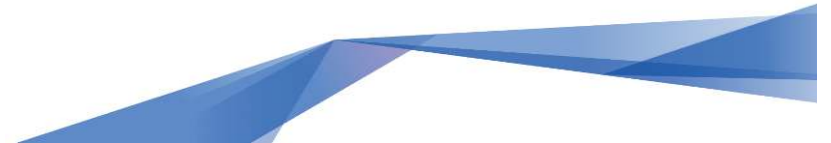
Final report

Economic impact of five Australian clinical quality registries:

Significant net positive returns on investments and positive benefit to cost ratio

Substantial benefits, reflecting improvements to clinical practice and outcomes over time

Significant value for money, when correctly implemented and sufficiently mature



Background

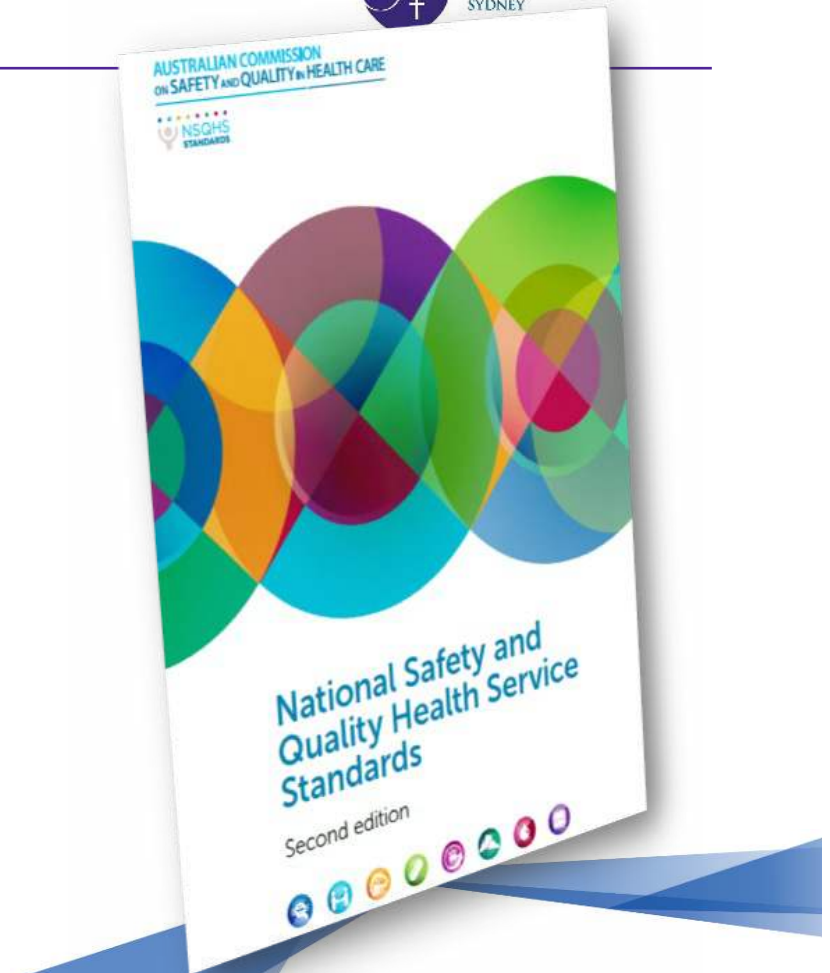
National Safety and Quality Health Service Standards

Standard 1.28

- Monitor variation in clinical practice and health outcomes

Standard 1.27

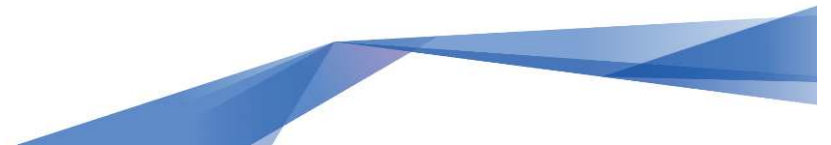
- Support evidence-based care



Aim



1. Identify **clinical registry participation** across SPHERE
2. Determine if, and how, registry data are being **used to influence local quality improvement activities**
3. Identify **educational needs of teams** to improve knowledge of implementation science and knowledge translation methods to use clinical registry data to drive practice change



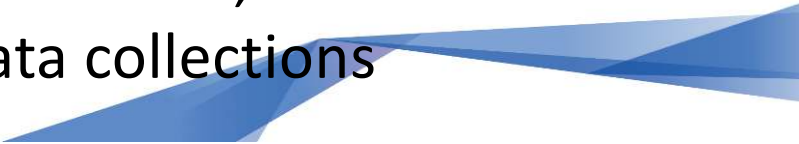
Method

- Cross-sectional, self-administered survey
- 7 hospitals across 4 SPHERE LHDs
- November 2019 - March 2020

Inclusion Criteria

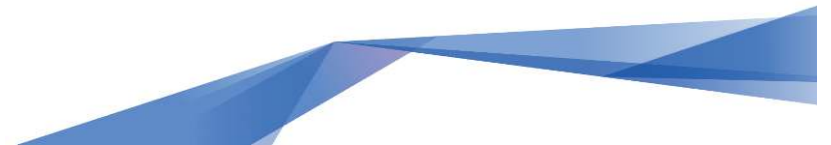
- Clinical quality registries, condition/disease registries and device/product registries

Exclusion Criteria:

- Drug registries, Clinical trials, Research studies, Time-limited clinical audits and point prevalence data collections
- 

