Living Guidelines

Methods and Processes

Contents

Release History

Version	Date	Author	Reason	Sections
1.0	1 December 2018	Kelvin Hill	Initial draft	All
1.1	14 January 2019	Kelvin Hill	Updated with initial feedback	All

Distribution

| Copy Type	Version	Issue Date	Issue To
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.

The Australian Government is partnering 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.

This document outlines the methodology being used for the Living Guidelines Project.

Figure 1: Vision for Stroke Living Guidelines Project
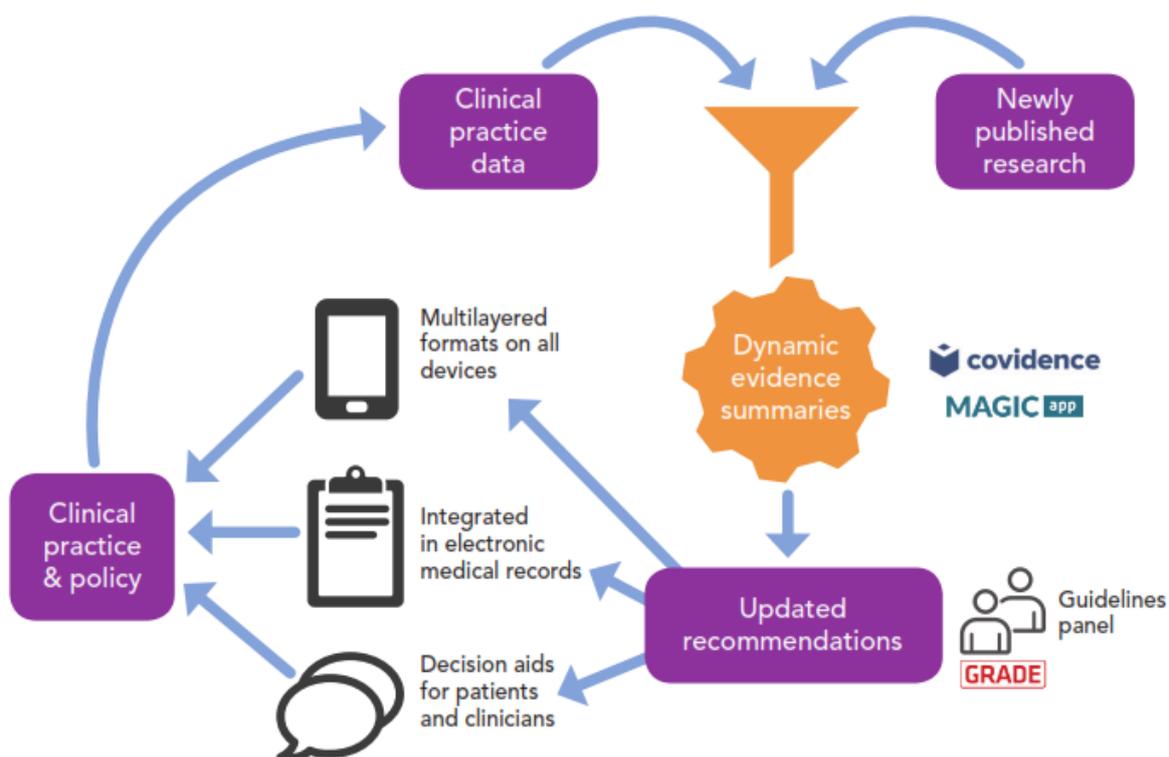
Definition of a Living Guideline

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[1].

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

- Are underpinned by continual, active monitoring of the evidence (i.e. monthly searches)
- 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 Cochrane Australia, funded by the Australian Government through the Medical Research Future Fund. The project brings together researchers, clinicians, academics, consumers, systematic reviewers and guideline developers who will work together to identify, review and summarise new research related to stroke care.

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

Governance of the project includes an Executive Project Group, a Content Development Group (CDG) and the Project Team (refer to Diagram 1 below).

Project Executive Project Group (EPG)

The EPG is responsible for:

- Provide strategic oversight of the development of the guidelines
- Accountable for the performance against the project plan and reporting back to the federal government;
- Provide governance and guidance, around this project, over the course of the project;
- Provide comments on progress reports on the Guidelines Project;
- Provide stewardship of the financial performance of the project against budget;
- Respond to any queries or issues raised by the Project Delivery Team (PDT) and Content Development Group (CDG) and the Project Manager;
- Provide comments and information with regards to the development of the guidelines, for consideration by the project's CDG and the Stroke Foundation; and,
- Providing input into the publications, presentations, and publications in peer reviewed journals and questions received from the public and media.

