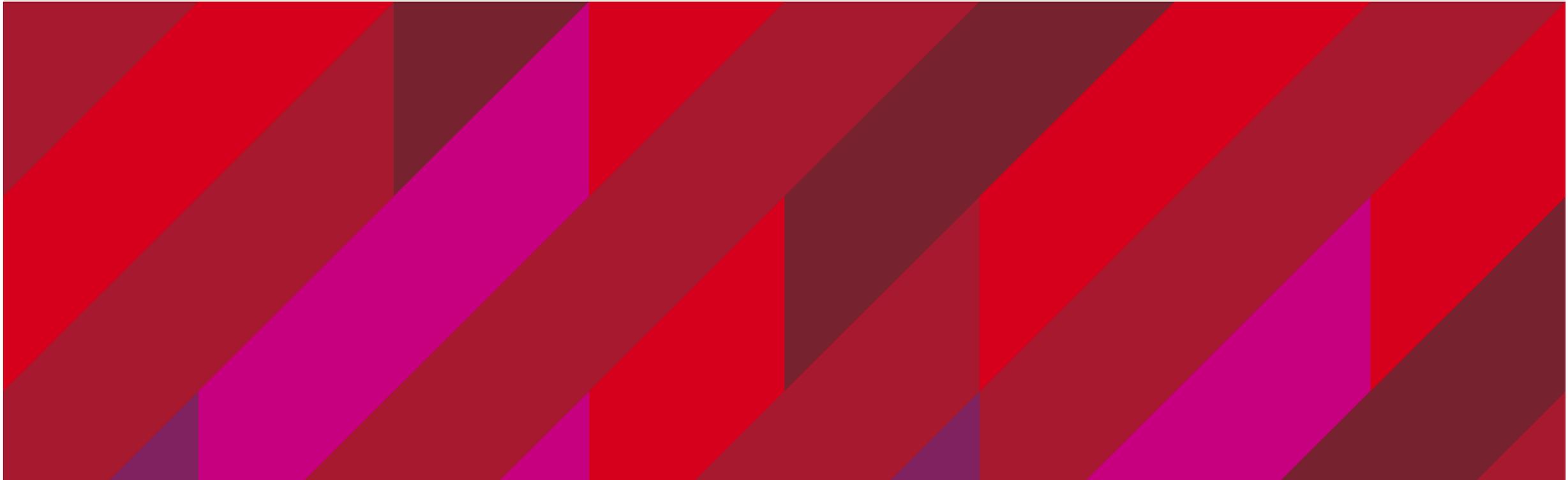# Can 'living' guidelines be made, and if so, will they be used?

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Conflicts of interest

- All authors declare no conflicts of interest

Clinical Practice Guidelines (CPGs)

- Statements that include recommendations intended to optimize patient care that are informed by a systematic review of evidence and an assessment of the benefits and harms of alternative care options.

- Have been a part of the health system since the 1990s in an effort to improve care to patients.

(Institute of Medicine, 2011)