Results

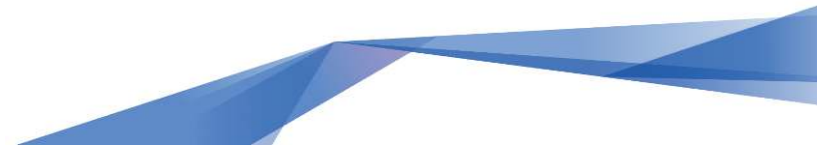
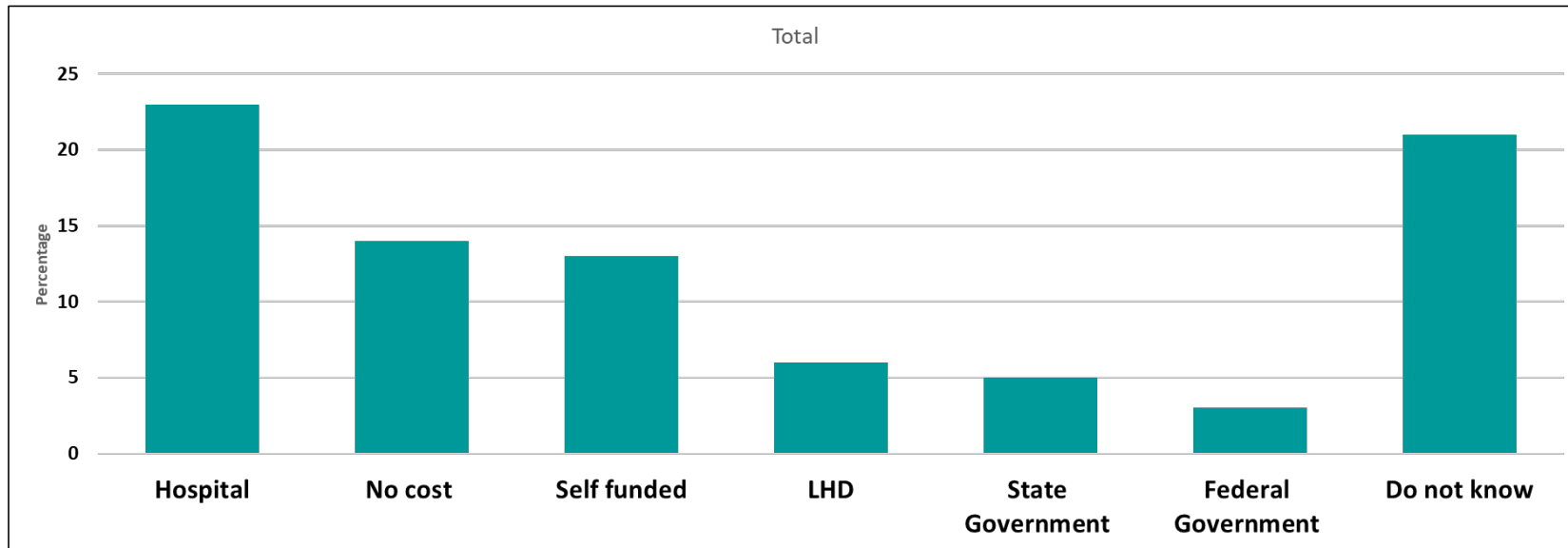
- 70% response rate (97/139)
- Contributing to **state** (25%), **national** (47%) and **international** (21%) registries
- 97% data collected by nurses
- 58% data collected via retrospective medical record audit



Funding Source



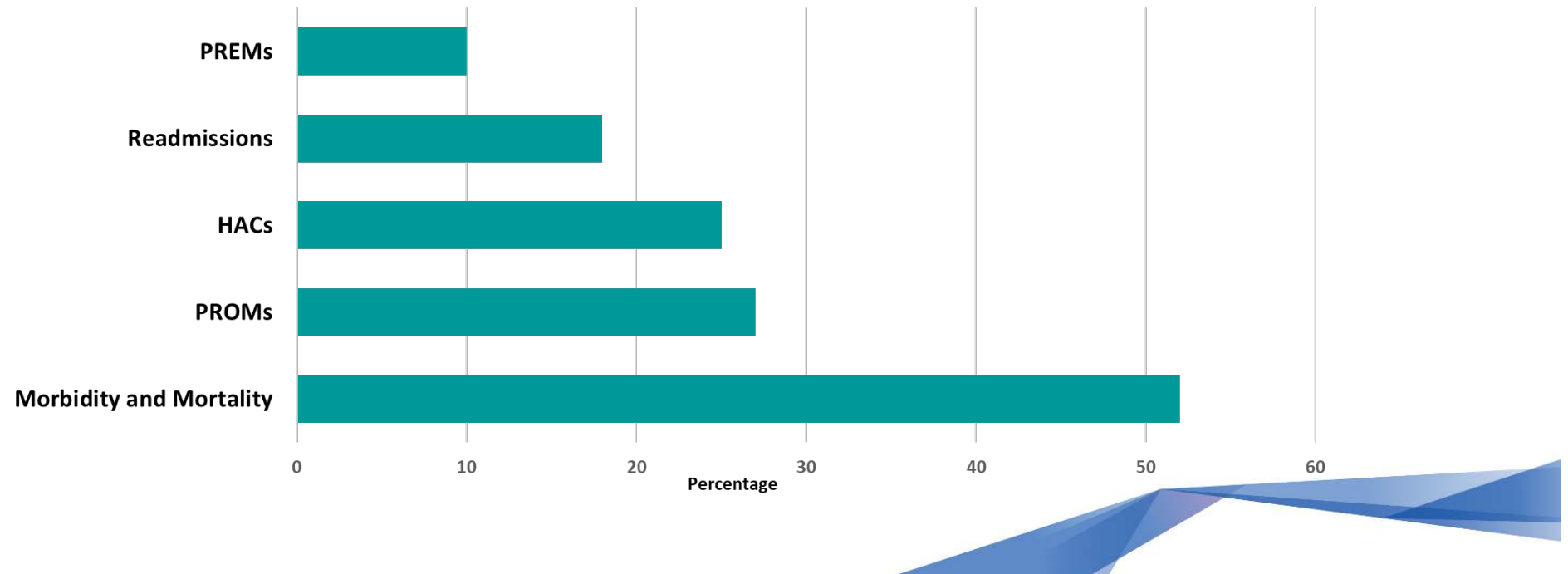
Few registries funded by state or federal governments