Membership

- Ms Sharon McGowan, Chief Executive Officer Stroke Foundation (chair)

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[1] 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.

- Professor Bruce Campbell, Chairperson of the Stroke Foundation Clinical Council and the Co- Chair of the Clinical Guidelines for Stroke Management Content Development Group (CDG)
- Associate Professor Coralie English, Co-Chair of the Clinical Guidelines for Stroke Management CDG
- Dr Lisa Murphy, Executive Director Stroke Services, Stroke Foundation
- Mr Kelvin Hill, National Manager Clinical Services, Stroke Foundation
- Dr Tari Turner, Senior Research Fellow on Project Transform, Cochrane Australia
- Associate Professor Julian Elliott, Senior Research Fellow, Cochrane Australia
- Professor Sally Green, Professorial Fellow at Monash University and Co-Director of Cochrane Australia
- Mr Steve McDonald, Co-Director of Cochrane Australia and is leading the Project Transform Guidelines work
- Ms Jennifer Muller, chair Consumer Council Stroke Foundation

Content Development Working Groups

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 Content Steering Committee who oversee and approve content changes (refer to Appendix 1 for list of members).
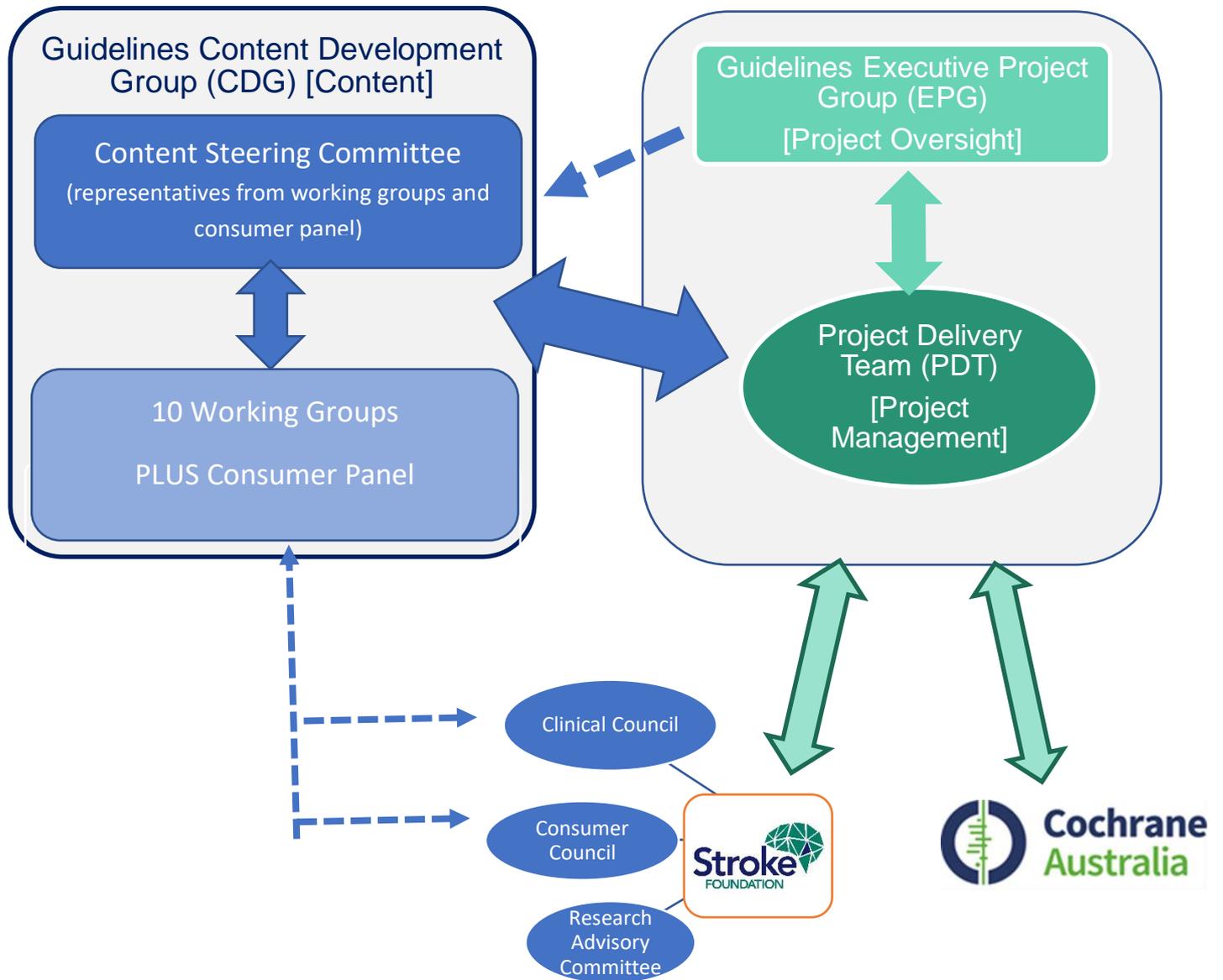
The CDG is responsible for:

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

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 will manage the day-to-day operations including the systematic review process and knowledge translation components to ensure the project is delivered successfully. The PDT will include project staff (Project Coordinator, Evidence Coordinator & Knowledge Translation Coordinator) along with Kelvin Hill (Stroke Foundation) and Tari Turner (Cochrane Australia). Other staff may be included in the PDT during the project as need arises.

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

Diagram 1: Project governance

Guidelines Content Development Group (CDG) [Content]

Content Steering Committee
(representatives from working groups and consumer panel)

10 Working Groups

PLUS Consumer Panel

Guidelines Executive Project Group (EPG)

[Project Oversight]

Project Delivery Team (PDT)

[Project Management]

Clinical Council

Consumer Council

Research Advisory Committee

Stroke FOUNDATION

Cochrane Australia

Process overview

Living Guideline development methodology is evolving and currently there are no established agreed methods but numerous potential approaches. This project will trial and refine a couple of different approaches and will be viewed as a continuous learning process.

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

Figure 1 Outline of the living guidelines cycle
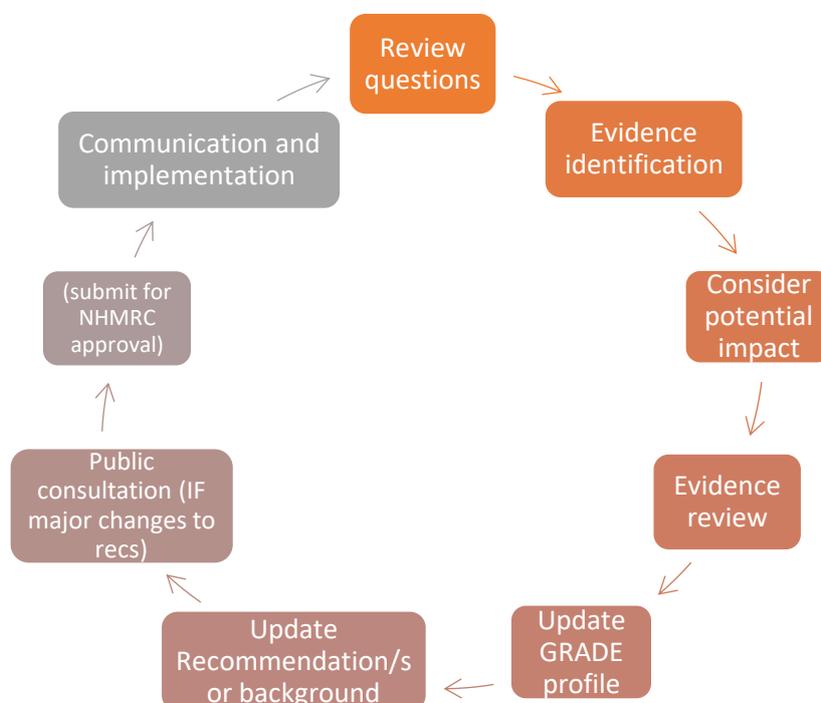
Overview of the steps in the cycle include:

1. Content working group will review and inform the PICO questions to be included. This will be reviewed annually.
2. On a monthly basis, we monitor the literature for relevant, new evidence:
   - Formal search of databases by project team (Pubmed and CENTRAL)
   - Informal monitoring from content experts and feedback from clinical community
   - Review of the Database of Research In Stroke (DORIS) which incorporates new trials identified by comprehensive search conducted by Cochrane Stroke Group
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. Content working group 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)
   - Updating risk of bias assessment
   - Further research will be searched to identify:
     o Preferences and values of patients on the topic

