

# **Living Guidelines**

# **Methods and Processes**

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# Release History

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# Distribution

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Draft	1.0	1 December 2018	Tari Turner, Per Olav Vandvik
Revised draft	1.1	14 January 2019	National and international experts

## **Background**

Translating research to clinical practice is challenging. Trustworthy clinical practice recommendations that are based on reliable and up to date systematic reviews are one important knowledge translation tool. However, systematic reviews and guidelines often struggle to deliver timely and trustworthy recommendations in response to increasing volume of new evidence.

The possibility of a living evidence approach has only recently been within reach, due to a number of technological and data-related innovations, such as online platforms, linked data, and machine learning. Concurrently, research groups are embracing larger collaborations, open and shared data, and the growth of the citizen science movement, opening up the possibility of communities with a common interest maintaining high value datasets and associated Living Systematic Reviews and guideline recommendations.

In 2018-2021, the Australian Government partnered with the Stroke Foundation and Cochrane Australia to revolutionise the rapid translation of health research discoveries into clinical practice by piloting 'living guidelines' for stroke management as outlined in Figure 1.

Since then, the Living Stroke Guidelines has continued. This document outlines the methodology currently used.

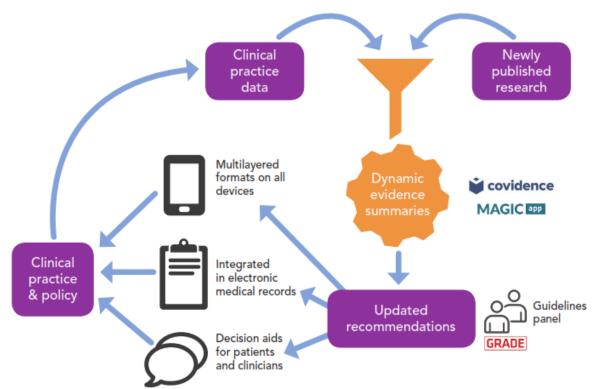


Figure 1: Stroke Living Guidelines Project

## Definition of a Living Guideline

A living guideline is defined as a prospective approach and active processes that use continuous surveillance and a rapid response to incorporate new relevant evidence identified into a clinical guideline<sup>1</sup>.

Practically, this means that living guidelines (and living systematic reviews):

- Are underpinned by continual, active monitoring of the evidence (i.e. at least every three months)
- Rapidly incorporating new important evidence (meaning data, studies or information) that is identified
- Are supported by up-to-date communication about the status of the guideline, and any new evidence being incorporated in the recommendation/s.

#### Who is involved?

The Living Stroke Guidelines is a partnership between the Stroke Foundation and the Australian Living Evidence Collaboration. The initial three-year pilot was funded by the Australian Government through the Medical Research Future Fund. The Guideline brings together researchers, clinicians, academics, consumers, systematic reviewers and guideline developers who work together to identify, review and summarise new research related to stroke care. Clinical experts from Australia and New Zealand are involved.

We also collaborate with the team at the *MAGIC Evidence Ecosystem Foundation* and the team at *Covidence*.

Governance of the project includes a Content Steering Committee and various working groups.

#### **Content Development Working Groups (CDG's)**

Ten content groups covering different topics or disciplines (e.g. acute medical, physiotherapy, nursing) and a consumer group are used to provide content and lived experience expertise. The lead/s for each group (including consumer panel) are involved in the multidisciplinary **Content Steering Committee** who oversee and approve content changes (refer to Appendix 1 for list of members).

The CDG is responsible for:

- 1. Periodically reviewing the literature surveillance topics (PICO's)
- 2. Assist in the evidence surveillance process as required
- 3. Assist reading and appraising included studies and updating the body of evidence for a question using GRADE methodology
- 4. Updating evidence summaries, supporting text and recommendations as needed
- 5. Coordinate relevant subgroups as needed
- 6. Respond to feedback from the public consultation

<sup>&</sup>lt;sup>1</sup> Martínez García L, Pardo-Hernández H, Sanabria AJ, Alonso-Coello P et al. Guideline on terminology and definitions of updating clinical guidelines: The Updating Glossary. J Clin Epidemiol. 2018 Mar;95:28-33.