Large scale studies on evidence-based care
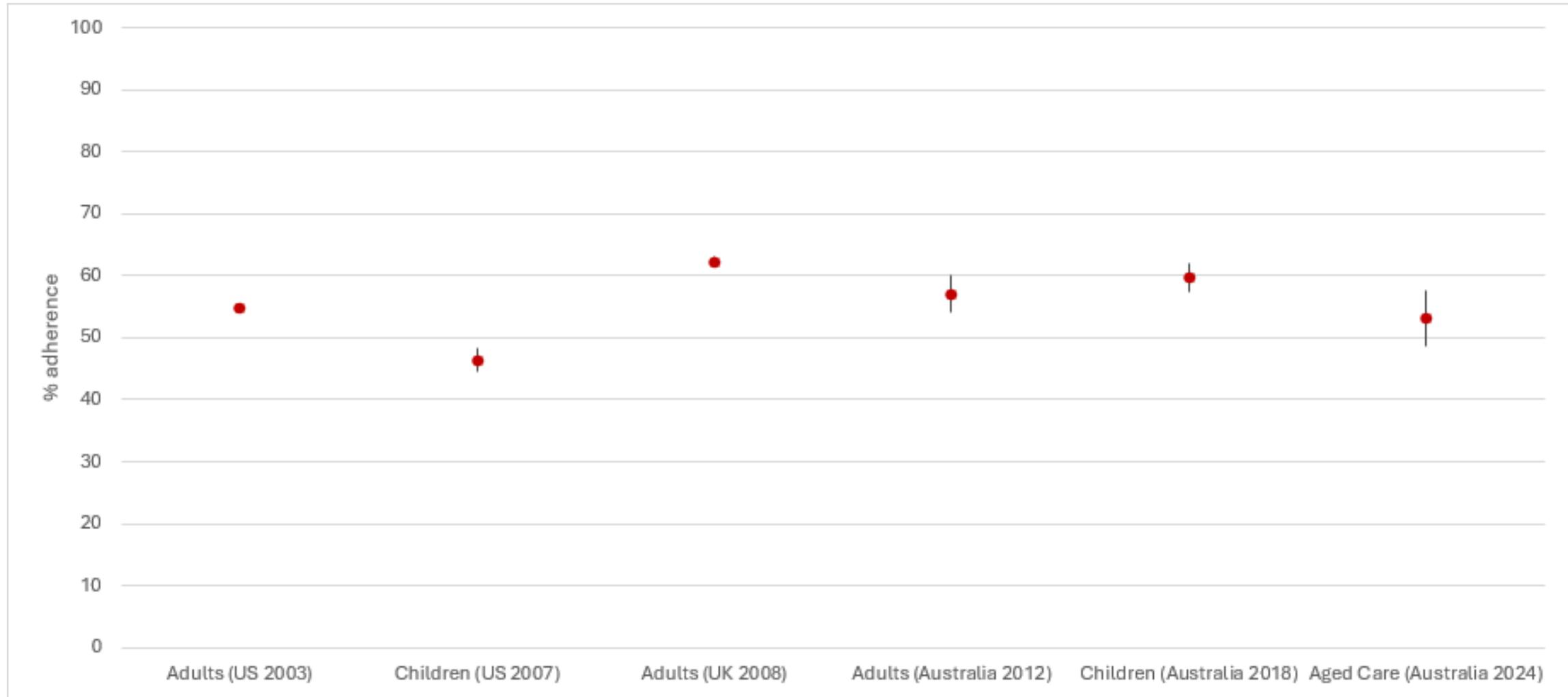
McGlynn 2003, Mangione-Smith 2007, Steel 2008, Runciman 2012, Braithwaite 2018, Hibbert 2024

Usability issues with clinical guidelines

- **Duplication** and **overlap**

- **Inconsistent** structure and content

- **Large document size**

- Large number of **repositories** and **guidelines**

- **Out of date guidelines**

Runciman et al, MJA, 2012

Consider this

Guidelines International Network: **2358 guidelines**

And this ...

- Number of **systematic reviews** published **each day**:

- 11

- Number of **randomised trials** published **each day**:

- 75

Bastian et al. PLOS Medicine 2007

Outdated recommendations

- Recommendations quickly become outdated, with 1 out of 5 recommendations being out of date after 3 years.

- Waiting more than 3 years to review a guideline is potentially too long.

