Overview

- Background to AuSCR for the uninitiated
  - Advancing 'registry science'

Stroke survivor follow-up in a national registry: Lessons learnt from respondents who completed telephone interviews

Karen M Barclay-Moss[1], Natasha A Lannin[2,3], Brenda Grabsch[1], Monique Kilkenny[1,4] and Dominique A Cadilhac[1,4]

Australian Stroke Clinical Registry

Background

- In Australia, stroke affects 1 person every 9 minutes

- Leading cause of adult disability and death

- Variability in the quality of care impacts outcome

- Returning home after stroke is challenging and the majority of survivors have unmet needs
  - psycho-social, mobility, speech, activities of daily living, memory and cognition, financial

- Many facets of health services research are possible

Australian Stroke Clinical Registry

- The **Australian Stroke Clinical Registry** was established to monitor care and outcomes for acute stroke and transient ischemic attack

- Opt-out approach, with waiver for deaths in hospital

- Online data collection integrated stroke data management system: the *Australian Stroke Data Tool (AuSDaT)*

- Hospital staff access online real-time data reports and data exports

- Patient follow-up via survey 90-180 days

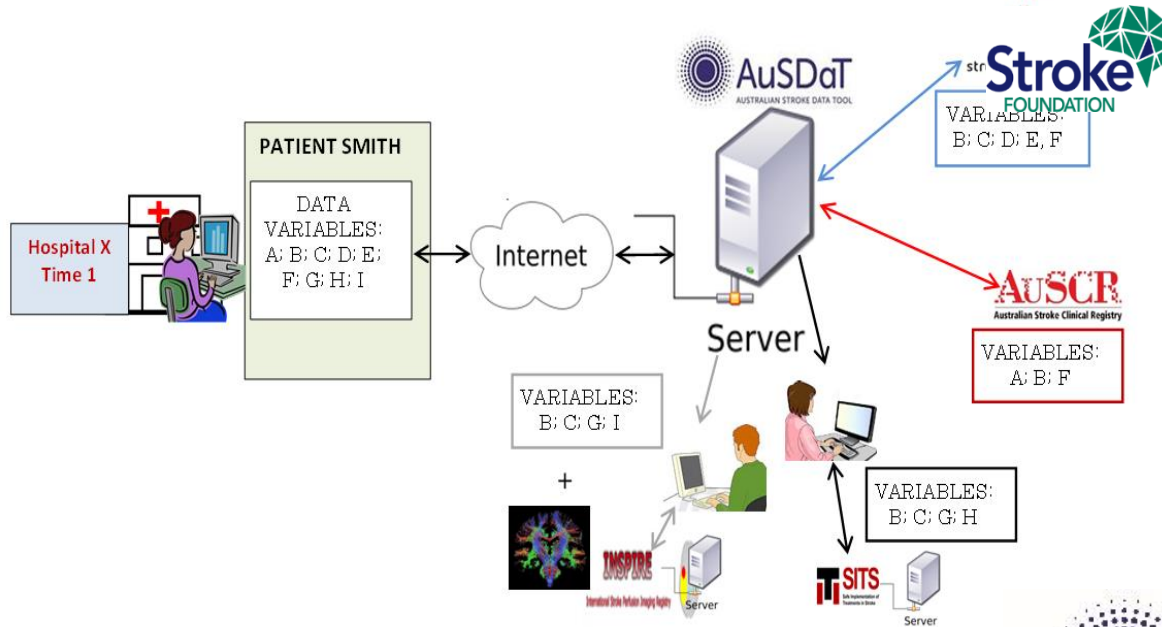- A secondary purpose is to be a resource for research

AuSCR
Australian Stroke Clinical Registry

Launch 2009

AuSDAT facilitates 'collect once use many'

Integrated, online data management system

AuSCR – Progress over 10 years

83
Approved hospitals

71671
Stroke/TIA Episodes

31902
Patients completed Follow Up

Opt-out rate: 2.3%
Annual linkage to national death index
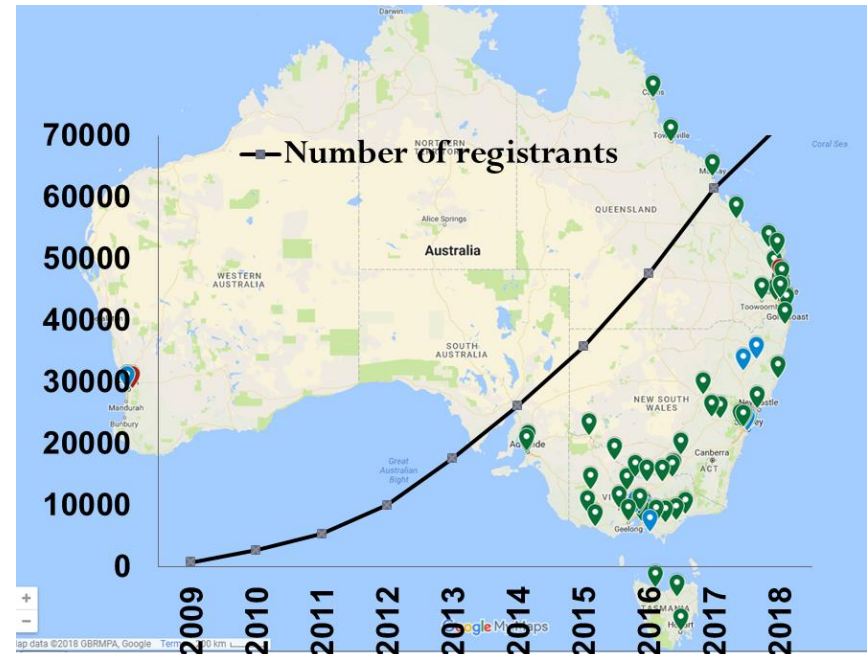
Patient Information Sheet:
"Collecting this information is necessary in order to contact you for follow-up, but also to accurately link your hospital stay with other hospital and health information systems related to, for example, any subsequent rehabilitation, health care needs and/or health outcomes so that we know how well you have recovered."

At 90-180 days: "Would you be willing to be contacted in the future to hear about possible stroke research projects that you may be eligible for?

AuSCR
Australian Stroke Clinical Registry

2017 AuSCR User Survey

What do you use the AuSCR live reports for?
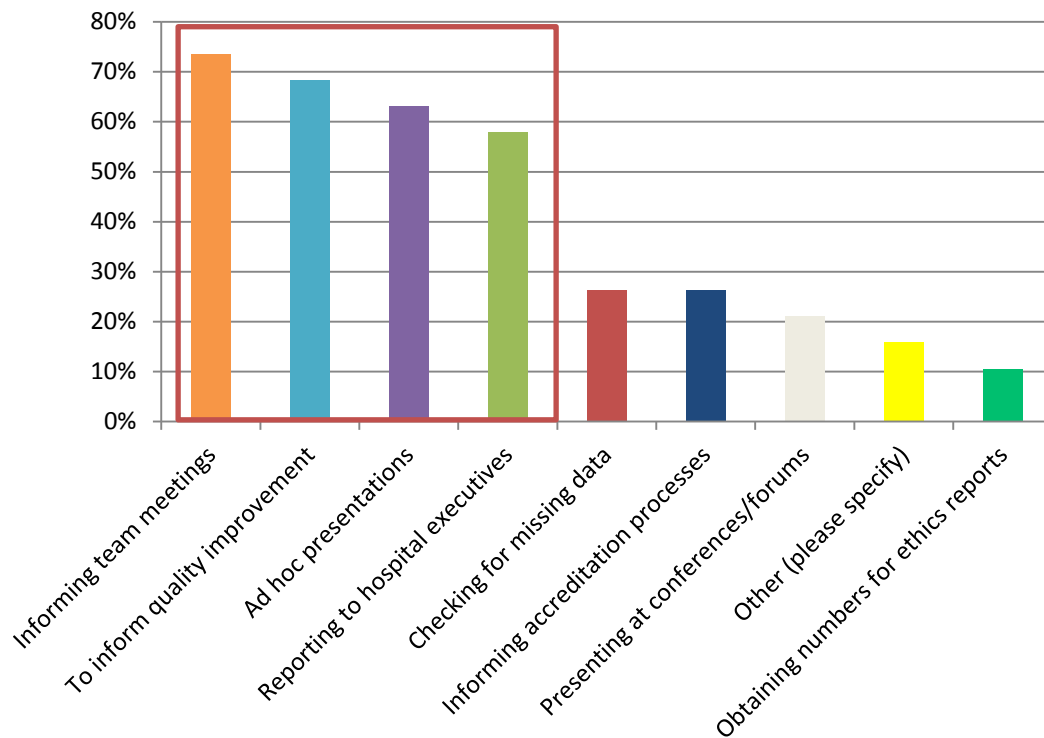
(Bar chart categories: Informing team meetings (~73%), To inform quality improvement (~68%), Ad hoc presentations (~63%), Reporting to hospital executives (~58%), Checking for missing data (~26%), Informing accreditation processes (~26%), Presenting at conferences/forums (~21%), Other (please specify) (~16%), Obtaining numbers for ethics reports (~11%))

Do you believe that involvement with the AuSCR has led to improvements to the hospital's stroke services?

- Yes — 68%
- No — 12%
- Unsure — 20%
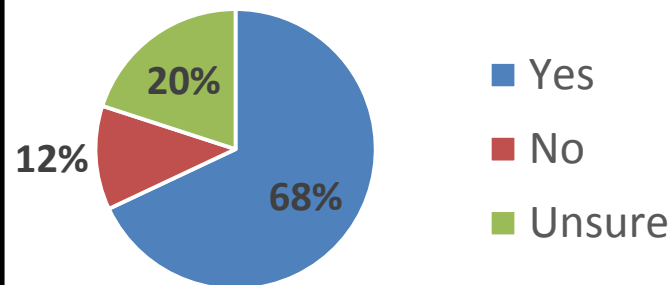
Telephone follow-up was more expensive but more efficient than postal in a national stroke registry

Natasha A. Lannin[a,b,c,d,*], Craig Anderson[d,e], Joyce Lim[d], Kate Paice[f], Chris Price[g], Steven Faux[h], Christopher Levi[i], Geoffrey Donnan[f], Dominique Cadilhac[f,j]

RCT: follow up method modified Dillman protocol telephone versus post (559 randomised)

- Response rate similar between the telephone and post (0.57%, 95%CI -4.8% to 6%).