- 7. Assist in the evaluation of the model as needed
- 8. Providing advice as requested on aspects of the proposed model of living guidelines.

#### **Project Development Team (PDT)**

The PDT manages the day-to-day operations including the systematic review process and knowledge translation components. The PDT includes project staff (Guidelines Coordinator & Knowledge Translation Coordinator) along with program oversight.

All content experts including consumers completed a declaration of Conflicts of Interest form and potential conflicts are managed in line with organisational policy.

#### Process overview

Figure 1 provides an overview of the guideline continuous guideline cycle.

Figure 1 Outline of the living guidelines cycle



Overview of the steps in the cycle include:

- 1. Content working group review and inform the PICO questions to be included. This is reviewed annually.
- 2. On a monthly basis, we monitor the literature for relevant, new evidence:
  - Formal search of databases by project team
  - Informal monitoring from content experts and feedback from clinical community
- 3. New evidence is reviewed by content experts to determine decision to include new evidence and to the potential impact on current recommendations. One of three options will be communicated for each topic:
  - a) No new relevant evidence
  - b) New relevant evidence unlikely to change current recommendations: integrate later

- c) New relevant evidence likely to change current recommendations: rapidly review
- 4. The project team incorporate the new evidence into the existing body of evidence (for decision to rapidly update or finally integrate) and broader context of clinical practice via:
  - Updating the Summary of Findings table (updated meta-analysis may be undertaken for select topics) including updating the certainty of evidence assessment
  - Further research is searched to identify:
    - o Preferences and values of patients on the topic
    - o Prognosis (e.g. baseline risk estimates) if deemed pertinent
    - Economic evaluations on the topic
- 5. The evidence summary (GRADE Evidence to Decision profile) is then updated
- 6. Clinical content experts and people with relevant lived experience (identified from Guidelines Consumer Panel) review the updated GRADE profile and draft changes to the recommendation, rationale and practical considerations
- 7. Updated information is considered and approved by multidisciplinary Content Steering Group and circulated for public consultation (minimum one month duration). Feedback is reviewed by project team and content experts and final approval provided by the Content Steering Committee.
- 8. Final updated guideline recommendation(s) are submitted to NHMRC for approval.
- 9. Updated recommendation are then disseminated and implemented as outlined by agreed Knowledge Translation plan.

#### **METHODS**

The Living Stroke Management Guidelines adheres to standards for trustworthy guidelines with an emphasis on patient involvement, management of conflicts of interests, as well as transparent and systematic processes for assessing the quality of evidence and for moving from evidence to recommendations.<sup>2,3,4</sup>

#### Review of questions which underlines the guideline development

Each year the Steering Committee review topics/PICOs involved in the guidelines. Particular attention is taken to review the ratings of importance and ratings of outcomes using experts and clinical data (audit/registry). Topics for undertaking a meta-analysis will be discussed and agreed.

Additional topics are also considered. Additional questions will need strong rationale for inclusion and 'retiring' other topics is also considered.

#### Identification of new evidence

Initial database searches

Monthly searches are undertaken in Pubmed using a broad stroke/TIA search string. Internal investigations using the previous guideline update found >98% of final references will be

<sup>&</sup>lt;sup>2</sup> Laine C, Taichman DB, Mulrow C. Trustworthy clinical guidelines. Annals of internal medicine. 2011;154(11):774-775.

<sup>&</sup>lt;sup>3</sup> Qaseem A, Forland F, Macbeth F, et al. Guidelines International Network: toward international standards for clinical practice guidelines. Annals of internal medicine. 2012;156(7):525-531.

<sup>&</sup>lt;sup>4</sup> 2016 NHMRC Standards for Guidelines. Accessed from https://nhmrc.gov.au/guidelinesforguidelines/standards

identified just using Pubmed as the initial database. Refer to Appendix 2 for workflow used. This broad approach will allow any new trials with relevant population (stroke/TIA) to be considered.

Where PICO questions need to be broadened due to population, separate searches are undertaken using the historical individual search strategy.