Data collected

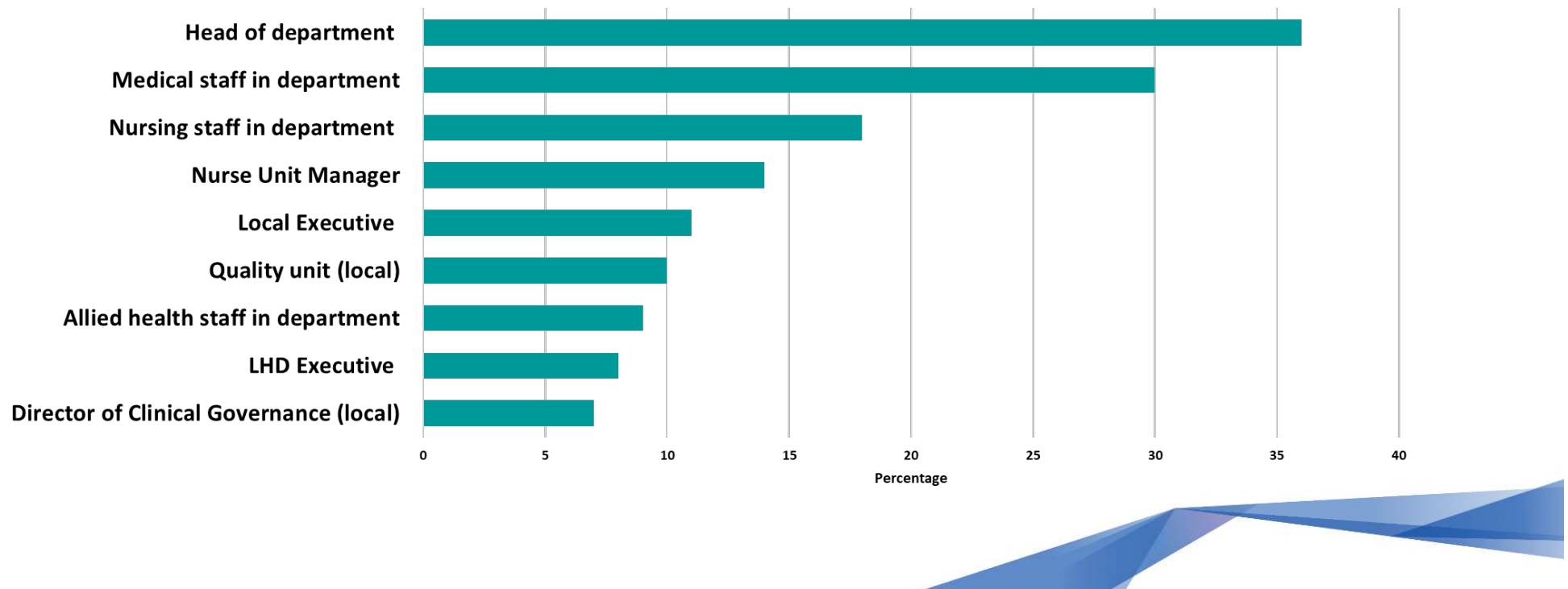


Approximately 50% collected patient outcome data



Who receives registry reports?

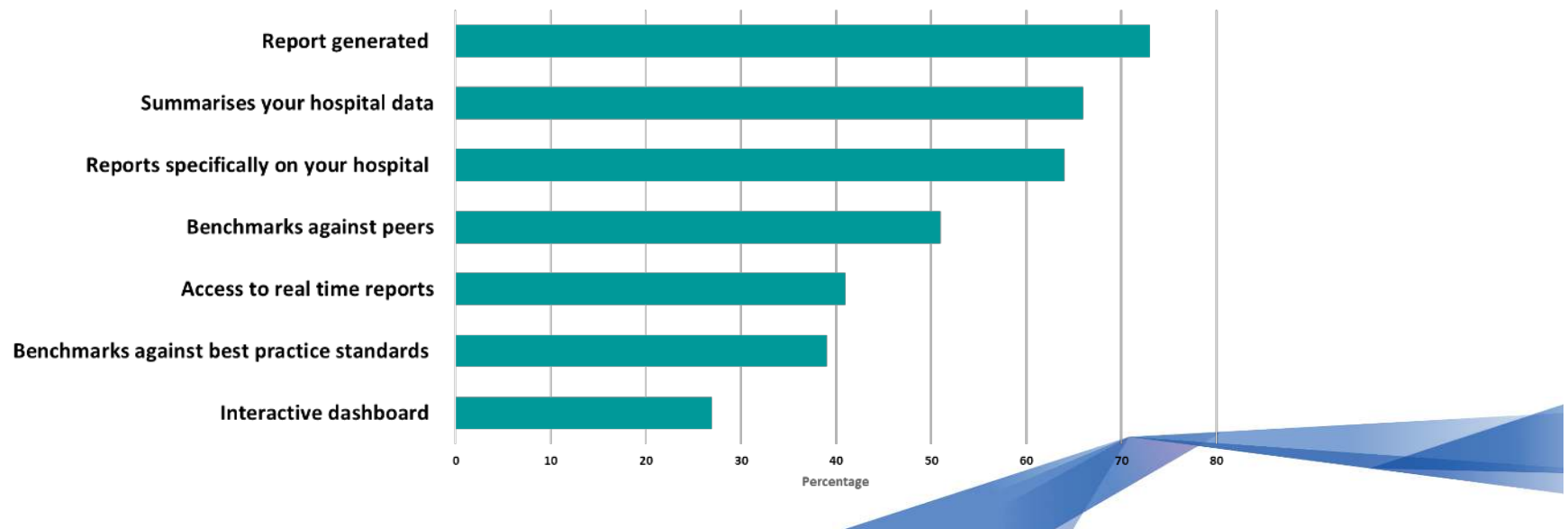
11% Executives; 10% Quality units; 7% Director Governance