- Shorter time to complete follow-up via telephone

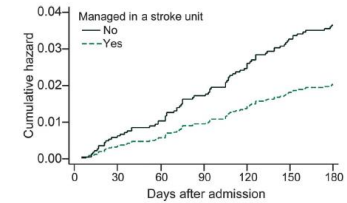- Average cost of telephone follow-up was greater ($13.82 versus $9.18 post)

www.auscr.com.au

Better outcomes for hospitalized patients with TIA when in stroke units

An observational study

Neurology 86 May 31, 2016

Figure Cumulative hazard of death to 180 days after TIA according to management in a stroke unit

Managed in a stroke unit
— No
-- Yes

Days after admission

Weekend hospital discharge is associated with suboptimal care and outcomes: An observational Australian Stroke Clinical Registry study

Monique F Kilkenny[1,2], Natasha A Lannin[3], Chris Levi[4],
Steven G Faux[5], Helen M Dewey[2,6], Rohan Grimley[1,7],
Kelvin Hill[8], Brenda Grabsch[2], Joosup Kim[1,2], Peter Hand[9],
Vanessa Crosby[10], Michele Gardner[11], Juan Rois-Gnecco[12],
Vincent Thijs[2,13], Craig S Anderson[14], Geoffrey Donnan[2],
Sandy Middleton[5,15] and Dominique A Cadilhac[1,2]; on behalf of
the AuSCR Consortium

Discharged weekend: fewer problems with mobility, self-care, undertaking usual activities, pain/discomfort and anxiety or depression. But had increased risk of death.

Brief Report

Quality of Life Is Poorer for Patients With Stroke Who Require an Interpreter

**An Observational Australian Registry Study**

Monique F. Kilkenny, PhD; Natasha A. Lannin, PhD; Craig S. Anderson, PhD;
Helen M. Dewey, PhD; Joosup Kim, PhD; Karen Barclay-Moss, BBSc(Hons); Chris Levi, PhD;
Steven Faux, FAFRM (RACP); Kelvin Hill, BAppSci; Brenda Grabsch, BSW;
Sandy Middleton, PhD; Amanda G. Thrift, PhD; Rohan Grimley, MBBS;
Geoffrey Donnan, MD; Dominique A. Cadilhac, PhD; on behalf of the AuSCR Consortium

More problems with self-care, pain, anxiety or depression and impacts on usual activities

Stroke. 2018;49:00-00.
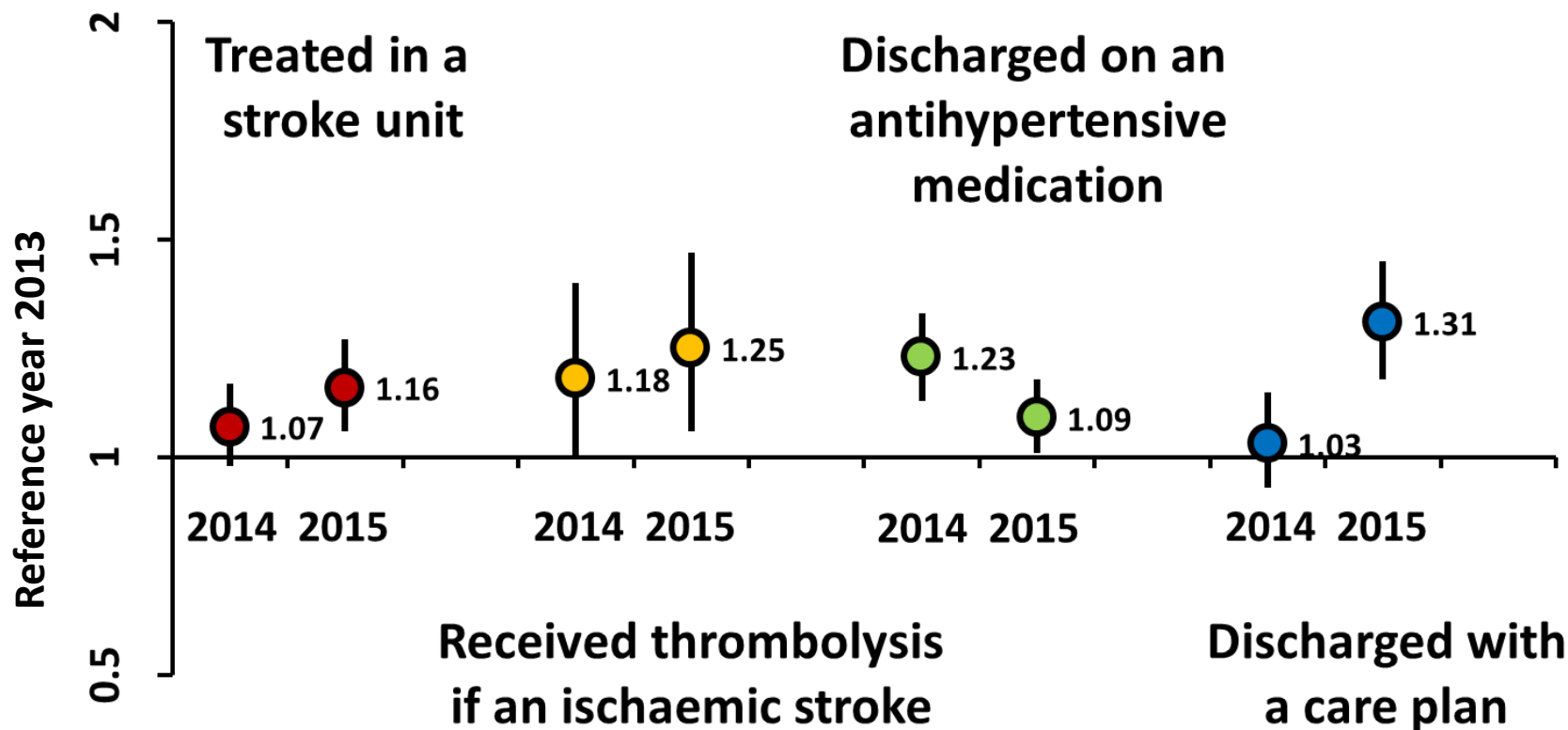
Does improving care make a difference?

Within 180 days:

70% reduced hazard of death

18-point increase in quality-of-life
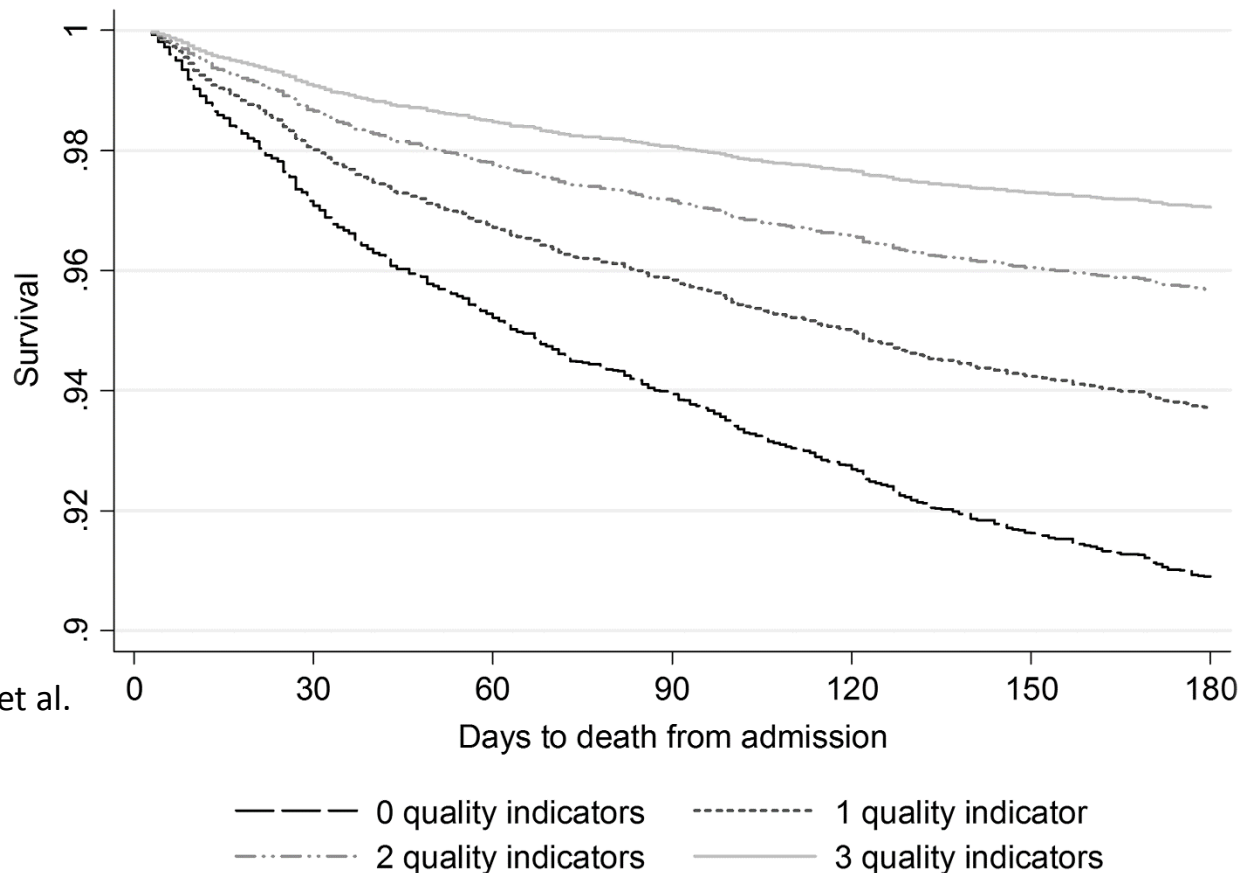
Cadilhac DA, Andrew NE, Lannin NA, et al. *Stroke;* 2017;48:1026-1032
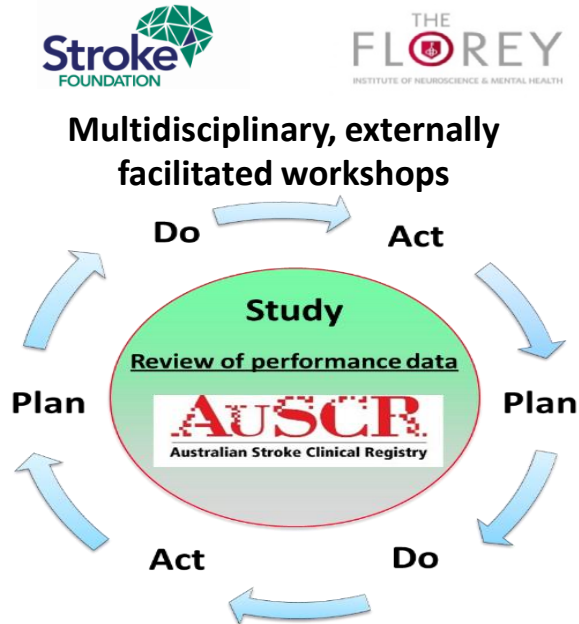
Hospital performance over 3 years

Improvement Science: facilitated quality improvement program

Strokelink (QLD) STELAR (VIC)

Multidisciplinary, externally facilitated workshops

Implementation of evidence-based agreed action plan by local team

Australian Stroke Clinical Registry

■ **Pre-STELAR**   ▨ **Post-STELAR**   ▧ **12 months post**

* p <0.01
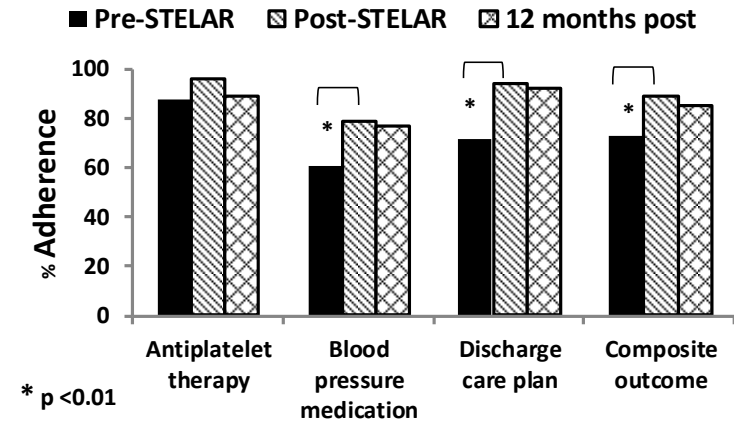
The net change in the composite outcome increased 16% after implementation with a non-significant decay effect at 12 months post implementation (12% improvement compared with pre-implementation or 4% decay effect).