Manual screening of RCTs and SRs are undertaken by one member of project team with clearly irrelevant topics initially excluded (e.g. non-human, trials of childhood stroke with age <18 years, non-stroke, studies involving subarachnoid haemorrhage). The evidence coordinator will allocate potential trials to each relevant topic within Covidence with the assistance of the Program Manager as needed.

Potential trials or SRs will then have full text review by two members of the working groups to confirm included new studies at least every 6 months (or when new evidence is deemed by project team to require rapid review).

#### Other sources searched

 The project team will also review any comments by stroke community within MAGIC and will check with content experts if they are aware of any other trials not already identified.

#### **Assess impact of new evidence**

Once a decision has been made to review a topic in response to new trials (either via rapid or slow stream) additional activities are undertaken:

- A search for any updated information on patient values and preferences and economic/resource considerations related to specific topic is undertaken by the project team.
- Prognostic studies are reviewed (if deemed necessary)
- Review comments made about new evidence within MAGIC (or check with experts).

#### **Update GRADE profiles**

Once new evidence has been identified and a decision has been made to update the body of evidence (GRADE profile) the trial/s data will be included for agreed outcomes within MAGIC (or alternatively data extraction and risk of bias undertaken within Covidence), and risk of bias undertaken. GRADE is a systematic and transparent assessment of the following minimum factors:

- Absolute benefit and harms for all patient-important outcomes through structured evidence summaries (e.g. GRADE Summary of Findings tables)
- Quality/certainty of the evidence
- Values and preferences of patients
- Resources and other considerations (e.g. feasibility, applicability, equity)

Each outcome will - if data are available through systematic reviews - include an effect estimate and confidence interval, with a measure of certainty in the evidence, as presented in Summary of Findings tables. If such data are not available narrative summaries will be provided.

Where meta-analysis has been agreed this will be undertaken by the project team in partnership with content experts. If meta-analysis is not undertaken, a narrative description

of the new evidence is provided in the summary tab. This will be completed centrally by the project team.

Patient values and preference literature (where available) are summarised by the project team and discussed with Consumer Panel representatives (email summary and or phone call). Models of seeking input from a wide range of consumers will also be trialled (e.g. survey).

New economic literature (where available) is reviewed and summarised by experts in economic literature.

#### Review and update recommendations and/or background

Draft changes (if any) to the recommendations are made (tracked changes). Changes are reviewed by content experts in coordination with project team.

Practical considerations are concurrently discussed with consumers and stakeholders to ensure it covers areas of importance (including description of interventions).

All aspects of MAGIC are reviewed and updated by the project team including the summary of changes proposed. All experts are invited to review and comment on draft changes with subsequent discussion and sign off by the Content Steering Committee.

Recommendations are rated either weak (conditional) or strong, as defined by GRADE.

If the panel members cannot reach consensus regarding evidence assessment or strength of recommendations, we report any final differences in opinion, with their rationale.

#### **Undertake public consultation**

Draft updates are circulated via existing networks seeking comments. Consultation is a minimum 4 weeks but we aim for 6-8 week duration.

Consultation information is promoted clearly within the MAGICapp along with the InformMe website.

All feedback is reviewed by content experts and agreed changes made. Final content is considered and signed off by the Content Steering Committee.

#### Review and submit for approval by NHMRC

Where minor changes have been made (e.g. increase grading of recommendation, change to wording in rationale, practical considerations which does not change the intent of the information) NHMRC is notified and the information is finalised and published as final. Where major changes have been made (e.g. new recommendations, change to the intent of the recommendation) the relevant documentation is submitted to NHMRC for formal consideration of approval. The decision to define a major versus minor change is made in consultation with the NHMRC.

#### **Dissemination and implementation**

Updates about any changes (background and/or recommendations) are clearly communicated to all relevant stakeholders. A national Knowledge Translation strategy is used with input from experts in implementation science. The strategy and related communications plan outlines recommended national approaches.