Registry reports

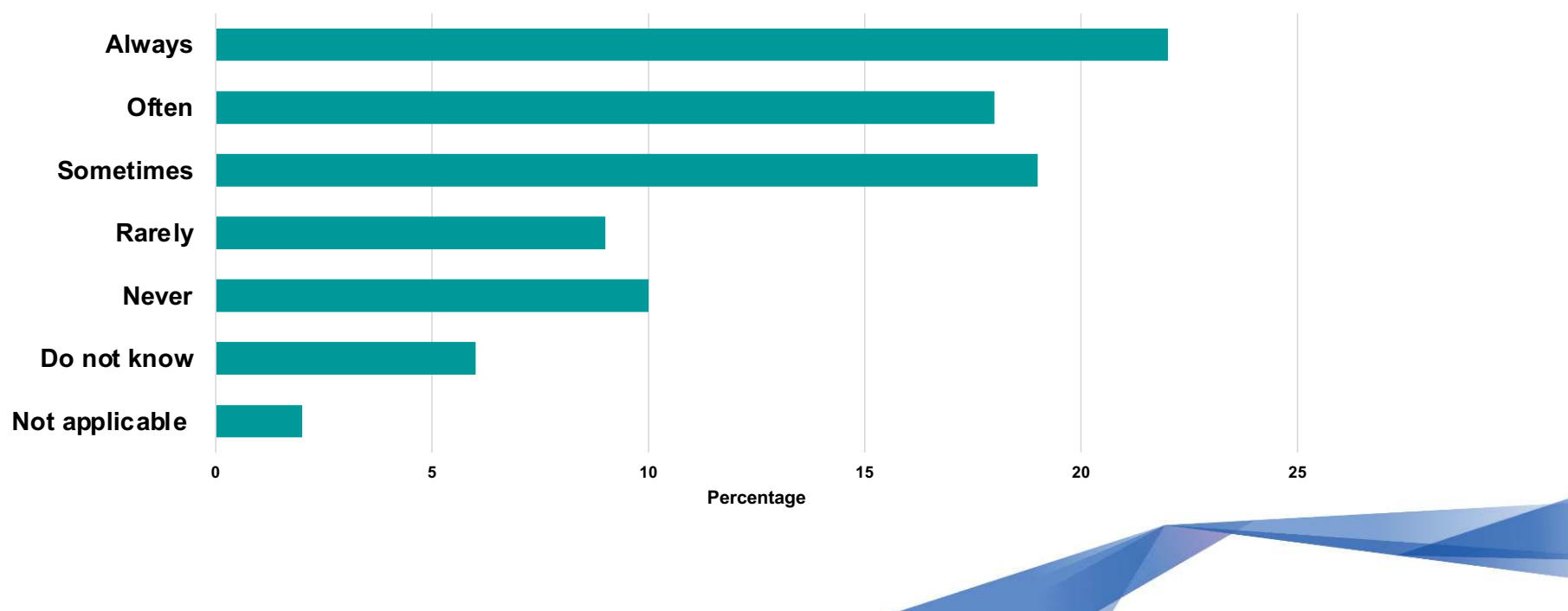
Less than 50% -

- Had access to real time reports
- Benchmarked results against best practice standards
- Had interactive dashboard



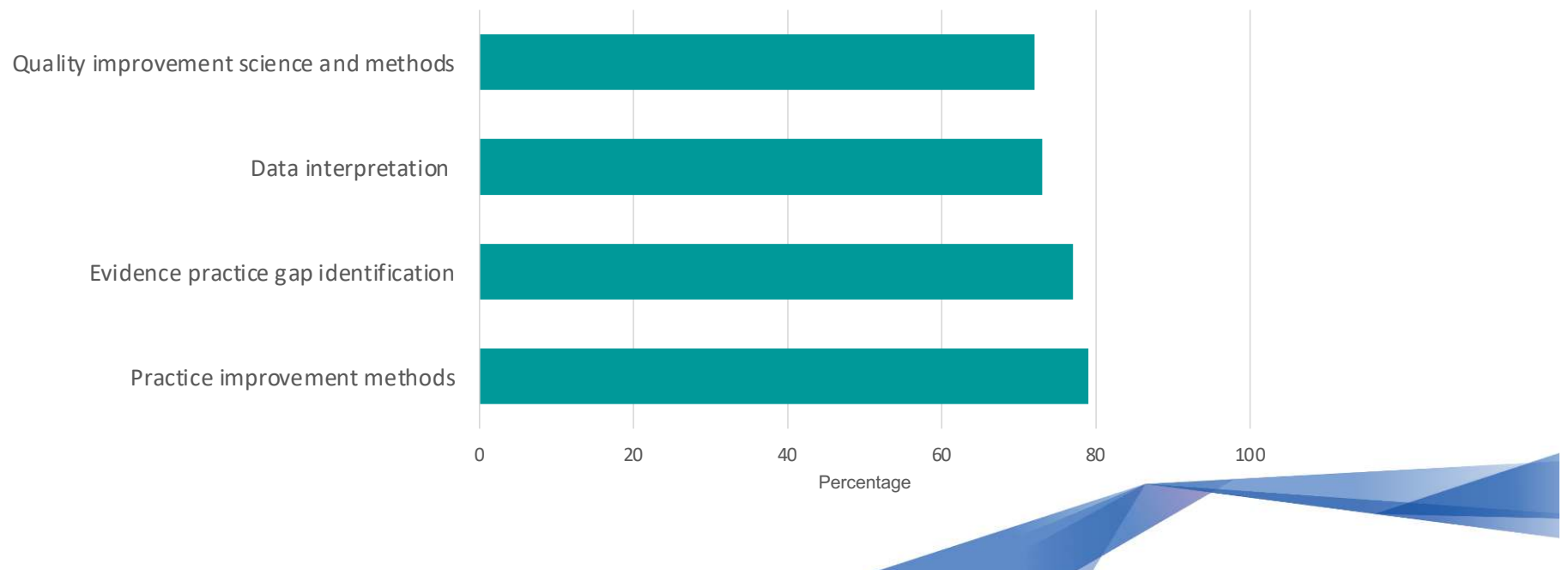
Use of data to improve clinical practice

<50% regularly used clinical data for quality improvement activities



Training needs

Over 75% reported quality improvement training would help support practice change



Recommendations

Funding

- Address inconsistent and inadequate funding

Visibility

- Engage with executive and governance units to incorporate registry data into clinical practice

Barriers

- Embedding use of registry data for quality improvement

Education

- Access to quality improvement training, coaching, mentoring
- Create culture focused on learning, ownership and accountability

International Journal for Quality in Health Care, 2021, 33(4), 1–10
DOI: <https://doi.org/10.1093/intqhc/mzab141>
Advance Access Publication Date: 6 October 2021
Original Research Article



Are clinicians using routinely collected data to drive practice improvement? A cross-sectional survey

JULIE GAWTHORNE^{1,2,*}, OYEBOLA FASUGBA^{2,*}, CHRIS LEVI^{3,15}, ELIZABETH McINNES², CALEB FERGUSON ⁴, JOHN J McNEIL⁵, DOMINIQUE A. CADILHAC^{6,7}, BRONWYN EVERETT⁸, RITIN FERNANDEZ⁹, MARGARET FRY ^{10,11}, HELEN GOLDSMITH¹², LOUISE HICKMAN¹¹, DEBORAH JACKSON¹¹, JANE MAGUIRE¹¹, EDEL MURRAY¹³, LIN PERRY^{11,14}, and SANDY MIDDLETON^{1,2}; On behalf of the Maridulu Budyari Gumal Sydney Partnership for Health, Education, Research and Enterprise Nursing & Midwifery Implementation Science Academy

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ORIGINAL ARTICLE

How registry data are used to inform activities for stroke care quality improvement across 55 countries: A cross-sectional survey of Registry of Stroke Care Quality (RES-Q) hospitals

Oyebola Fasugba^{1,2} | Rupal Sedani³ | Robert Mikulik⁴ | Simeon Dale^{1,2} |
Miroslav Vařecha³ | Kelly Coughlan^{1,2} | Benjamin McElduff^{1,2} | Elizabeth McInnes^{1,2} |
Sabina Hladíková³ | Dominique A. Cadilhac^{5,6}  | Sandy Middleton^{1,2} 

¹Nursing Research Institute, St Vincent's Health Network Sydney, St Vincent's Hospital Melbourne and Australian Catholic University, Sydney, New South Wales, Australia

²School of Nursing, Midwifery and Paramedicine, Australian Catholic University, Sydney, New South Wales, Australia