- o Prognosis (e.g. baseline risk estimates) if deemed pertinent
- o Economic evaluations on the topic
5. The evidence summary (GRADE profile) is then updated
6. Clinical content experts, people with relevant lived experience (identified from Guidelines Consumer Panel) and methodologists will review the updated GRADE profile and proposed changes to the recommendation, rationale and practical considerations
7. Updated information will be approved by multidisciplinary Content Steering Group and circulated for public consultation (minimum one month duration). Feedback will be reviewed by project team and content experts. Any changes will be reviewed and approved by Content Steering Group.
8. Final updated guideline recommendation(s) will be submitted to NHMRC for approval.
9. Updated recommendation will be disseminated and implemented as outlined by agreed Knowledge Translation plan.

METHODS

The Stroke Management Guidelines adheres to standards for trustworthy guidelines with an emphasis on patient involvement, strict 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.[2,3,4]

Review of questions which underlines the guideline development

At the commencement of the project and then yearly, the content working groups will review topics/PICOs involved in the guidelines. Particular attention will be taken to review the ratings of importance and ratings of outcomes using experts and clinical data (audit/registry) during the annual face-to-face meeting (national conference). Initially all topics will be updated from the previous search conducted mid-2016. Topics for undertaking a meta-analysis will be discussed and agreed.

Additional topics will be considered by the Content Steering Committee. Additional questions will need strong rationale for inclusion and 'retiring' other topics may need to be considered.

Identification of new evidence

Initial database searches

Monthly searches will be undertaken in Pubmed using a broad stroke/TIA search string (this approach will be tested against the current detailed search strategy used in previous guideline updates -including research type [RCT & SR]). Internal investigations using the previous guideline update found >98% of final references will be identified just using Pubmed as the initial database. Refer to Appendix 1 for workflow used. This broad approach will allow any new trials with relevant population (stroke/TIA) to be considered.

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[2] Laine C, Taichman DB, Mulrow C. Trustworthy clinical guidelines. Annals of internal medicine. 2011;154(11):774-775.

[3] 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.

[4] 2016 NHMRC Standards for Guidelines. Accessed from https://nhmrc.gov.au/guidelinesforguidelines/standards

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 will be undertaken by one member of project team (Evidence Coordinator) 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.

Title and abstracts are then reviewed independently (using Covidence) by two members of the project team with a third person adjudicating if needed.

Potential trials or SRs will then have full text review (lead by Evidence Coordinator) with final confirmation of included new studies by content experts.

Other sources searched

- Cross reference at this time will occur from the DORIS (www.askdoris.org) to ensure no trials are missed.
- 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.

At the end of each month's surveillance numbers of screening/included new trials will be recorded.

The initial approach will search and update all topics. However, several scenarios will be modelled to identify the impact and methods for prioritisation of topics to ensure guideline sustainability. These include:

a) Review of all topics included in a guideline
b) Prioritisation of topics and decision as to which topic has frequent (monthly) surveillance vs less frequent (6-12 months) surveillance

To determine high priority topics living systematic reviews should meet all three of the following criteria will be met[5]:

1. The review question is a priority for decision making: is the question of sufficient importance to health decision-making to make the allocation of the necessary resources worthwhile?

2. There is an important level of uncertainty in the existing evidence. The review is only likely to be useful where the current body of evidence does not provide an adequate basis for the answer to the review question to be considered certain and settled. Review conclusions with a high level of certainty are those with the GRADE rating of 'high', and are not likely to change with the addition of new evidence.

3. There is likely to be emerging evidence that will impact on the conclusions. Continuous reviews are appropriate when the research field is moving relatively quickly and new evidence is being generated which would influence policy and practice.

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[5] Cochrane Living Systematic Reviews: Interim guidance for pilots (version 0.3, 21 April 2017)

Assess impact of new evidence

Each time the searches are run and screened, there may or may not be new studies identified, and they may or may not impact on the recommendation/s (e.g. change in strength or direction or if a new recommendation is needed).