Martínez García, CMAJ, 2014

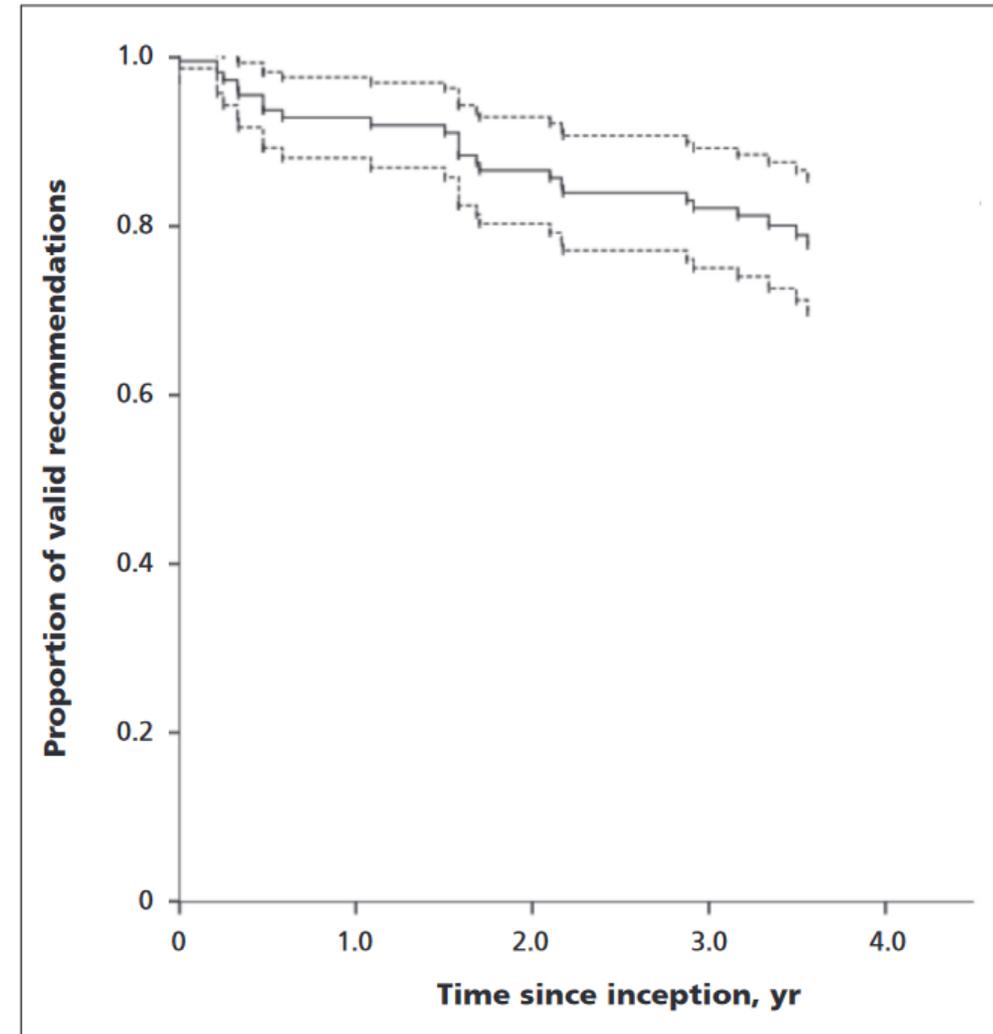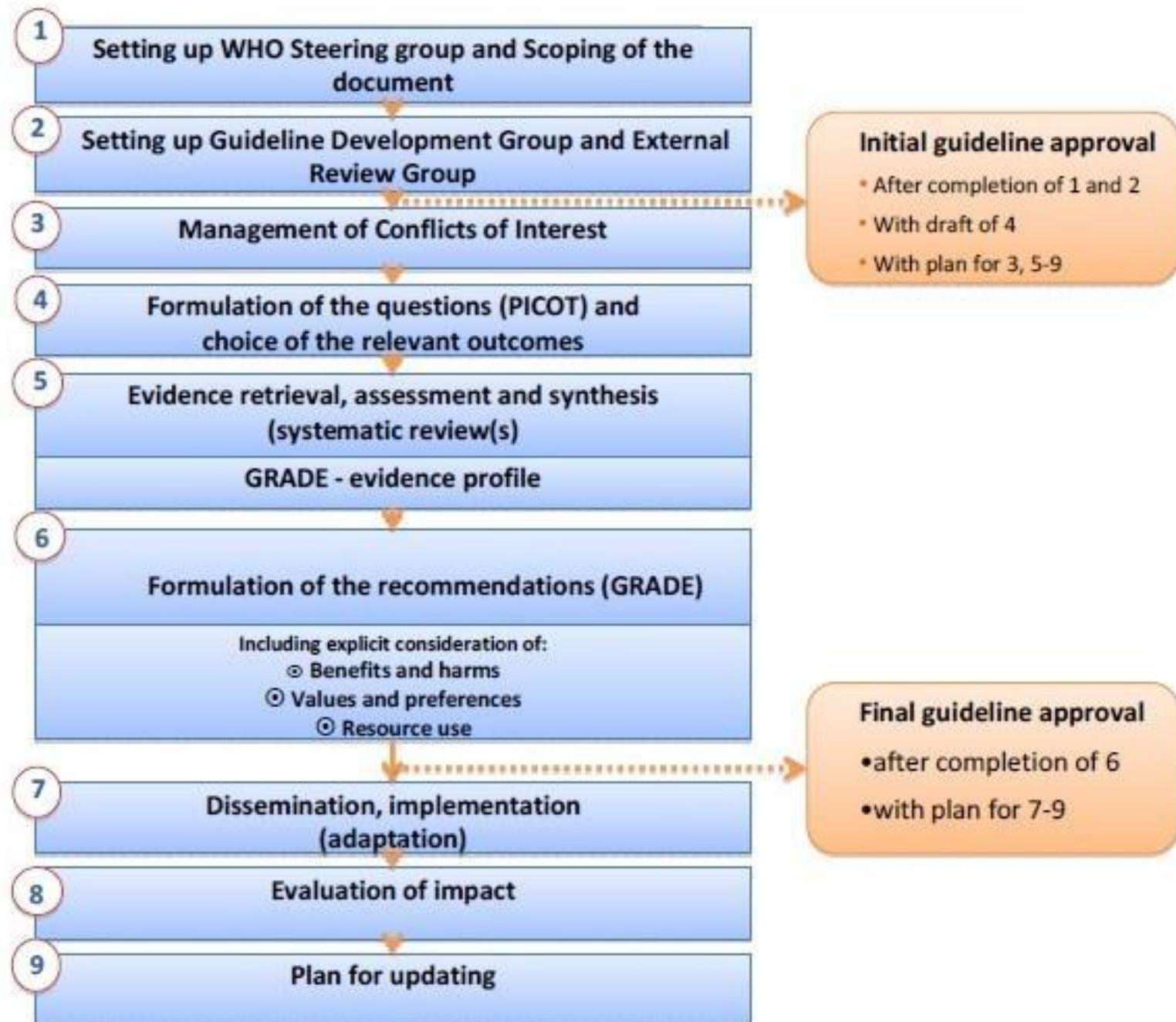