³International Clinical Research Centre, St. Anne's University Hospital, Brno, Czech Republic

⁴International Clinical Research Centre, Neurology Department, St. Anne's University Hospital and Masaryk University, Brno, Czech Republic

⁵Stroke and Ageing Research, School of Clinical Sciences at Monash Health, Monash University, Clayton, Victoria, Australia

⁶Stroke Theme, Florey Institute of Neuroscience and Mental Health, University of Melbourne, Heidelberg, Victoria, Australia

Footnote to go here

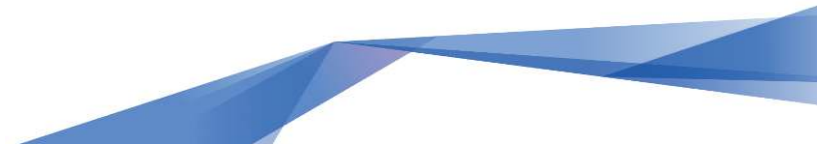
Day/Month/Year

Page 17

Background



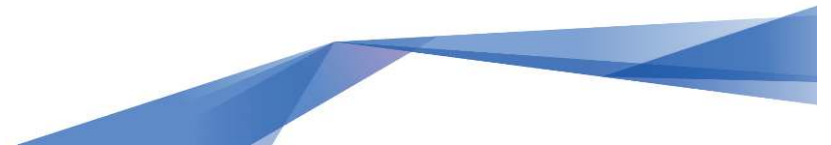
- The **Registry of Stroke Care Quality (RES-Q)** is a global Clinical Quality Registry for continuous monitoring, evaluation and improvement of stroke care quality since 2016
- Captures performance/quality measures that allow standardised comparison of stroke care quality internationally
- Provides feedback to hospitals via dashboards and downloadable reports with benchmarking at both hospital and national levels



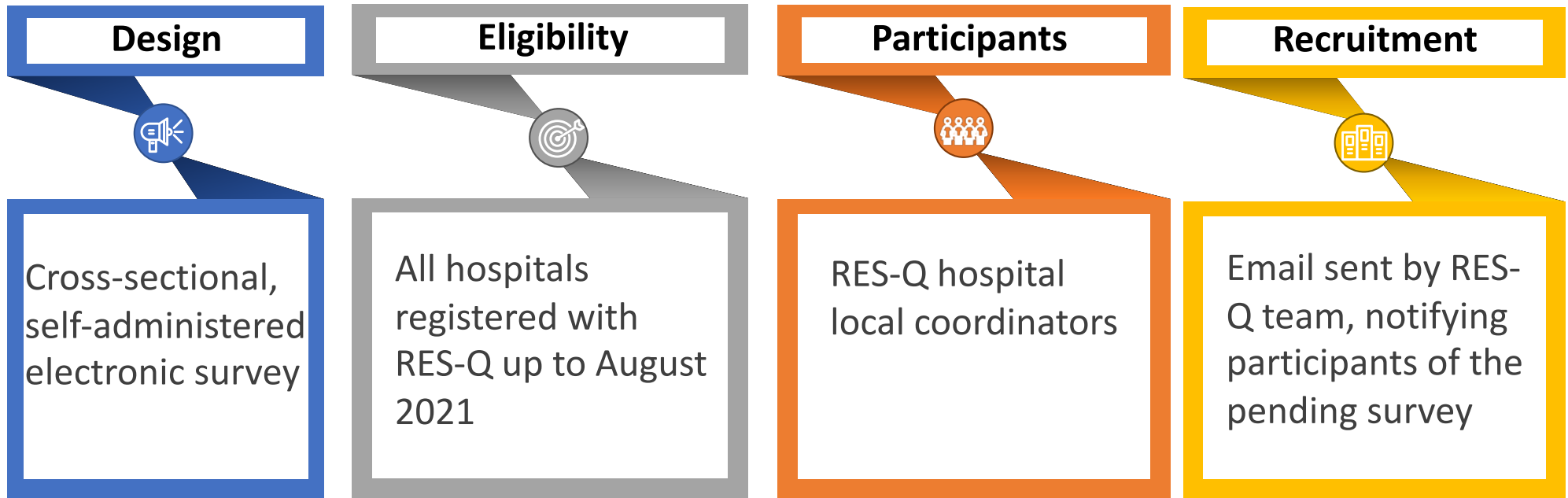
Aims



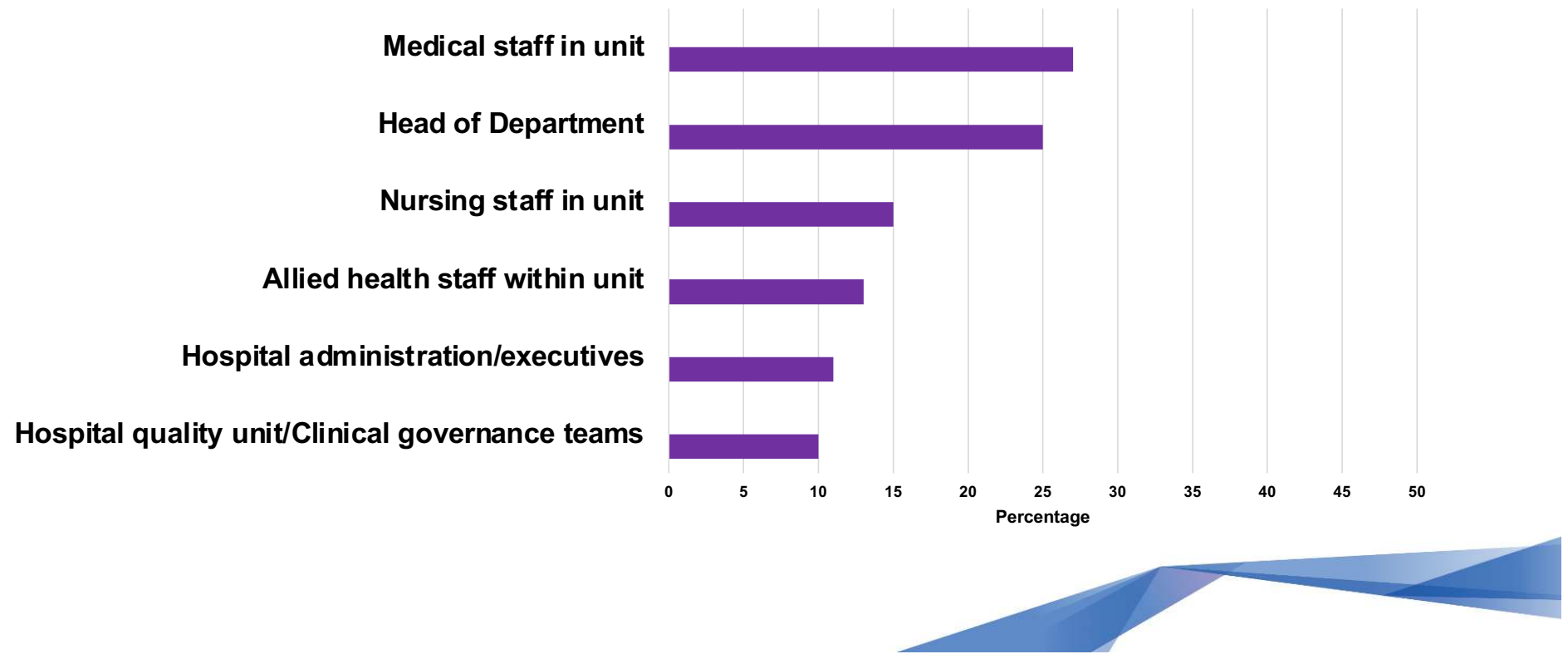
- To determine if, and how, RES-Q data are being used to inform local quality improvement activities
- To identify educational needs of stroke clinicians to improve use of RES-Q data to drive practice change