To assist with this step, content experts will be sent an email with new trial/s identified asking to firstly confirm trial inclusion and then secondly seeking comments on the potential impact of the trials on the current recommendations. We propose decision is needed at this stage with experts (either chairs or group of experts relevant to each topic) to agree if new trial is likely to have a significant impact on current recommendation by reflecting on three questions below

Experts to consider the following questions (based on Garner 2016[6] and Agbassi 2014[7]) to judge the impact of new evidence:

- For key outcomes, does the new evidence change the overall direction of the effect, substantially reduce uncertainty (e.g. make a previously non-statistically significant effect now significant), have a clinically meaningful impact on the size of the effect? Does the new evidence effect the overall balance of benefits and harms to a clinically important extent?
- Is there any additional information in the new evidence that is not covered in the existing evidence-base (new relevant populations or subgroups, variations in intervention type or dose, new outcomes)?
- Is there a good reason (e.g., new stronger evidence will be published soon, changes to current recommendations are not clinically important) to postpone updating the guideline?

There are three possible scenarios:

1. No new evidence (studies, data, information) identified = communicate no changes

2. New evidence, but no important impact on review findings = integrate later (slow stream)

3. New evidence, important impact on review findings = integrate rapidly (rapid stream)

If new evidence is deemed to have little or no impact it will be put on a 'slow stream' where no immediate action is taken and await subsequent monthly surveillance (but will be actioned within 6 months). If new evidence is deemed to potentially have moderate or major impact on the recommendations a 'rapid stream' is initiated. It will be imperative to regularly communicate (i.e. monthly) the status of each of the guidelines topics. If a rapid stream is used this would include communication of new evidence and integration is in progress.

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 Evidence Coordinator.
- Prognostic studies are reviewed (if deemed necessary)
- Economic studies are searched
- Review comments made about new evidence within MAGIC (or check with experts).

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[6] Garner, Hopewell, Chandler, MacLehose, Schunemann, Akl, et al. When and how to update systematic reviews: consensus and checklist. BMJ, 354; i3507.

[7] Agbassi, Messersmith, McNair, Brouwers. Priority-based initiative for updating existing evidence-based clinical practice guidelines: the results of two iterations. Journal of Clinical Epidemiology, 67:12; 1335-1342

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 will be imported within MAGIC and reviewed (or alternatively data extraction and risk of bias undertaken within Covidence), data extracted for outcomes and risk of bias undertaken. GRADE is a systematic and transparent assessment of the following factors:

- Absolute benefit and harms for all patient-important outcomes through structured evidence summaries (e.g. GRADE Summary of Findings tables)
- Quality 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 Evidence Coordinator in partnership with content experts. If meta-analysis is not undertaken, a narrative description of the new evidence is provided in the summary tab.

An analysis of different approaches to data extraction will be undertaken to test the validity and acceptability of various approaches: 1. Risk of bias/data imports done centrally by project team 2. Risk of bias/data imports done by experts 3. Combination (cross check)

Patient values and preference literature (where available) will be 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) will be reviewed by experts in economic literature.

With support of the Evidence Coordinator, content experts will update (with track changes to show differences) content within MAGIC. Data related to patient value and preferences will be entered by the Evidence Coordinator who will also make changes suggested by economic experts.

Review and update recommendations and/or background

Draft changes (if any) to the recommendations will be made (tracked changes) by content expert/s. Changes to the rationale will be drafted by content experts in coordination with project team.

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

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

Recommendations will be rated either weak or strong, as defined by GRADE.

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

Undertake public consultation

Draft updates will be circulated via existing networks seeking comments. Consultation will be for 6 week duration. Automatic email notification for consumers and clinicians when update draft recommendation will be trialled.

Consultation information will be promoted clearly with the MAGICapp along with the InformMe website.

All feedback will be reviewed by content experts and agreed changes made. Final content will be 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 will be notified and the information will be 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 will be submitted to NHMRC for formal consideration of approval. The decision to define a major versus minor change will be made in consultation with the NHMRC.

Dissemination and implementation

Updates about any changes (background and/or recommendations) will be clearly communicated to all relevant stakeholders. A national Knowledge Translation strategy will be developed and utilised with input from experts in implementation science. The strategy and related communications plan will outline recommended national approaches. Specific strategies will be implemented and evaluated with end users during the project.

Other references

Andrews JC, Schunemann HJ, Oxman AD, et al. GRADE guidelines: 15. Going from evidence to recommendation-determinants of a recommendation's direction and strength. Journal of clinical epidemiology. 2013;66(7):726-735.

Balshem H, Helfand M, Schunemann HJ, et al. GRADE guidelines: 3. Rating the quality of evidence. Journal of clinical epidemiology. 2011;64(4):401-406.

Guyatt GH, Oxman AD, Kunz R, et al. Going from evidence to recommendations. Bmj. 2008;336(7652):1049-1051.