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Medicine, Nursing and Health Sciences

Motivating clinician behavior change – feedback of achievable benchmarks

Motivating clinician behavior change – feedback of 90-180 day patient reported outcomes
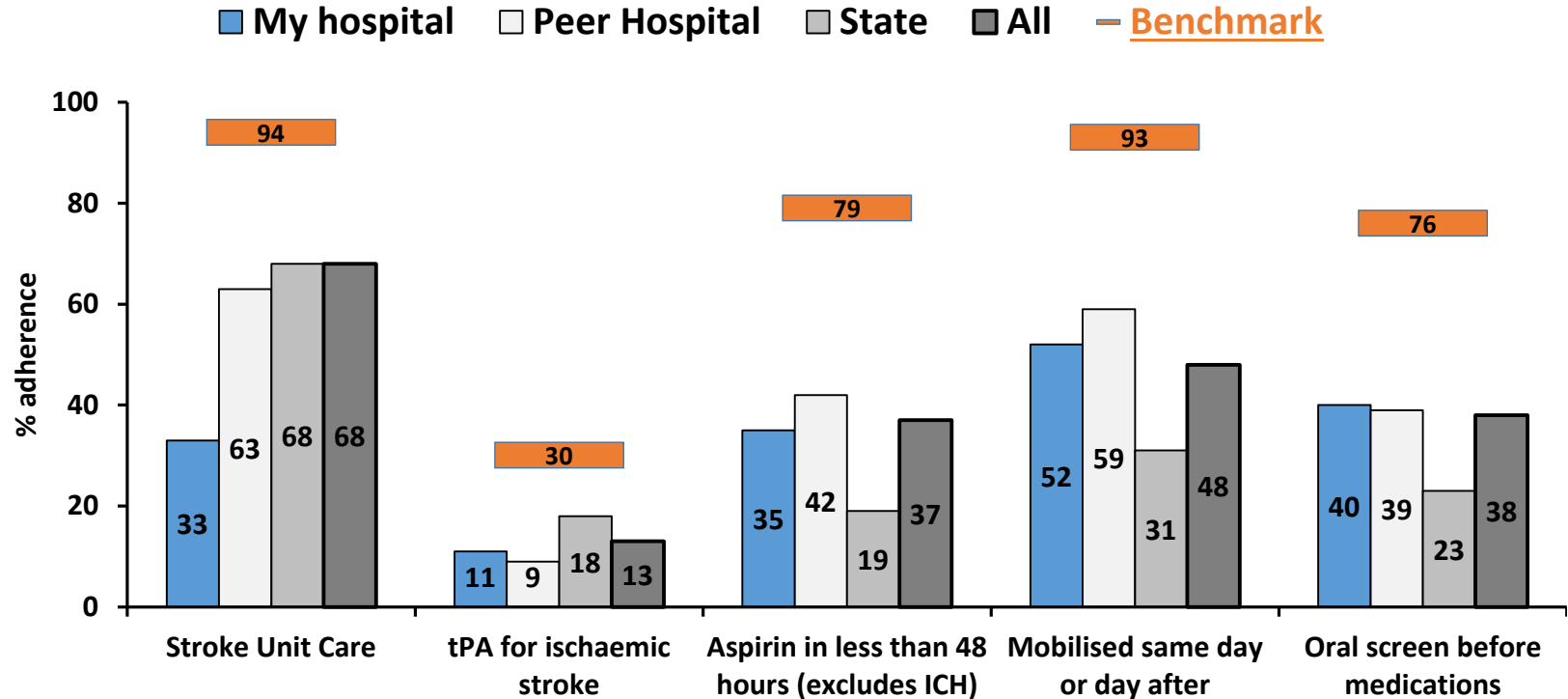

AuSCR QLD: Median HRQoL score (VAS) by hospital

- 2015 follow-up data (y-axis, scale 50–90)
- Normative population aged 70-79 years 83: (sd 23)
- QLD Median VAS score
- Clinically meaningful difference = 8 points (Kim et al, 2015)
- YOUR HOSPITAL
- Sites below the median
- Sites above the median

HRQoL: Health related quality of life, VAS: Visual analogue scale of the EQ-5D
Scores adjusted for age, gender, stroke severity, stroke type, in-hospital stroke, and previous stroke

Australian Stroke Clinical Registry

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Competing projects and responder burden
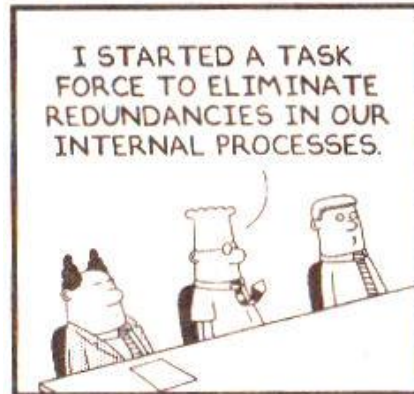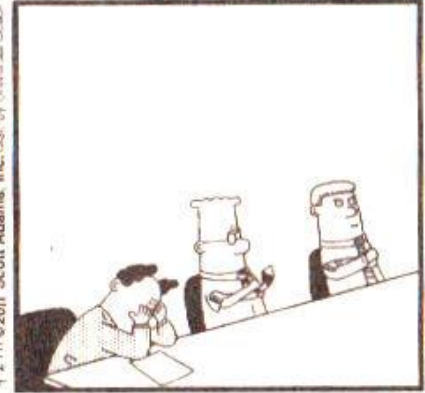
This Photo by Unknown Author is licensed under CC BY-SA

The VST Project: 2010-2017

Stroke symptom onset < 4.5 hours

Paramedics notify hospital

Regional Hospital

EMERGENCY HOSPITAL Main Entrance

➢ Rapid triage and assessment

➢ CT brain and CTA

Phone 1300 TELEMED
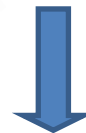
Assessment by VST stroke specialist

Rapid review of brain

Video consultation with family and regional clinician

KEEP CALM AND MAKE A DIFFERENTIAL DIAGNOSIS

Acute stroke therapies delivered within acceptable timeframe - tPA, ECR -

90 day outcomes

THE FLOREY
INSTITUTE OF NEUROSCIENCE & MENTAL HEALTH

STROKE
TELEMEDICINE

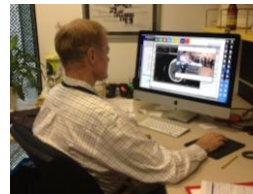**Aim:** To evaluate a nurse-initiated multidisciplinary organisational intervention to improve the **T**riage, **T**reatment and **T**ransfer of stroke patients in Emergency Departments

Design

- Implementation study using a **Cluster RCT**
- EDs randomised into two groups: intervention or control
- Intervention becomes new 'business as usual'
- Evaluated at the level of the patient

## 90-Day *Computer assisted telephone interview (CATI)*

- **Death and dependency**
  - Modified Rankin Scale (mRS) ≥ 2, Barthel Index (BI); Short Form 36 Health Questionnaire (SF-36)
- **Other outcome data – processes of care**
  - Retrospective medical record audit from a prospectively recruited patient sample

  Principal investigator: Prof Sandy Middleton

Methods: *Working smarter not harder…*

▶ Meetings to avoid multiple contacts with patients at the same time-point

▶ Process of data collection and data sharing developed

▶ Relevant ethics and project governance committee approvals

▶ Memorandums of Understanding established
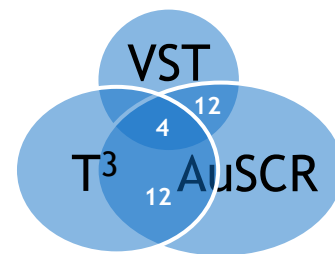
	AuSCR	VST	T^3
Acute stroke	**+ TIA admitted**	**< 4.5 hrs of onset admitted and non-admitted cases**	**Treated on Stroke Unit**
Follow up	**mail/phone**	**mail/phone**	**phone**
Consent procedure	**Opt-out**	**Opt-out**	**Opt-in/ Opt-out**

AuSCR governance structure
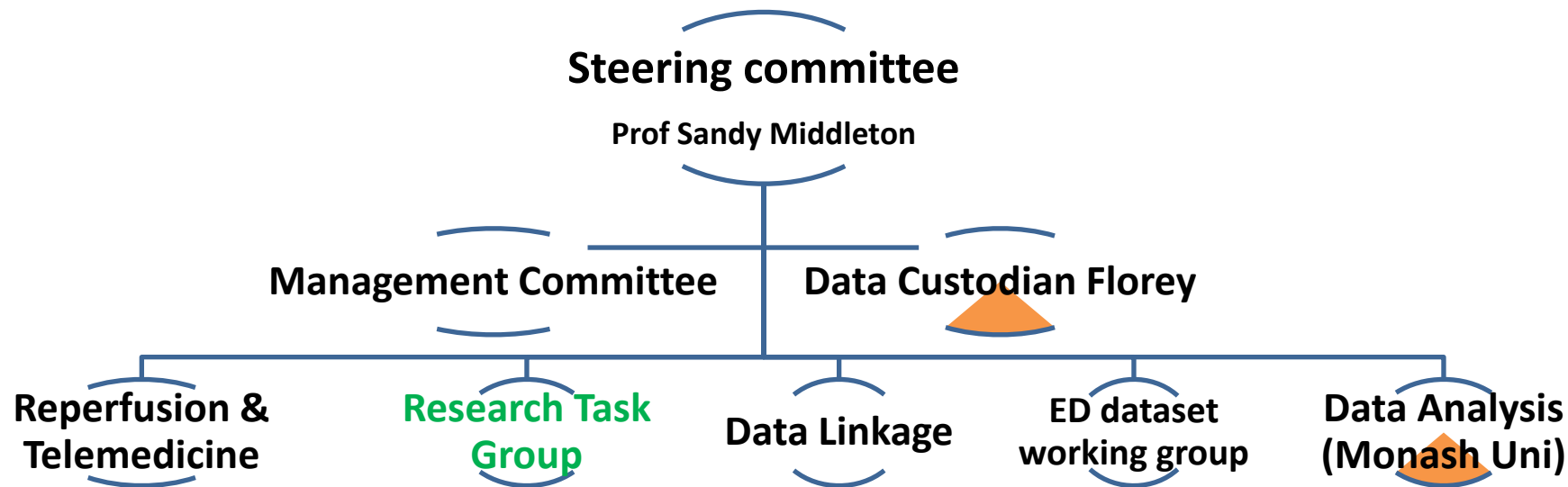
Steering committee