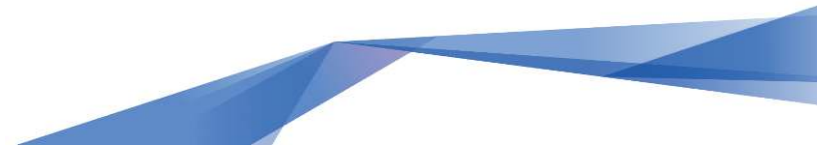
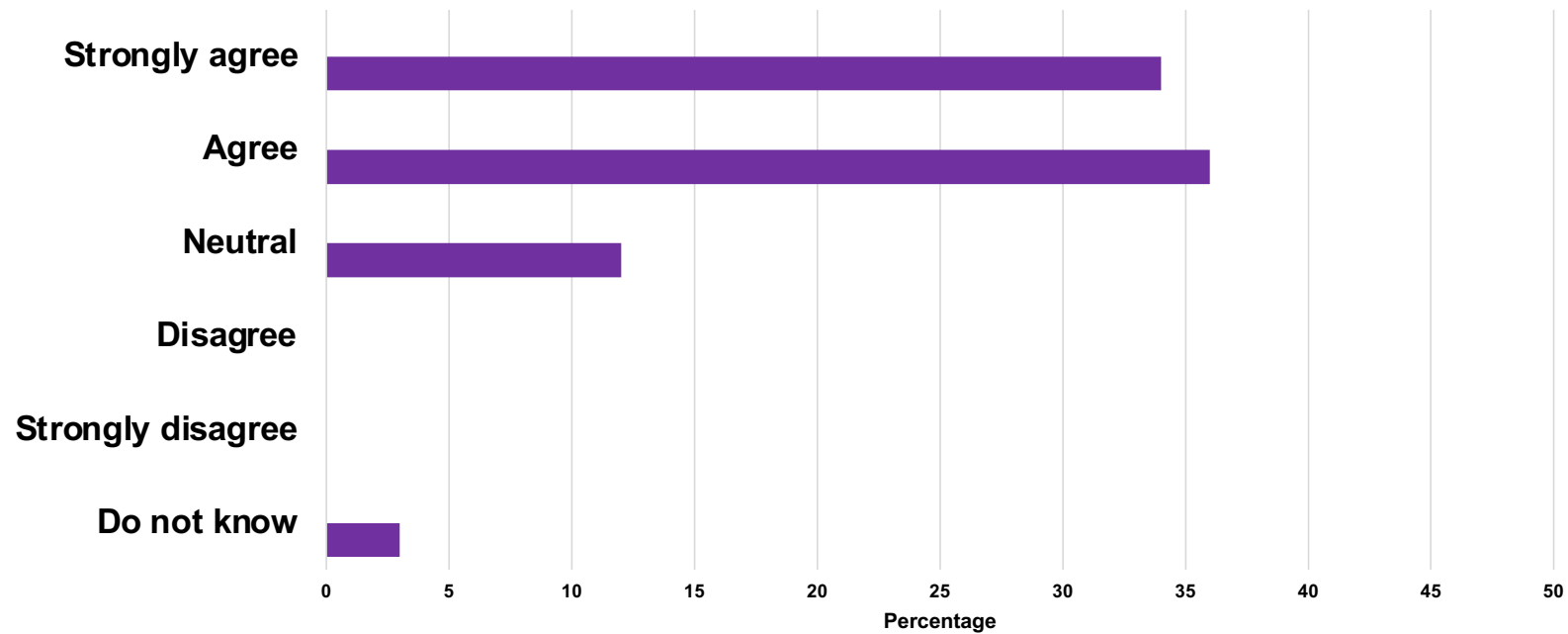
Method



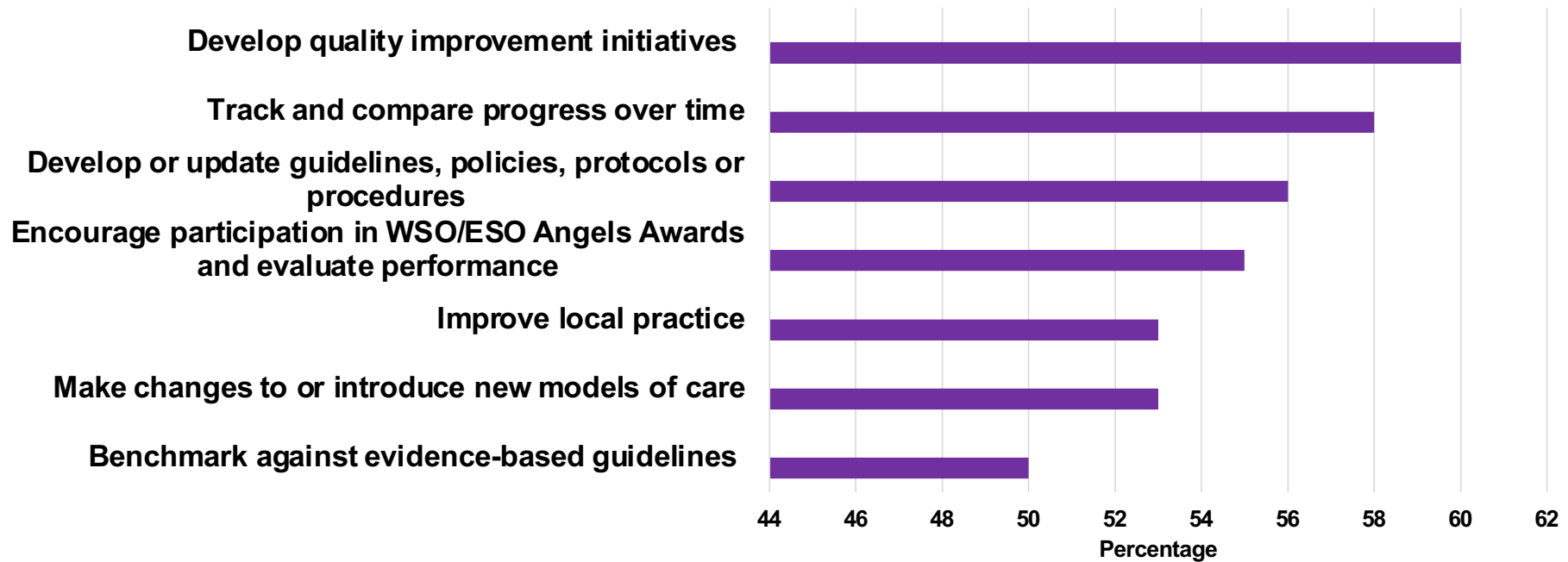
Who receives monthly feedback?