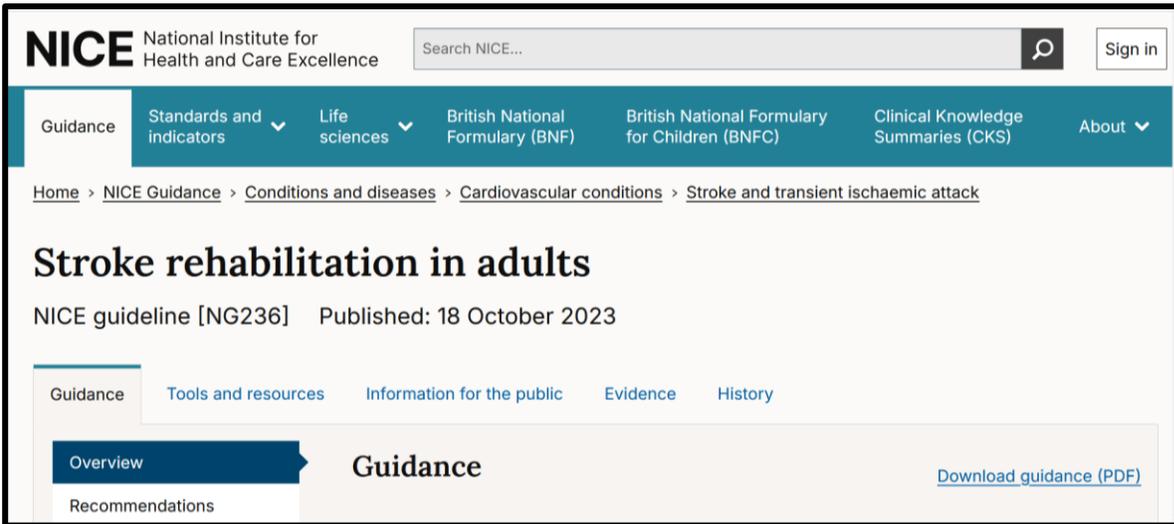https://www.cmaj.ca/content/cmaj/186/16/1211.full.pdf