Prof Sandy Middleton

Management Committee   **Data Custodian Florey**

Reperfusion & Telemedicine   **Research Task Group**   **Data Linkage**   **ED dataset working group**   **Data Analysis (Monash Uni)**

https://auscr.com.au/research/research-proposal-procedures/
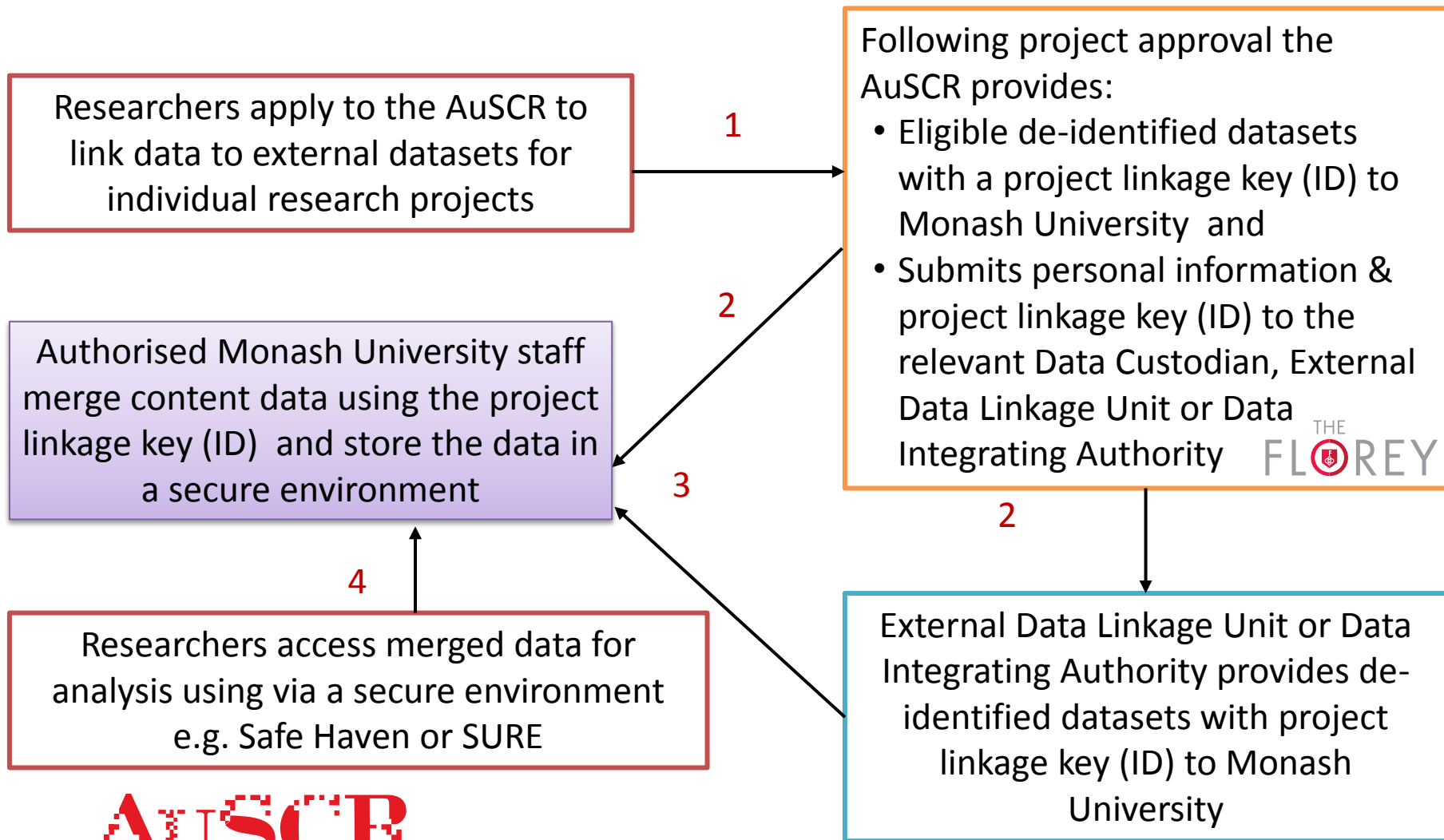
Enabling data access for research

- Since 2011 data have been requested for research
  - 21 applications received, 19 approved and 2 currently under review
  - 11 peer reviewed publications from 12 completed projects to date

Number of applications received per year for AuSCR Data
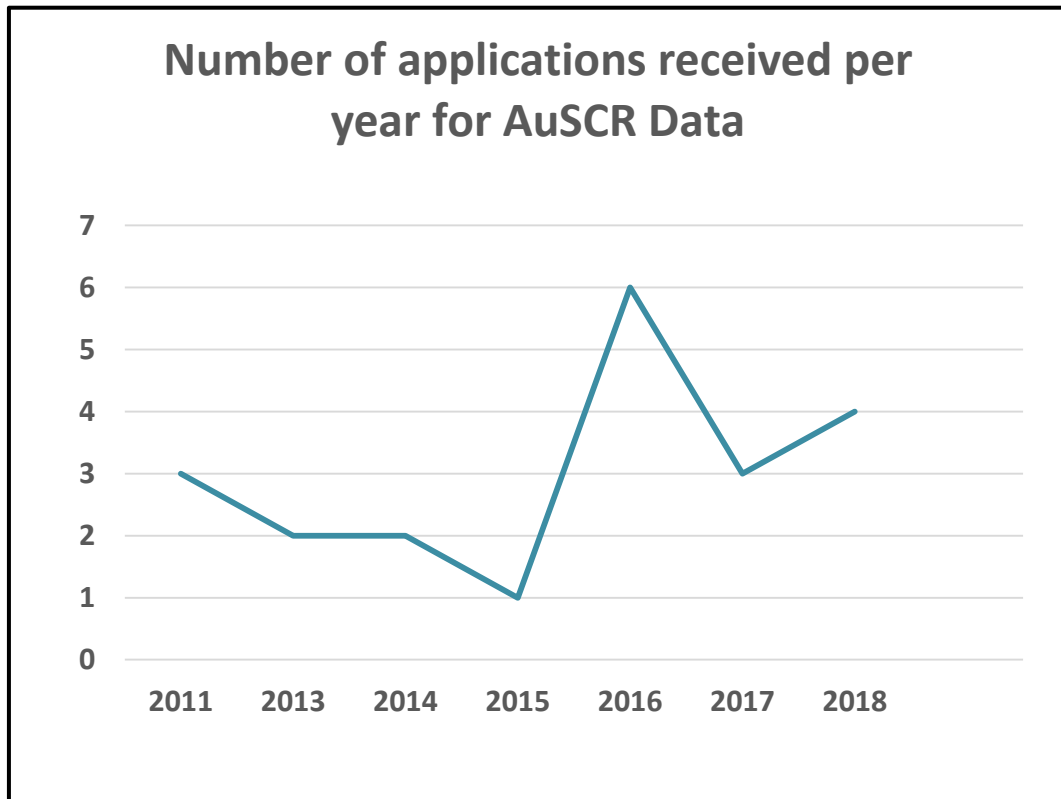
Potential for research and a greater understanding of long term patient outcomes

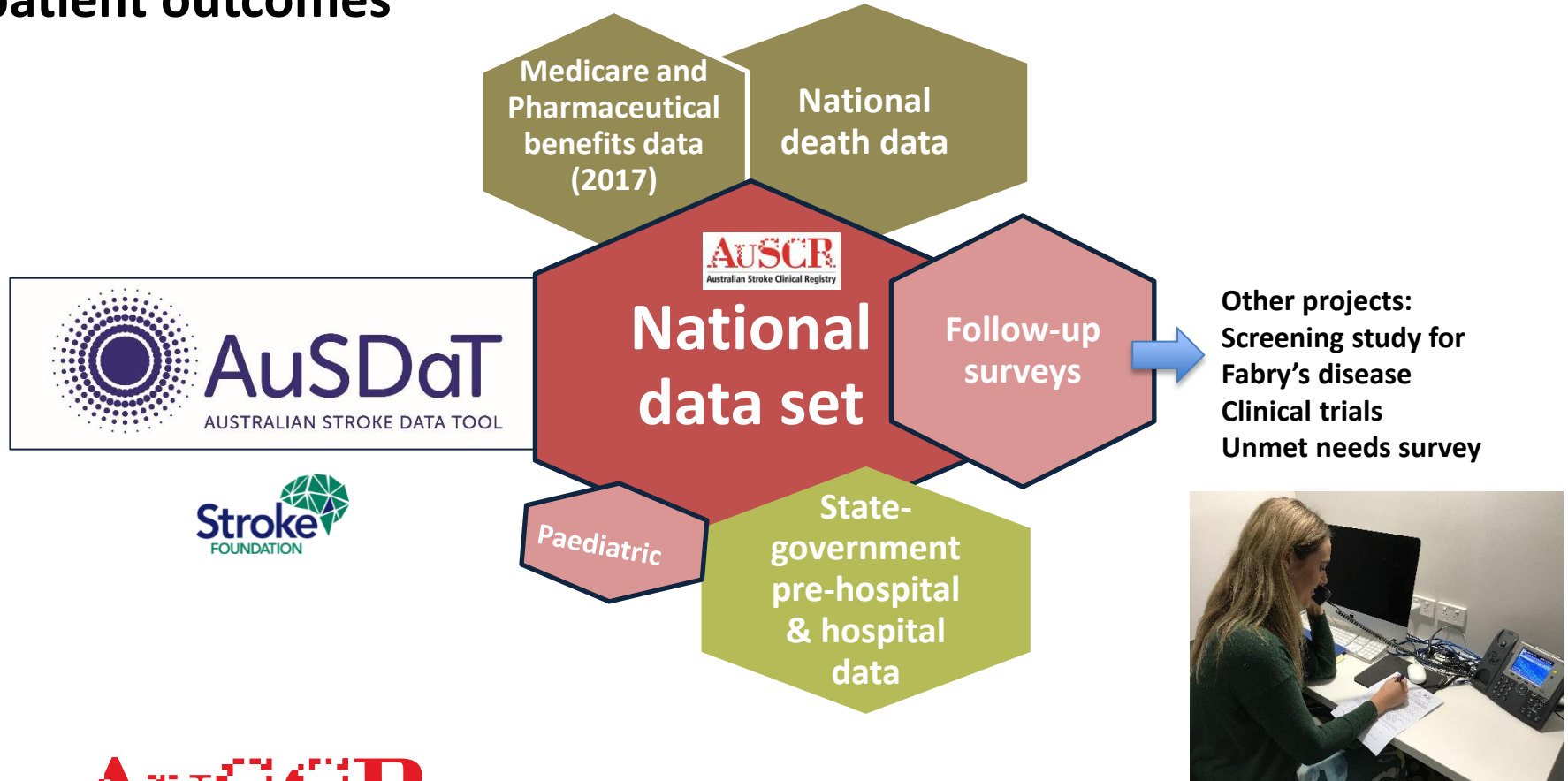| Example projects*	RCT	Comparative effectiveness/ data linkage	Surveys
Australian Survey of Unmet needs (Stroke Foundation)		**X**	**X** **N=791**
Stroke123 (NHMRC Partnership grant 2012-15) • QI study within Queensland: 23 hospitals • Cross-jurisdictional data linkage: Vic, WA, QLD, NSW		**X** **15,482 patients from 40 hospitals**	**X** **N=215 clinicians**
Comparing compensatory and restorative approaches to memory rehabilitation post stroke (PhD project Monash University: Toni Withiel)	**X** **N=65**		
Inspiring Virtual Enabled Resources following Vascular Events (iVERVE) pilot project	**X** **N=54**		
Shared Team Efforts Leading to Adherence Results (STELAR)	**Step Wedge 9 hospitals**	**X pilot project**	
Fabry's pilot screening project			**X** **n=59**
PRECISE (NHMRC Project grant #1141848) (2018-20)		**X**	**X**