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# **Appendix 1: Content Development Group Members**

(Highlighted members are working group leads who make up the Executive Steering Group)

Title	Name	Discipline	Organisation	State	Working Group
A/Prof	Amal Abou-Hamden	Vascular neurosurgery	Royal Adelaide Hospital	SA	Acute Medical
A/Prof	Amanda Patterson	Dietetics	Uni of Newcastle	NSW	Dietetics
Dr	Andrew Gauden	Neurosurgery	Monash Health	VIC	Acute Medical
A/Prof	Andrew Wong	Neurology	Royal Brisbane & Women's Hospital	QLD	Acute Medical
Prof	Anna Ranta	Neurologist	Capital & Coast District Health Board	New Zealand	Acute Medical
Ms	Annie Dent	Speech Pathology		NSW	Speech Pathology
Dr	Annie Winkler	Rehabilitation medicine	Prince of Wales Hospital	NSW	Rehabilitation Medicine
	Ashleigh Glynn	Occupational therapy	Caulfield Hospital, Alfred Hospital	VIC	Occupational therapy
Ms	Aylissa Canning	Nursing	Princess Alexandra Hospital	QLD	Nursing
Prof	Beata Bajorek	Pharmacy	University of Technology	NSW	Acute Medical
Dr	Bindu Joseph	Nursing	Federation University Australia	VIC	Nursing
Mr	Brendon Haslam	Physiotherapy	University of Melbourne	VIC	Physiotherapy
Ms	Brittni Nielsen	Occupational therapy	Caulfield Hospital	VIC	Occupational therapy
Prof	Bruce Campbell	Neurology	The Royal Melbourne Hospital	VIC	Acute Medical
Prof	Caleb Ferguson	Nursing	Western Sydney Uni	NSW	Nursing
Dr	Carl Hanger	Geriatrics	Burwood Hospital	New Zealand	Rehabilitation Medicine
Prof	Carolyn Unsworth	Occupational therapy	Dept of Neuroscience, Monash Uni	VIC	Occupational therapy
Dr	Cecilia Cappelen- Smith	Neurology	Liverpool Hospital	NSW	Acute Medical
Dr	Chloe Mutimer	Acute Medical	Royal Melbourne Hospital	VIC	Acute Medical
Prof	Chris Bladin	Ambulance	Ambulance Victoria	VIC	Acute Medical
Dr	Claire Lynch	Occupational therapy	Australian Catholic University	VIC	Occupational therapy

Prof	Coralie English	Physiotherapy	University of Newcastle	NSW	Physiotherapy
A/Prof	Dana Wong	Neuropsychology	LaTrobe university	VIC	Psychology
	Danielle Gould	Physiotherapy	Eastern Health	VIC	Physiotherapy
Ms	Danielle Sansonetti	Occupational Therapy	ABI Rehabilitation Centre, Caulfield Hospital	VIC	Occupational Therapy
Mr	Danny Kinsella	Nursing	Alfred Hospital	VIC	Nursing
A/Prof	Darshan Ghia	Neurology	FSH and SJOG Subiaco hospitals UWA	WA	Acute Medical
Dr	Davide de Sousa	Physiotherapy	Ryde Hospital	NSW	Physiotherapy
Dr	Dawn Simpson	Physiotherapy	University of Newcastle	NSW	Physiotherapy
Dr	Deirdre Cooke	Occupational therapy	Function for Life		Occupational therapy
Dr	Di Marsden	Physiotherapy	John Hunter Hospital	NSW	Physiotherapy
Dr	Dijana Dragicevich	Speech Pathology	Bloom Healthcare	NSW	Speech Pathology
Prof	Dominique Cadilhac	Program evaluation and health economics	Monash University	VIC	Economics
Ms	Donna Jay	Nursing	Shoalhaven District Memorial Hospital	NSW	Nursing
Dr	Duncan Maddox	Neurology	The Princess Alexandra Hospital	QLD	Acute Medical
Dr	Emily Brogan	Speech pathology	Centre of Research Excellence in Aphasia Recovery and Rehabilitation, Edith Cowan University	WA	Speech Pathology
Dr	Emily Dalton	Occupational therapy	University of Melbourne	VIC	Occupational therapy
	Emily Neal	Speech Pathology	Prince of Wales Hospital	NSW	Speech Pathology
Dr	Emma Finch	Speech pathology	University of Queensland	QLD	Speech Pathology
Prof	Emma Power	Speech Pathology	University of Technology, Sydney	NSW	Speech Pathology
Dr	Emma Schneider	Occupational Therapy	Alfred Health and Swinburne University	VIC	Occupational Therapy
A/Prof	Erin Godecke	Speech pathology	Edith Cowan University	WA	Speech Pathology
Mr	Fahad Shaikh	Nursing	Western Sydney Uni	NSW	Nursing