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Guyatt GH, Oxman AD, Vist GE, et al. GRADE: an emerging consensus on rating quality of evidence and strength of recommendations. Bmj. 2008;336(7650):924-926.

Kristiansen A, Brandt L, Alonso-Coello P, et al. Development of a novel, multilayered presentation format for clinical practice guidelines. Chest. 2015;147(3):754-763.

Siemieniuk RA, Agoritsas T, Macdonald H, Guyatt GH, Brandt L, Vandvik PO. Introduction to BMJ Rapid Recommendations. BMJ 2016;354:i5191

Vandvik PO, Brandt L, Alonso-Coello P, et al. Creating clinical practice guidelines we can trust, use, and share: a new era is imminent. Chest. 2013;144(2):381-389.

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
Assoc Prof	Andrew Wong	Neurology	Royal Brisbane & Women's Hospital	Queensland	Acute Medical
Ms	Anne-Louise (Annie) Dent	Speech Pathology	RPA Hospital	New South Wales	Speech Pathology
Dr	Annie McCluskey	Occupational Therapy	Faculty of Health Sciences	New South Wales	Occupational Therapy
A/Prof	Beata Bajorek	Pharmacy	University of Technology	New South Wales	Rehabilitation Medicine
Prof	Bruce Campbell	Neurology	The Royal Melbourne Hospital	Victoria	Acute Medical
Dr	Caleb Ferguson	Nursing	Western Sydney Uni	New South Wales	Nursing
Dr	Cecilia Cappelen-Smith	Neurology	Liverpool Hospital.	New South Wales	Acute Medical
A/Prof	Coralie English	Physiotherapy	University of Newcastle	New South Wales	Physiotherapy
Ms	Danielle Sansonetti	Occupational Therapy	ABI Rehabilitation Centre, Caulfield Hospital	Victoria	Occupational Therapy
Mr	Danny Kinsella	Nursing	Alfred Hospital	Victoria	Nursing
Dr	Darshan Ghia	Neurology	FSH and SJOG Subiaco hospitals	Western Australia	Acute Medical
Mr	Davide de Sousa	Physiotherapy	Ryde Hospital	NSW	Physiotherapy
A/Prof	Deborah Hersh	Speech Pathology	Edith Cowan University	Western Australia	Speech Pathology
Dr	Di Marsden	Physiotherapy	John Hunter Hospital	New South Wales	Physiotherapy
Ms	Dijana Dragicevich (Wolffram)	Speech Pathology	Royal North Shore Hospital	New South Wales	Speech Pathology
Prof	Dominique Cadilhac	Program evaluation and health economics	Monash University	Victoria	Economics
Ms	Elizabeth Lynch	Physiotherapy	University of SA	South Australia	Physiotherapy

Assoc Prof	Emma Power	Speech Pathology	University of Technology, Sydney	New South Wales	Speech Pathology
Ms	Emma Schneider	Occupational Therapy	Caulfield Hospital	Victoria	Occupational Therapy
Assoc Prof	Erin Godecke	Speech pathology	Edith Cowan University	Western Australia	Speech Pathology
Dr	Ferdinand Miteff	Interventional Neurology	University of Newcastle	New South Wales	Acute Medical
Dr	Fiona Simpson	Dietetics	Sydney University	New South Wales	Dietetics
Ms	Genevieve Hendrey	Physiotherapy	Caulfield Hospital	Victoria	Physiotherapy
Dr	Heidi Janssen	Physiotherapy	Hunter Medical Research Institute	New South Wales	Physiotherapy
Prof	Hugh Grantham	Ambulance	Researcher Curtin University; Flinders Medical centre	South Australia	Acute Medical
Assoc Prof	Janet Bray	Nursing	Monash University	Victoria	Nursing
Ms	Jo James	Dietetics	Flinders Medical Centre	South Australia	Dietetics
Ms	Jo Murray	Speech Pathology	Flinders University	South Australia	Speech Pathology
Ms	Jodie Marquez	Physiotherapy	University of Newcastle	New South Wales	Physiotherapy
Prof	Jonathan Golledge	Vascular Surgery	Townsville Hospital	Queensland	Acute Medical
A/Prof	Jonathan Knott	Emergency Medicine	Royal Melbourne Hospital / Uni Melbourne	Victoria	Acute Medical
Dr	Joosup Kim	Public health research	Monash University	Victoria	Economics
Dr	Juan Rois	Rehabilitation	Ipswich Hospital	Queensland	Rehabilitation Medicine
Ms	Judy Martineau	Dietetics	Wesley Hospital	Queensland	Dietetics
Mr	Karl Schurr	Physiotherapy	Bankstown-Lidcombe Hospital	New South Wales	Physiotherapy
Dr	Kate Laver	Occupational Therapy	Flinders University	South Australia	Occupational Therapy
Ms	Kelly Coughlan	Nursing	SVHA & ACU Nursing Research Institute	New South Wales	Nursing