*numerous research fellows, early career researchers, PhD, and honours projects

Pilot randomised clinical trial of an e-health discharge support intervention for stroke:

iVERVE (Inspiring Virtual Enabled Resources following Vascular Events)

Professor Dominique Cadilhac

Co-authors:

NE Andrew, D Busingye, J Cameron, AG Thrift, T Purvis J Li, I Kneebone, V Thijs, ML Hackett, NA Lannin, MF Kilkenny on behalf of the ReCAPS investigators

Background

- Returning home after stroke is challenging and the majority of survivors have unmet needs[1]

- In Australia, short acute lengths of stay (average ~5 days) contribute to sub-optimal discharge planning

  - ~ 1 in 2 receive discharge care plans in hospital

  - Health promotion education is limited and rarely reinforced

  - ~ 1 in 3 return to hospital after discharge for acute stroke within 90 days

- Electronic technology to support recovery and self-management after stroke may be useful but has rarely been used and effectiveness is unknown

  - Existing research limited to medication adherence[2] or depression[3] reduction in stroke

1. Andrew NE, et al. *Qual Life Res*. 2016; 2. Kamal AK, et al. BMC Neurol. 2015;15:212;
3. Smith GC, et al. Rehabil Psychol. 2012;57:196-206

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iVERVE: Inspiring virtual enabled resources following vascular events

Comprehensive post-discharge support system comprising:

- Standardised goal setting for patient-centred recovery and secondary prevention
- Aligned electronic support and educational messages
  - Ability to be tailored and delivered via SMS or email
  - Messages can be personalised (include name) and individualised

- Developed by interdisciplinary team including engineers and consumers with independent review of messages[4]

4. Cadilhac et al, Patient Prefer and Adherence, 2018 Jul 11;12:1213-1224
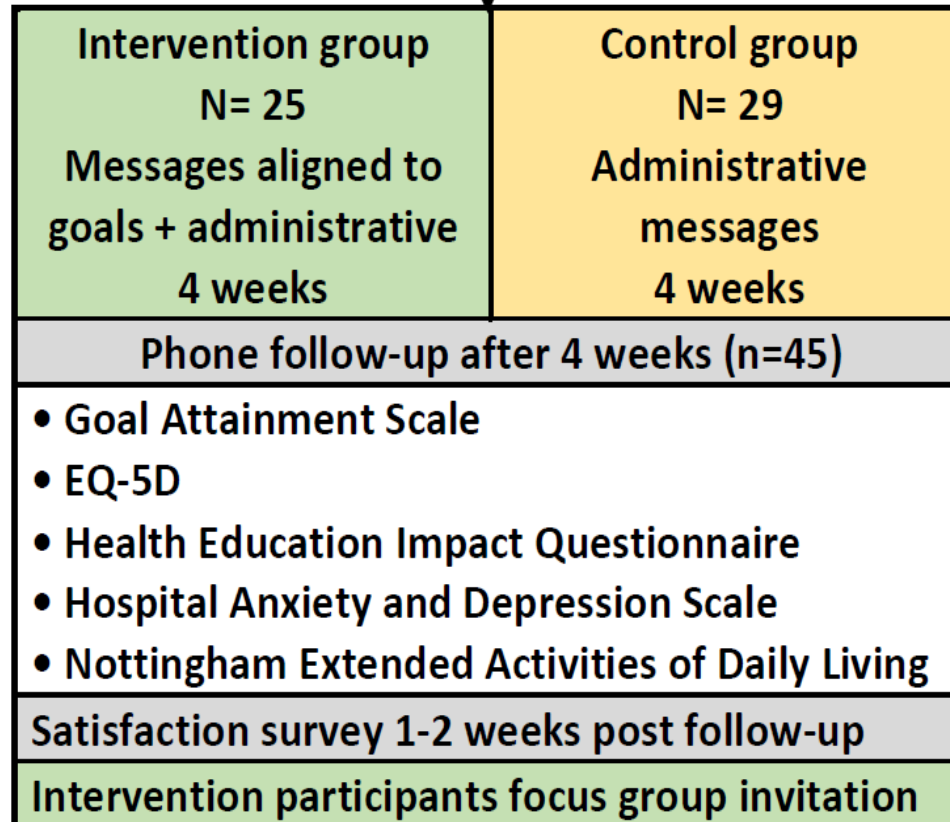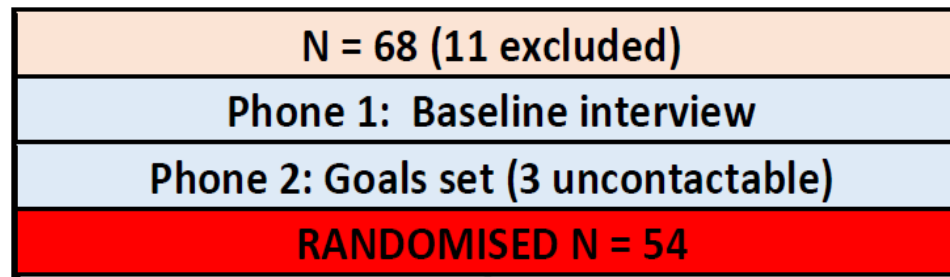
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Aim and methods

To assess the feasibility and acceptability of the **iVERVE** electronic post-discharge support system designed for survivors of stroke

- Early phase I, pilot RCT with assessor and patient blinding and intention-to-treat analysis
- Patients recruited from the **Australian Stroke Clinical Registry** mailout n=340
  - Confirmed stroke
  - Aged ≥18 years
  - 6-12 months post discharge from acute care
  - Living within 50 km of Monash University
  - Agreed to be contacted for future research

Australian Stroke Clinical Registry
www.auscr.com.au

- **Feasibility**: message transmission failures, data completeness, responder burden, retention
- **Acceptability**: satisfaction survey and focus group
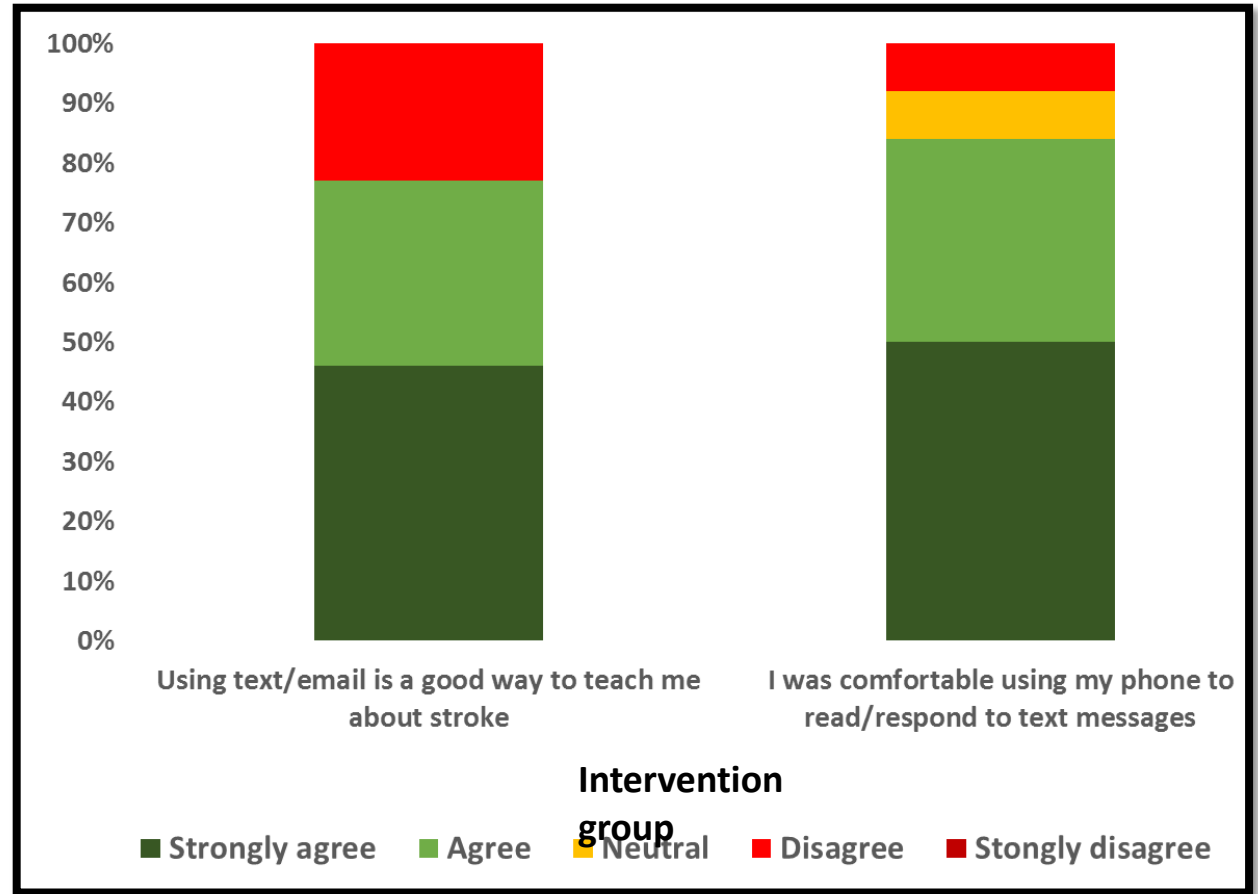- **Potential effectiveness**: goal attainment and self-efficacy

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iVERVE trial design and participation

| N = 68 (11 excluded) |
| Phone 1: Baseline interview |
| Phone 2: Goals set (3 uncontactable) |
| **RANDOMISED N = 54** |

| Intervention group N= 25 Messages aligned to goals + administrative 4 weeks | Control group N= 29 Administrative messages 4 weeks |

| Phone follow-up after 4 weeks (n=45) |

- Goal Attainment Scale
- EQ-5D
- Health Education Impact Questionnaire
- Hospital Anxiety and Depression Scale
- Nottingham Extended Activities of Daily Living

| Satisfaction survey 1-2 weeks post follow-up |
| Intervention participants focus group invitation |