Participation has led to improvements



RES-Q data influences clinical practice – Always or often



Conclusion



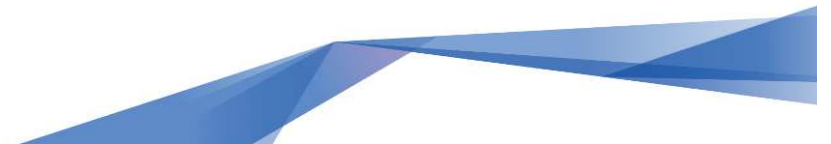
Registry data are a valuable resource for hospitals to use in monitoring the quality of care and identifying areas for improvement



Educating staff in quality improvement science may help develop competency and improve use of registry data in clinical practice

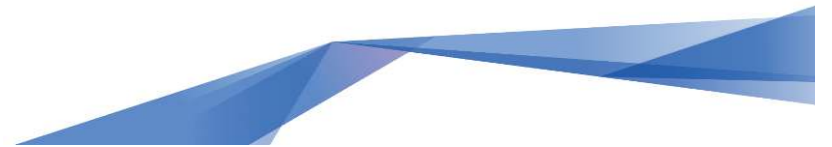


Not quite there yet ... but potential is huge



AUSCER

Australian Stroke Clinical Registry



Addition of new hospital

Hospital added to lead HREC approval

- Where not possible, (some hospitals request own ethical review), separate HREC application submitted



Site Specific Assessment

- Submitted via ERM (where possible)
- Includes site-specific documents such as patient information sheet, post-discharge contact letter

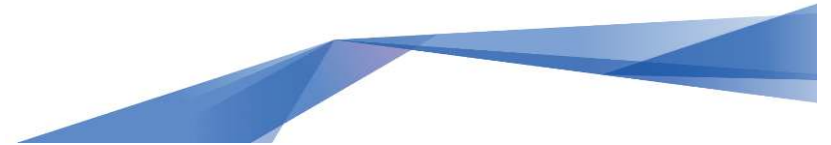


Site Approval

- Hospital added to the AuSCR program
- Training provided

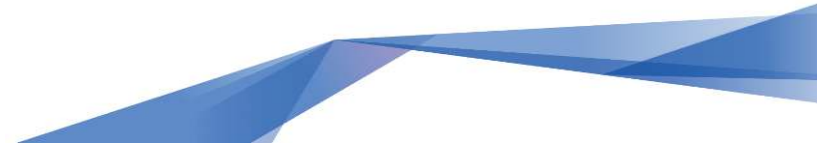
Opt out approach

- Best practice for Clinical Quality Registries (CQR)
- In line with the National Statement on Ethical Conduct in Human Research (chapter 2.3)
- Explicit consent on all patients not feasible
- Low risk
- In public interest
- Mechanisms exist for people to receive information, decline participation, and keep information secure
- Patients provided information and participation is presumed unless they take action to decline involvement

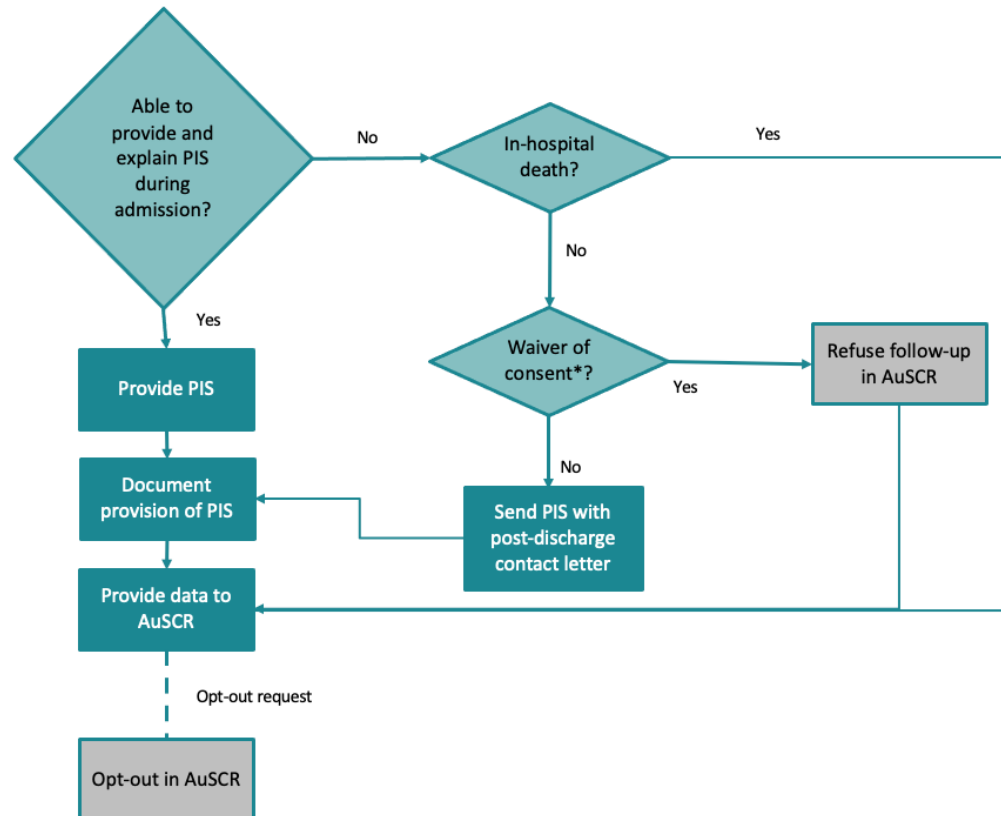


Opt out approach

- Patients can choose to have just their personal details removed from the registry or all details removed
- Opt-out rate for the AuSCR is 2.2%
- **Waiver of consent** for patients who:
 - die in hospital
 - documented as being incapable of understanding written information
 - no next-of kin or responsible person who is able to receive the information