Ms	Kylie Wall	Speech Pathology	University of Queensland	Queensland	Speech Pathology
Mr	Lachlan Parker	Ambulance	Queensland Ambulance Service	Queensland	Acute Medical
Dr	Lauren Sanders	Neurology	St Vincent's Hospital	Victoria	Acute Medical
Prof	Maree Hackett	Psychology	The George Institute for Global Health	New South Wales	Psychology
A/Prof	Melinda Truesdale	Emergency Medicine	Royal Melbourne Hospital	Victoria	Acute Medical
Dr	Nadine Andrew	Physiotherapy	Monash University	Victoria	Physiotherapy
Dr	Natalie Ciccone	Speech Pathology	Edith Cowan University	Western Australia	Speech Pathology
Dr	Nawaf Yassi	Neurology	Royal Melbourne Hospital	Victoria	Acute Medical
Assoc Prof	Petrea Cornwell	Speech Pathology	Menzies Health Institute	Queensland	Speech Pathology
Dr	Philip M.C. Choi	Neurology	Box Hill Hospital	Victoria	Acute Medical
Assoc Prof	Prue Morgan	Physiotherapy	Monash University	Victoria	Physiotherapy
Ms	Sandra Lever	Nursing	Ryde Hospital	New South Wales	Nursing
Prof	Sandy Middleton	Nursing	SVHA & ACU Nursing Research Institute	New South Wales	Nursing
Ms	Sarah Kuhle	Nursing	Redcliffe Hospital	Queensland	Nursing
Ms	Simeon Dale	Nursing	SVHA & ACU Nursing Research Institute	New South Wales	Nursing
A/Prof	Stacey George	Occupational Therapy	Flinders University	South Australia	Occupational Therapy
Assoc Prof	Stacey Jankelowitz	Neurology	University of Sydney	New South Wales	Acute Medical
Assoc Prof	Steven Faux	Rehabilitation	St Vincent's Hospital	New South Wales	Rehabilitation Medicine
Prof	Thanh Phan	Neurology	Monash Medical Centre	Victoria	Acute Medical
Assoc Prof	Tim Kleinig	Neurology	Royal Adelaide Hospital	South Australia	Acute Medical
Dr	Lisa Murphy	NSF Policy	NSF	Victoria	Other
Mr	Wayne Loudon	Ambulance	Ambulance Metro North - QLD	QLD	Acute Medical
Dr	Yash Gawarikar	Neurology	Calvary Hospital	ACT	Acute Medical

Dr	Amal Abou-Hamden	Vascular neurosurgery	Royal Adelaide Hospital	SA	Acute Medical
Ms	Amanda Patterson	Dietetics	Uni of Newcastle	NSW	Dietetics
Dr	Dana Wong	Neuropsychology	LaTrobe university	VIC	Psychology
Ms	Donna Jay	Nursing	Shoalhaven District Memorial Hospital	NSW	Nursing
Dr	Emma Finch	Speech pathology	University of Queensland	QLD	Speech Pathology
Assoc Prof	John Laidlaw	Neurosurgery	Royal Melbourne Hospital	VIC	Acute Medical
Ms	Kate Jaques	Nursing	Mater Hospital	QLD	Nursing
Dr	Kate Scrivener	Physiotherapy	Macquarie Uni	NSW	Physiotherapy
Ms	Katie Cox	Psychology	George Institute for global health	NSW	Psychology
Ms	Kerry Boyle	Nursing	Hunter New England Health, Stroke service	NSW	Nursing
Ms	Laura Jolliffe	Occupational therapy	LaTrobe Uni	VIC	Occupational Therapy
Ms	Lesley MacDonald-Wicks	Dietetics	Uni of Newcastle	NSW	Dietetics
Dr	Lyndal Hickey	Social Work	Dept Health and Human Services	VIC	Other
Ms	Michelle Courtney-Harris	Orthoptics	University of technology, Sydney	NSW	Other
Ms	Miia Rahja	Public health research	Flinders University	SA	Occupational Therapy
Ms	Natalie Fini	Physiotherapy	Uni Melb	VIC	Physiotherapy
Prof	Natasha Lannin (Tash)	Occupational therapy	La Trobe Uni	VIC	Occupational Therapy
Prof	Nigel Stocks	General Practice	Adelaide Uni	SA	Rehabilitation Medicine
Ms	Nikki Mitchell	Nursing	RPA	NSW	Nursing
Prof	Peter Mitchell	Neuro radiology	Royal Melbourne Hospital	VIC	Acute Medical
Dr	Ramesh Sahathevan	Neurology	Ballarat Health Service	VIC	Acute Medical
Dr	Rene Stolwyk	Neuropsychology	Monash University		Psychology
Dr	Sabine Allida	Psychology	The George Institute for Global Health	NSW	Psychology
Dr	Sonia Brownsett	Speech Pathology	QUT	QLD	Speech Pathology