N= 20 (80%) completed

N= 25 (86%) completed

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Acceptability

Summary

- The iVERVE tailored electronic messaging support system for self-management after stroke was feasible and acceptable in a chronic stroke population

- The use of electronic messaging to support comprehensive goal achievement after stroke has potential in terms of effectiveness

- Preference is to use with patients after discharge from acute hospitals to home

- ReCAPs Phase II RCT in progress to assess the potential feasibility and effectiveness of this intervention after acute stroke

MONASH University

Nadine E. Andrew[1], Monique Kilkenny[1,2], Rebecca Naylor[3], Tara Purvis[1], Erin Lalor[3], Natasha Moloczij[2], Dominique A. Cadilhac[1,2], on behalf of the National Stroke Foundation

Aims

From the perspective of community dwelling stroke survivors and their carers we seek to:

- To describe the levels of long-term unmet needs

- To identify the greatest areas of long-term unmet needs

Survey methods

Direct	Indirect
Australian Stroke Clinical Registry (**AuSCR**)	Stroke Foundation (SF) website and email signature
Selected hospitals (not covered by AuSCR)	Advertisements
StrokeConnect support groups (SF)	Stroke Support Groups
StrokeConnect On-line forum (SF)	Word of mouth (snowballing)
	Professional publicity opportunities

Participants

	Survivors	Carers
Number	500	291
Median age (Q1, Q3)	67 (58, 75)	64 (54, 71)
% male	61	27
Median time since stroke (Q1, Q3)	2 (1, 4)	N/A

173 AuSCR registrants completed the Needs Survey (median age 69 years, 67 % male; 77 % ischaemic stroke)

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Stroke FOUNDATION

- **Overall, 84% had unmet needs**

Health, **Leisure, Work,** **Support (external emotional),** **Finances,** **Everyday living**

Substudy using the AuSCR registrants (data linkage project)

- To investigate the association between HRQoL following stroke at 3-6 months and self-reported long-term unmet needs
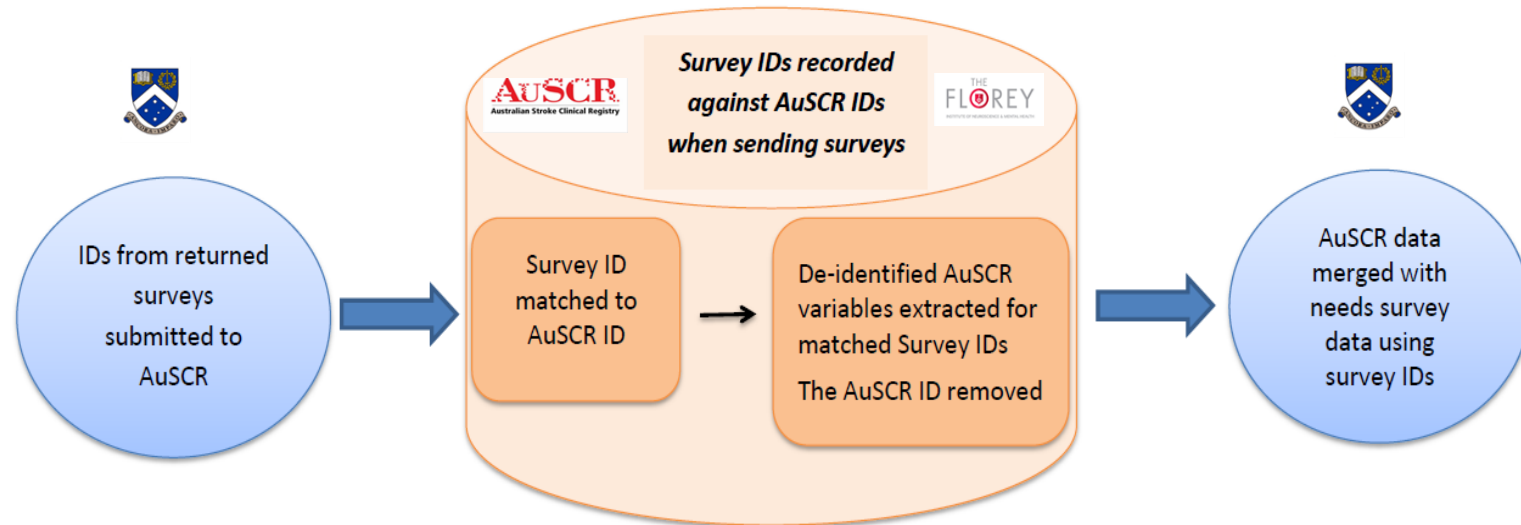
CrossMark

Is health-related quality of life between 90 and 180 days following stroke associated with long-term unmet needs?

N. E. Andrew[1] · M. F. Kilkenny[1,2] · N. A. Lannin[3,4] · D. A. Cadilhac[1,2]

Study methods

Data linked from AuSCR (subset) who participated in the Needs Survey ID numbers using


Data linkage approvals were granted by the AuSCR research task group, the Stroke Foundation and Monash University HREC

Variable	Non-AuSCR Needs Survey Responders N=591 n (%)	AuSCR Needs Survey Responders N=173 n (%)	AuSCR Needs Survey Non-Responders N=426 n (%)
Age median (Q1, Q3)			
At stroke onset	NA	69 (60, 79)	70 (59, 80)
At survey completion	69 (60, 77)	70 (60, 78)	NA
Male	326 (60)	115 (67)*	227 (54)*
Born in Australia	382 (72)	119 (73)	270 (66)
Ischaemic Stroke	NA	134 (77)	347 (82)
Able to walk independently on admission	NA	71 (45)	146 (39)

* Statistically significant difference

Proportion of participants with unmet needs across each domain (n=173)
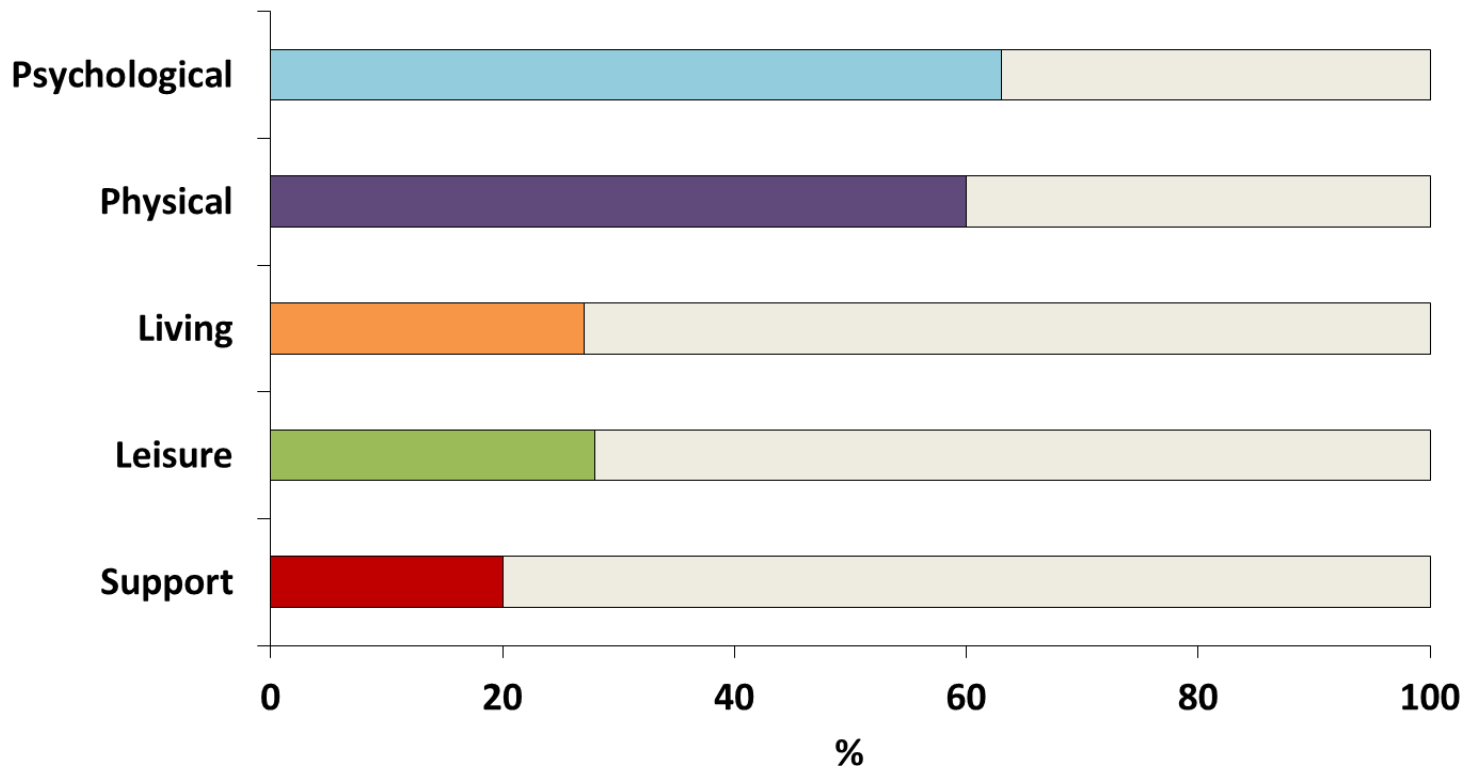
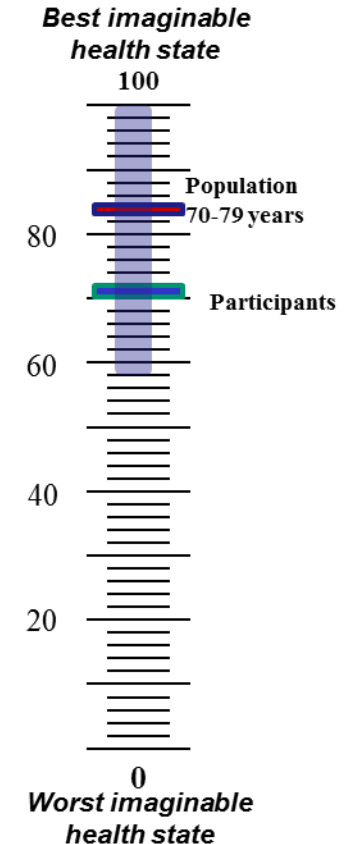*Psychological needs = fatigue, emotional, concentration, cognition, reading and memory needs*

Physical needs = mobility, falls, bladder, pain, speech, vision and swallowing needs

EQ5D VAS – Multivariable Results

- For each 2- point decrease in the VAS at 3-6 months post-stroke there was one additional unmet need reported at median 2 years

  IRR: 0.98, (95%CI: 0.97, 0.99), p<0.01

Models adjusted for age, gender, stroke type, ability to walk on admission, admitted to a stroke unit, level defined as hospital

Best imaginable health state

100

Population
70-79 years

80

Participants

60

40

20

0

Worst imaginable health state

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Summary of findings

- Linear relationship between the EQ-5D VAS at 3-6 months and the overall number of unmet needs at 2 years

- Lower EQ5D subscales scores for mobility, self care and usual activities were associated with unmet physical and psychological health needs

CrossMark

Is health-related quality of life between 90 and 180 days following stroke associated with long-term unmet needs?