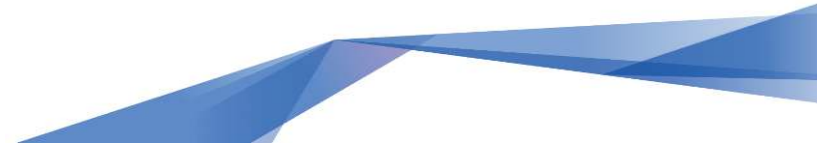


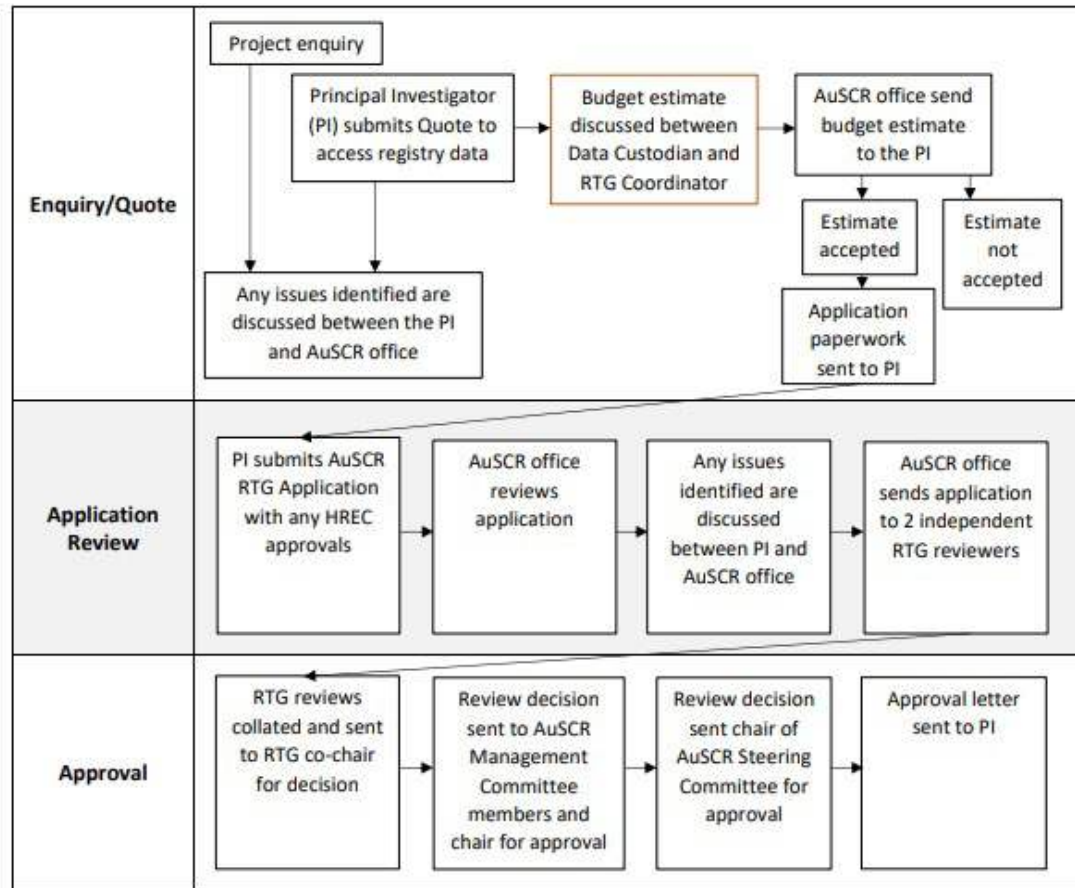
Opt out



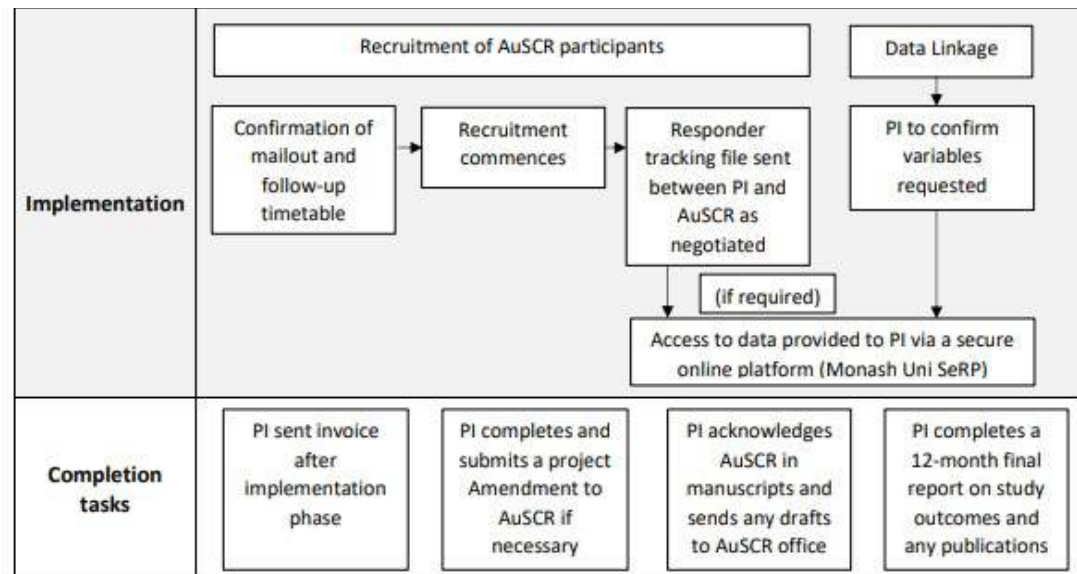
PIS: Patient Information Sheet

*All patients who are deemed, in their medical record, as being incapable of understanding written information and do not have a next-of kin or responsible person who is able to receive the information are not required to receive information about the AuSCR and no follow-up information will be needed





- Research is an important element of CQRs
- External researchers may request data from the registry



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