Ms	Susan Starr	Speech pathology	St V's Sydney	NSW	Speech Pathology
Ms	Toni Heinemann	Occupational therapy	Osborne Park	WA	Occupational Therapy
Dr	Tony Bragg	Geriatrics	Shoalhaven District Health	NSW	Rehabilitation Medicine
A/Prof	Anna Ranta	Neurologist	Capital & Coast District Health Board	NZ	Acute Medical
Ms	Barbara Wolfenden	Stroke survivor		VIC	Consumer
Ms	Brenda Booth	Stroke survivor		NSW	Consumer
Mr	Brian Beh	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
Mr	Gregg Oughton	Stroke survivor		WA	Consumer
Ms	Hannah Derwent	Stroke survivor		ACT	Consumer
Mrs	Helen Ebzery	Carer (of mum)		VIC	Consumer
Ms	Jenny Holmes	Carer (of son)		Tas	Consumer
Mrs	Jessica D'Lima	Carer (of husband)		VIC	Consumer
Ms	Joan Douglas-Haynes	Carer (of husband)		VIC	Consumer
Mr	John Popham	Stroke survivor		NSW (Semi rural)	Consumer
Ms	Julie Davey	Stroke survivor		VIC	Consumer
Ms	Karen Bayly	Stroke survivor		VIC	Consumer
Ms	Karen Wyatt	Stroke survivor		VIC	Consumer
Ms	Kathryn Moffat	Carer (of father)		Qld	Consumer
Mr	Kevin English	Stroke survivor		NSW	Consumer
Ms	Kim Beesley	Carer (of daughter)		NSW	Consumer
Ms	Kim Draper	Stroke survivor		VIC (Regional)	Consumer
Ms	Majella Green	Carer (of husband)		VIC	Consumer
Ms	Maryanne Bawden	Stroke survivor		NSW	Consumer
Ms	Meliame Fifita	Stroke survivor		VIC	Consumer
Ms	Natalie Jollow	Carer (of father)		NSW	Consumer
Mr	Paul Douglas-Haynes	Stroke survivor		Vic (Regional)	Consumer

Mr	Peter Eriksen	Stroke survivor		VIC	Consumer
Ms	Priya Sharma	Stroke survivor		NSW	Consumer
Mr	Rod Smith	Stroke survivor		VIC	Consumer
Ms	Sally Byatt	Stroke survivor		NSW	Consumer
Ms	Samantha Owen	Stroke survivor		Vic (Rural)	Consumer
Mr	Setten Stephenson	Stroke survivor		NSW	Consumer
Ms	Shelagh Brennand	Stroke survivor		QLD	Consumer
Mr	Stephen Carpenter	Stroke survivor		Tas	Consumer
Ms	Sue Bowden	Stroke survivor		NSW (Regional)	Consumer
Ms	Toni Arfaras	Stroke survivor		VIC	Consumer

Appendix 2: Literature Surveillance Workflow

PubMed database

Search for Stroke articles

Specific search string for:
- o Economics
- o Patient values

Captured and considered as needed

First cut for obviously irrelevant (e.g. animal studies, laboratory studies)

EndNote

Included

Specific searches for:
- Systematic reviews
- RCTs

Excluded

Excluded

Excluded

Included

Included

Confirm inclusion and assessment of potential impact by content working group

Export to Covidence

Covidence Step 1

Allocate into chapters / topics

Covidence Step 2
Title & abstract screening
Full text screening
(Double screening)

Excluded

Excluded pile 3
Contains Stroke SRs and RCTs not covered in the 89 questions

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