N. E. Andrew[1] · M. F. Kilkenny[1,2] · N. A. Lannin[3,4] · D. A. Cadilhac[1,2]

Australian Stroke Clinical Registry
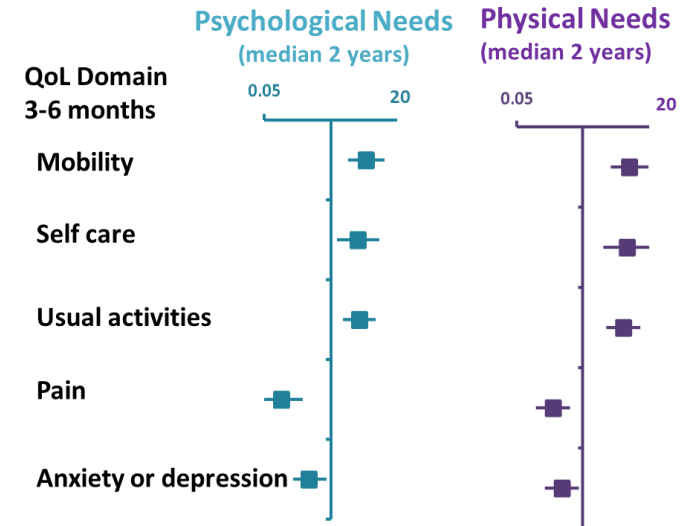
Frontiers in data linkage research

- Data already available and adds extra information to routinely collected data
- Validates quality e.g. missing data, clinical coding practices
- Allows longitudinal analysis
- Supports various study designs
    - Trends over time
    - Comparison of groups treated vs not treated e.g. thrombolysis
    - Cost and economic evaluations
- Research into rare events or small sub-populations – large sample sizes

AuSCR
Australian Stroke Clinical Registry

# Factors influencing self-reported anxiety or depression following stroke or TIA using linked registry and hospital data.

Thayabaranathan T, Andrew NE, Kilkenny MF, Stolwyk R, ..., Cadilhac DA on behalf of the Stroke123 investigators and AuSCR consortium.

Australian Stroke Clinical Registry

MONASH University
Medicine, Nursing and Health Sciences

Rationale for study

- 30-50% of survivors experience problems with mood[1]

Important to understand the factors associated with anxiety/depression post-stroke to find ways to reduce their prevalence


1. Crichton S, et.al. 2016
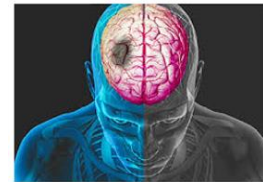
Methods – Data sources

- Observational study, using data prospectively collected from the Australian Stroke Clinical Registry
    - 2009-2013
    - Queensland hospitals (n=23)
    - Quality of care indicators (e.g. access to stroke unit, discharged on care plan)
    - Quality of Life (EQ-5D-3L) at 90-180 post-stroke
        - Anxiety/Depression domain
- Patient level data were linked to Queensland Government held hospital admission and emergency data
    - Comorbidities - ICD-10 codes from last 5 years

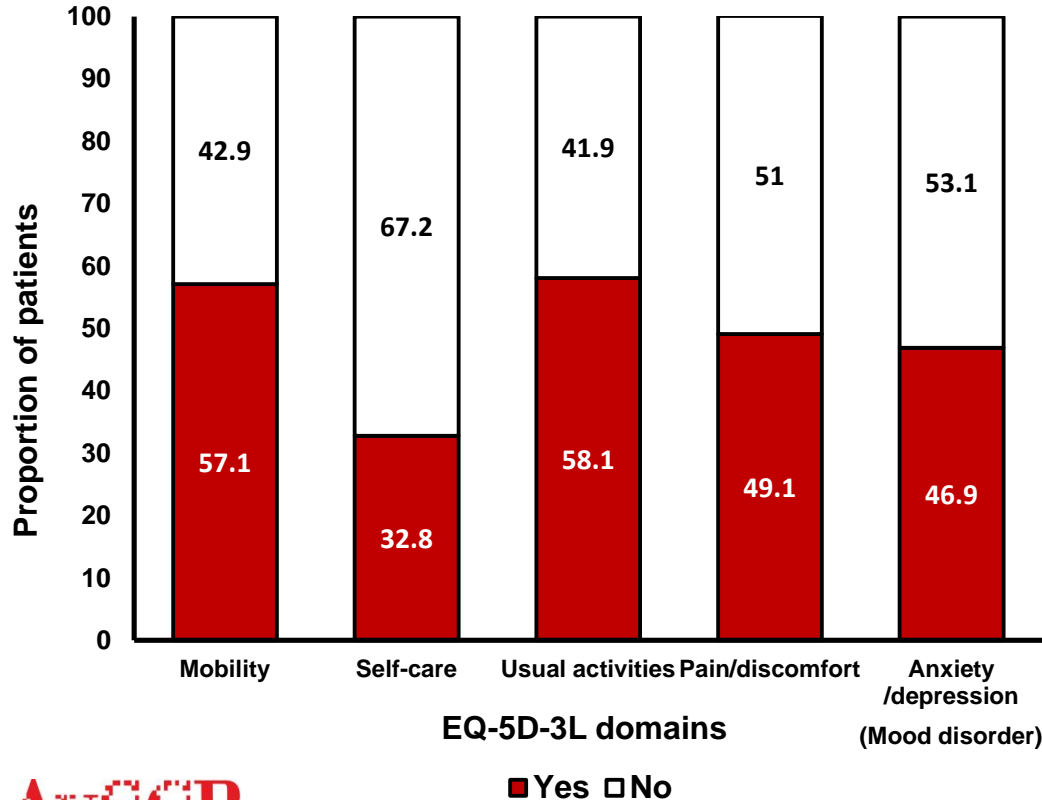# Obtaining cross-jurisdictional data linkage takes time
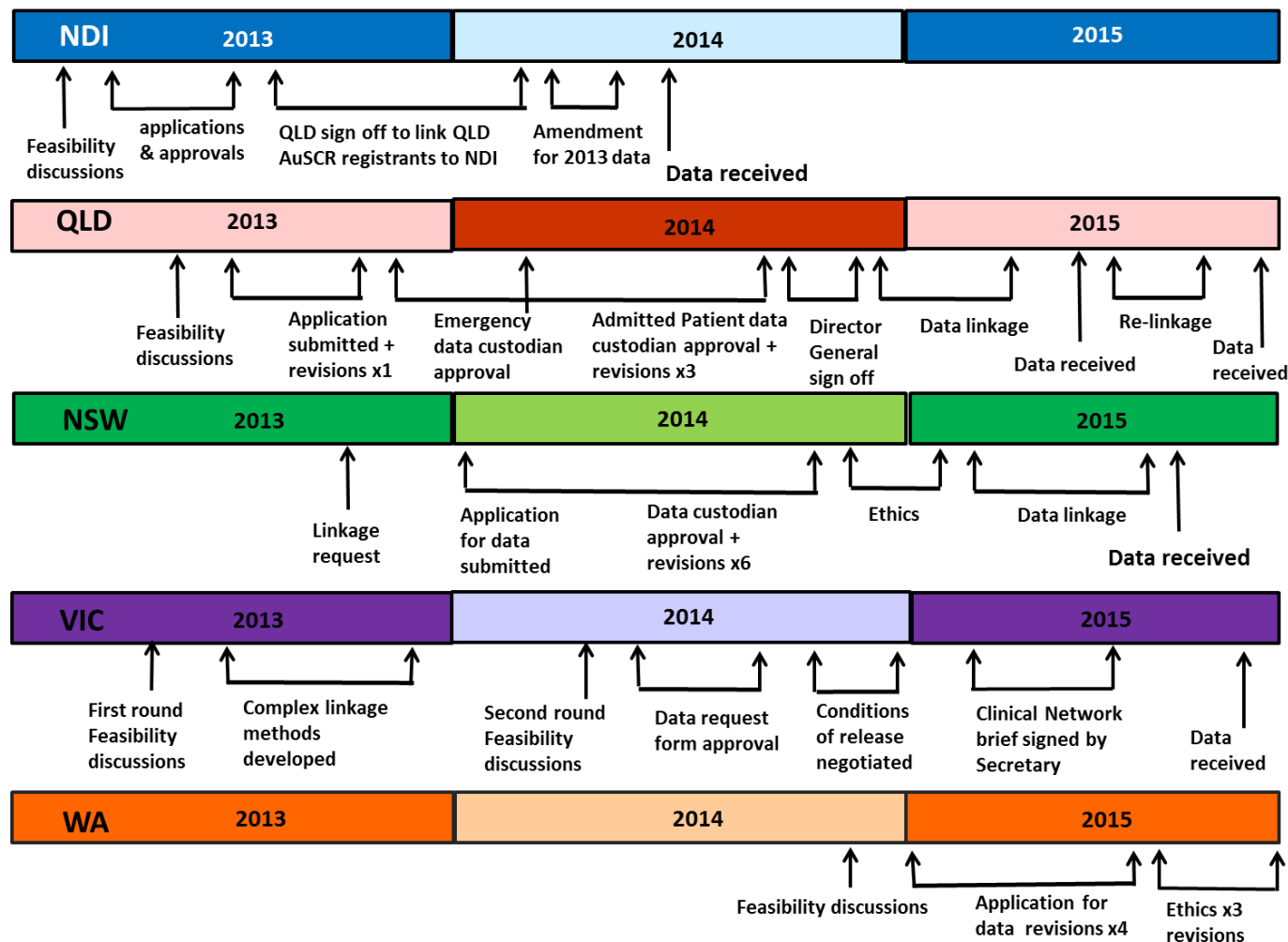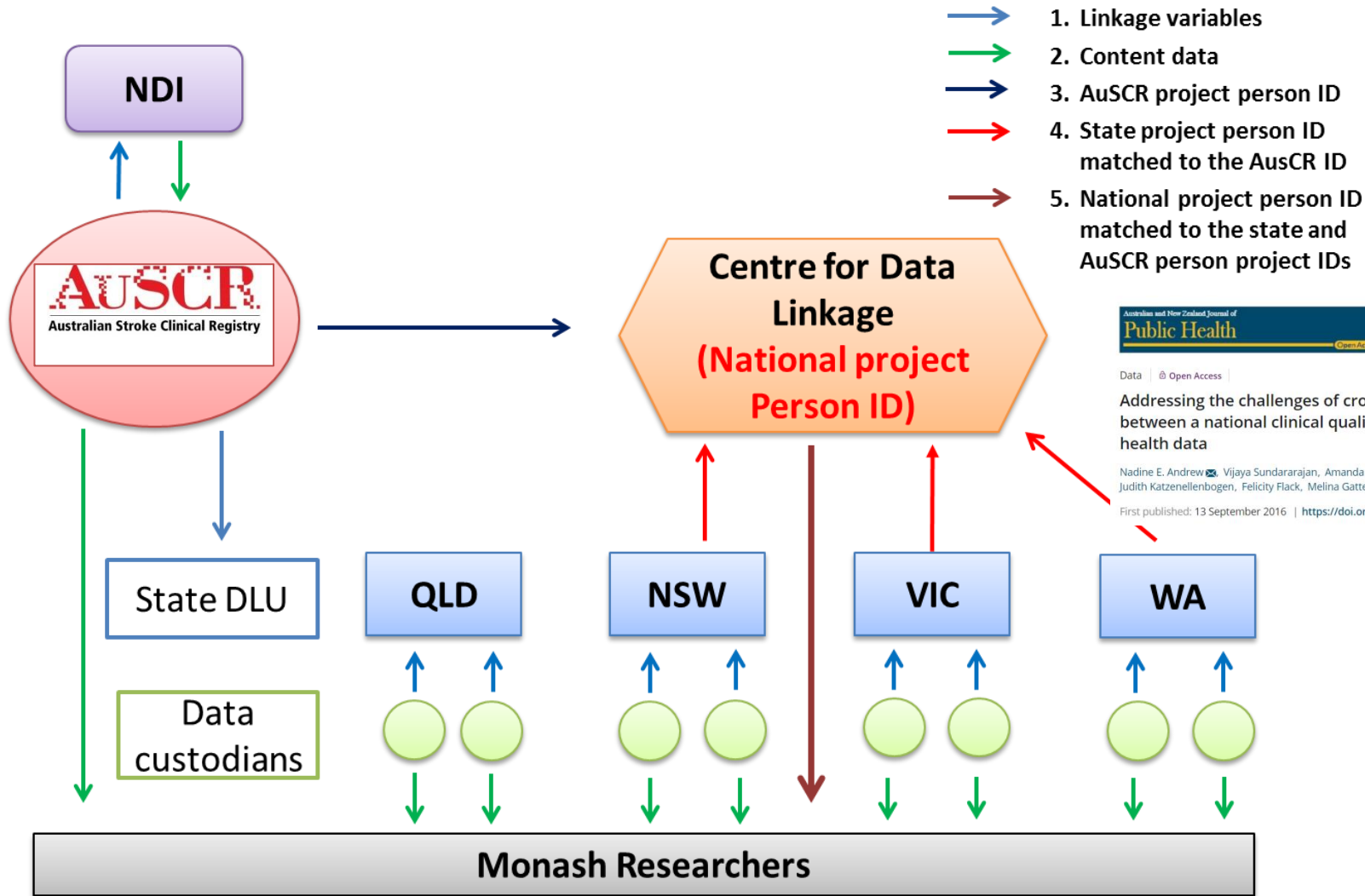
Result: ~50% self-reported issues with mood post-stroke