Dr	Felix Ng	Neurology	Royal Melbourne Hospital	VIC	Acute Medical
Dr	Ferdi Miteff	Interventional Neurology	University of Newcastle	NSW	Acute Medical
Dr	Fiona Simpson	Dietetics	Sydney University	NSW	Dietetics
Dr	Freyr Patterson	Occupational therapy	University of Queensland	QLD	Occupational therapy
Dr	Genevieve Tole	Physiotherapy	Caulfield Hospital	VIC	Physiotherapy
Ms	Gillian Edmonds	Nursing	Fiona Stanley Hospital	WA	Nursing
	Hayley Scott	Occupational therapy	Western Health	QLD	Occupational therapy
Dr	Heidi Janssen	Physiotherapy	Hunter Medical Research Institute	NSW	Physiotherapy
Dr	Henry Zhao	Neurology	Royal Melbourne Hospital	VIC	Acute Medical
Dr	Hilary Madder	Neuro- anaesthesiology	Alfred Hospital	VIC	Acute Medical
Prof	Hugh Grantham	Ambulance	Researcher Curtin University; Flinders Medical centre	SA	Acute Medical
Dr	Ibrahim Abubakar	Pharmacy	Royal Hobart Hospital	TAS	Rehabilitation Medicine
Dr	Ines Serrada	Physiotherapy	UniSA	SA	Physiotherapy
	Jane O'Connell	Occupational therapy	Gold Coast Health	QLD	Occupational therapy
A/Prof	Janet Bray	Nursing	Monash University	VIC	Nursing
Ms	Jaslyn Nash	Occupational therapy	Royal North Shore Hospital	NSW	Occupational therapy
Dr	Jessica Nolan	Physiotherapy	Curtin University	WA	Physiotherapy
Dr	Jo Murray	Speech Pathology	Flinders University	SA	Speech Pathology
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Dr	John Ly	Neurology	Monash Health and Infinite Neurology	VIC	Acute Medical
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Dr	Joosup Kim	Public health research	Monash University	VIC	Economics
Dr	Juan Rois	Rehabilitation	lpswich Hospital	QLD	Rehabilitation Medicine

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Dr	Marie-Claire Smith	Physiotherapy	University of Auckland	New Zealand	Physiotherapy
Prof	Marie-Louise Bird	Physiotherapy	University of Tasmania	TAS	Physiotherapy
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Ms	Michelle Courtney- Harris	Orthoptics	University of technology, Sydney	NSW	Other
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Dr	Simone Dorsch	Physiotherapy	Australian Catholic University	NSW	Physiotherapy
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Prof	Steven Faux	Rehabilitation	St Vincent's Hospital	NSW	Rehabilitation Medicine
Ms	Susan Starr	Speech pathology	St V's Sydney	NSW	Speech Pathology
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Dr	Tenelle Hodson	Occupational therapy	Griffith university	QLD	Occupational Therapy
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	Tiffany Vuong	Dietetics	St George Hospital	NSW	Dietetics
Prof	Tim Kleinig	Neurology	Royal Adelaide Hospital	SA	Acute Medical
Prof	Tissa Wijeratne	Neurology	Western health, Melbourne	VIC	Acute Medical
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Dr	Yash Gawarikar	Neurology	Canberra Region Neurology and Pain Centre	ACT	Acute Medical
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Mrs	Zara Youngblutt	Physiotherapy	St George Hospital	NSW	Physiotherapy
	Ali Reidy	Stroke survivor		NT (remote)	Consumer
	Amy Jennings	Stroke survivor		NSW	Consumer
Dr	Barbara Wolfenden	Stroke survivor		VIC	Consumer
Ms	Brenda Booth	Stroke survivor		NSW	Consumer
Mr	Brian Beh	Stroke survivor		NSW	Consumer
Mr	Brian Mulhern	Stroke survivor		NSW	Consumer
Ms	Christine Owens	Carer (of brother)		USA	Consumer
Mr	Clive Kempson	Stroke survivor		VIC	Consumer
Mr	Duncan Mitchell	Stroke survivor		WA	Consumer
	Elisha Deegan	Stroke survivor		TAS	Consumer
Mr	Eric Knapp	Stroke survivor		NZ	Consumer
Mr	Gary Kagan	stroke survivor		VIC	Consumer
Ms	Hannah Derwent	Stroke survivor		ACT	Consumer
Mrs	Helen Ebzery	Carer (of mum)		VIC	Consumer
Mrs	Jessica D'Lima	Carer (of husband)		VIC	Consumer