N=2853; median age 74; 45% female; 60% ischaemic stroke

Visual analogue scale

Normative population aged 70-79 years
83

AuSCR QLD
No anxiety/depression
80

AuSCR QLD
Yes anxiety/depression
60

100 — Best imaginable health state

0 — Worst imaginable health state (0=Died)

48
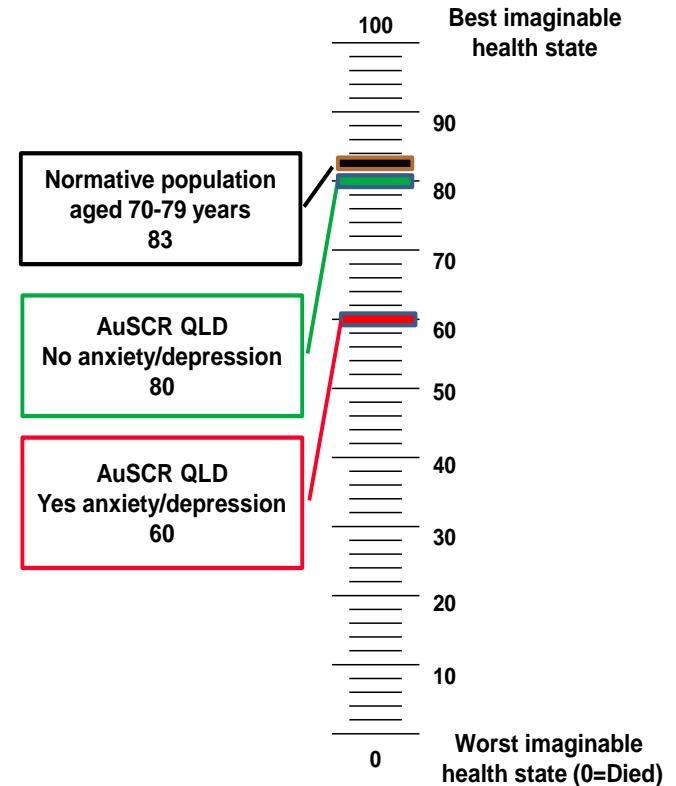
Predicted probability of issues with anxiety & depression by age and comorbidities

A 35 year old who has 10 comorbidities has ~80% chance of reporting anxiety or depression
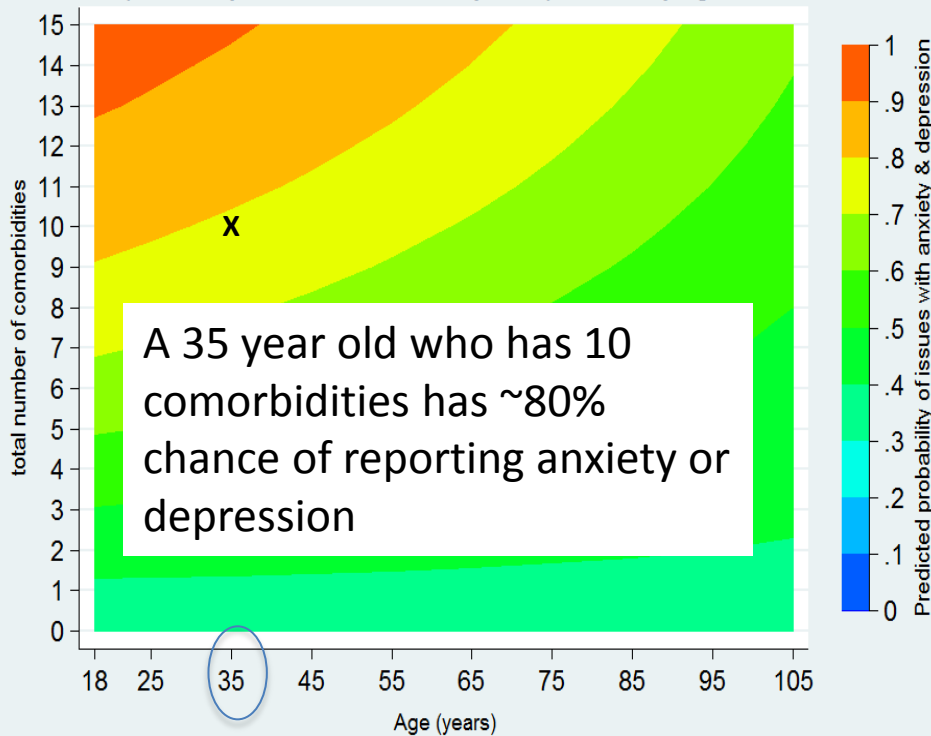
The curvature shows how the effect of age on the predicted probability of reporting anxiety or depression differs across levels of comorbidities.

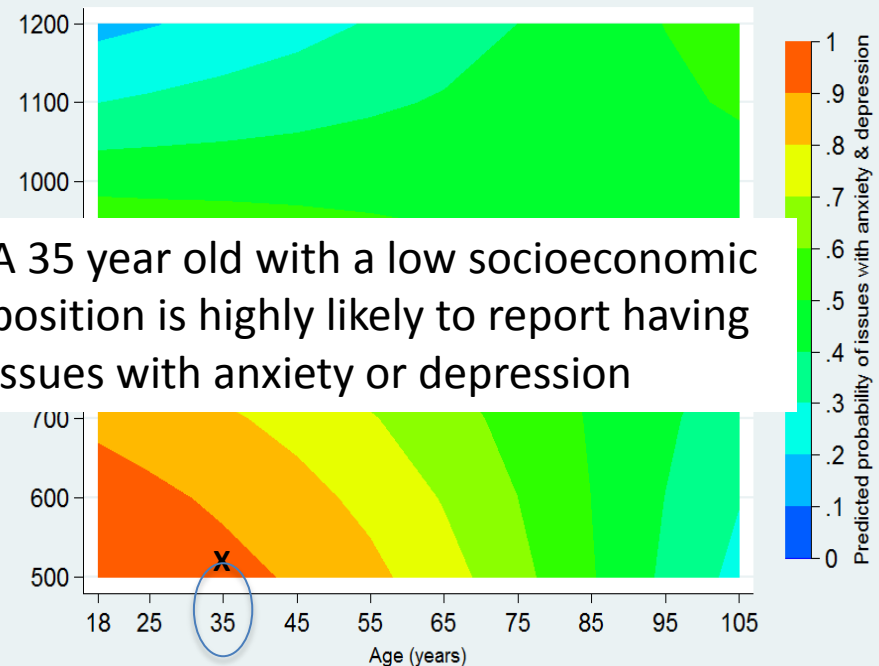Two-way contour to graphs of predictions from statistical models

Predicted probability of issues with anxiety & depression by age and ses

A 35 year old with a low socioeconomic position is highly likely to report having issues with anxiety or depression

Summary of findings

- Main factors associated with self-reported anxiety or depression on EQ-5D-3L at 90-180 days post-stroke
  - Previous anxiety or depression
  - Hemiplegia
  - Dementia
  - Low socioeconomic status
  - Smoking
- No difference for quality of care received in hospital between those who self-reported anxiety or depression on EQ-5D-3L and those who had reported no issues at 90-180 days post-stroke

The next challenges

BEFORE event

Stroke event

AFTER event

A comprehensive view of the patient journey

Summary

- Registries have an essential role in facilitating the monitoring of healthcare to improve patient outcomes
  - No change in patient outcomes without feedback loop & further benefit from facilitated QI programs (important 'registry' science)
- Must keep data minimal and focussed on clinical usefulness
- Lack visibility and impact if not contributing to academic debate
- Has advantages since stroke is complex and we lack evidence for many aspects of care and longer term outcomes
- Can explore a range of important research questions using various designs

Success factors

- Important platform for health services research if designed well

- Clear governance and policies for supporting research

- Data optimisation though linkage

- Foresight in seeking consent to contact registrants for future research and undertake data linkage

- Strong clinical and academic leadership

- Grants in the early years provided the opportunities for research in a range of applied and technical areas while building capacity

- Valued as an important resource for clinical care and research

AuSCR
Australian Stroke Clinical Registry

For further information

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STROKE TELEMEDICINE

Australian Stroke Clinical Registry