Haynes	Carer (of husband)	VIC (Regional)	Consumer
Jo Hardcastle	Carer (of partner)	QLD	Consumer
Jouna Kolose	Stroke survivor	VIC	Consumer
Karen Bayly	Stroke survivor	VIC	Consumer
Kerrie-Anne Teo	Carer (of husband)	ACT	Consumer
Kevin English	Stroke survivor	VIC	Consumer
Kim Beesley	Carer (of daughter)	NSW	Consumer
Kim Draper	Stroke survivor	VIC (Regional)	Consumer
Kylie Head	Stroke survivor and carer (of mum)	NZ	Consumer
Letisha Living	Stroke survivor	QLD	Consumer
Luke Davies	Stroke survivor	VIC (regional)	Consumer
Martin Pace	Stroke survivor	NSW	Consumer
Nichola Browning	Carer (of daughter)	WA	Consumer
Paul Douglas- Haynes	Stroke survivor	VIC (Regional)	Consumer
Priya Sharma	Stroke survivor	NSW	Consumer
Rebecca Moore	Stroke survivor	QLD	Consumer
Rosalynd O'Shannassy	Stroke survivor	NSW (Regional)	Consumer
Sally Byatt	Stroke survivor	NSW	Consumer
Samantha Owen	Stroke survivor	VIC (Rural)	Consumer
Toni Arfaras	Stroke survivor	VIC	Consumer
Tony Finneran	Stroke survivor	NSW	Consumer
	Jo Hardcastle Jouna Kolose Karen Bayly Kerrie-Anne Teo Kevin English Kim Beesley  Kim Draper Kylie Head  Letisha Living Luke Davies Martin Pace Nichola Browning  Paul Douglas-Haynes Priya Sharma Rebecca Moore Rosalynd O'Shannassy Sally Byatt Samantha Owen Toni Arfaras	Jo Hardcastle Carer (of partner)  Jouna Kolose Stroke survivor  Karen Bayly Stroke survivor  Kerrie-Anne Teo Carer (of husband)  Kevin English Stroke survivor  Kim Beesley Carer (of daughter)  Kim Draper Stroke survivor  Kylie Head Stroke survivor  and carer (of mum)  Letisha Living Stroke survivor  Luke Davies Stroke survivor  Martin Pace Stroke survivor  Nichola Browning Carer (of daughter)  Paul Douglas-Haynes  Priya Sharma Stroke survivor  Rebecca Moore Stroke survivor  Rosalynd O'Shannassy  Sally Byatt Stroke survivor  Toni Arfaras Stroke survivor	Jo Hardcastle Carer (of partner)  Jouna Kolose Stroke survivor  Karen Bayly Stroke survivor  Kerrie-Anne Teo Carer (of husband)  Kevin English Stroke survivor  Kim Beesley Carer (of daughter)  Kim Draper Stroke survivor  Kylie Head Stroke survivor  Letisha Living Stroke survivor  Luke Davies Stroke survivor  Nichola Browning Carer (of daughter)  Paul Douglas-Haynes  Priya Sharma Stroke survivor  Rosalynd O'Shannassy  Sally Byatt Stroke survivor  Stroke survivor  Rosalynd Orshannassy  Samantha Owen Stroke survivor  VIC (Regional)  NSW  VIC (Regional)  NSW  Rebecca Moore Stroke survivor  NSW  NSW  Samantha Owen Stroke survivor  VIC (Rural)  VIC (Rural)

**Appendix 2: Literature Surveillance Workflow** 