Figure 2: Kaplan–Meier survival curve (solid line) of clinical guideline recommendations with 95% confidence intervals (dashed lines).

What normally happens

World Health Organisation; Khodambashi, 2014

What normally happens

Stroke rehabilitation in adults

NICE guideline [NG236]   Published: 18 October 2023

This guideline updates and replaces NICE guideline CG162 (2013).

Recommendations

1.1 Organising health and social care for people needing rehabilitation after stroke

1.2 Planning and delivering stroke rehabilitation

1.3 Telerehabilitation

1.4 Providing support and information

1.5 Cognitive functioning

1.6 Psychological functioning

1.7 Fatigue

1.8 Vision

1.9 Hearing

1.10 Mouth care

1.11 Swallowing

1.12 Communication

1.13 Movement

1.14 Managing shoulder pain

1.15 Spasticity

1.16 Self-care

1.17 Long-term health and social support

149 points across all recommendations

https://www.nice.org.uk/guidance/ng236

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149 points across all recommendations

The rate of evidence production is outstripping our ability to produce guidelines

Living guidelines – what's different?

- Frequent surveillance for (often monthly review of) new studies, and

- Updating of individual recommendations (instead of the whole guideline) as relevant new evidence becomes available.

Akl EA et al. J Clin Epidemiol. 2017;91:47-53.

Hill K et al. J Clin Epidemiol. 2022;142:184-93.

Stroke Foundation Living Stroke Guidelines

- In 2017, the Stroke Foundation in Australia (Stroke Foundation) partnered with Cochrane Australia to become one of the first organisations in the world to transition to **living guideline** development methods.

- The 2017 Stroke Foundation guidelines included more than 300 recommendations addressing over 80 clinical topics.

- Supported by the Australian Government in 2018, a pilot study was launched to test the creation of a near real-time, closed-loop evidence system in which global evidence and local data are continually integrated with clinical expertise.

Hill K et al. J Clin Epidemiol. 2022;142:184-93.

English C et al. Int J Stroke. 2019;14(4):337-9.

Stroke Foundation; 2021

Governance and resources

- 108 volunteer clinical experts

- 35 people with lived experience

- 5 project staff (2.5 FTE)

- 11 people on the executive group

Hill K et al. J Clin Epidemiol. 2022;142:184-93.

Guidelines Project Executive Group (project oversight)

Guidelines Content Development Group

Steering Committee (leads from each working group plus NZ representative)

Working groups (10 clinical groups & 1 consumer group)

Writing groups (2-5 clinical experts and 2-3 consumers per topic)

Guideline Delivery Team (program coordination and evidence support)

The Living Guidelines process

- 392 individual recommendations in
- 8 chapters
- 89 topics

Hill K et al. J Clin Epidemiol. 2022;142:184-93.

Process for developing guidelines

https://strokefoundation.org.au/what-we-do/for-health-professionals/living-stroke-guidelines
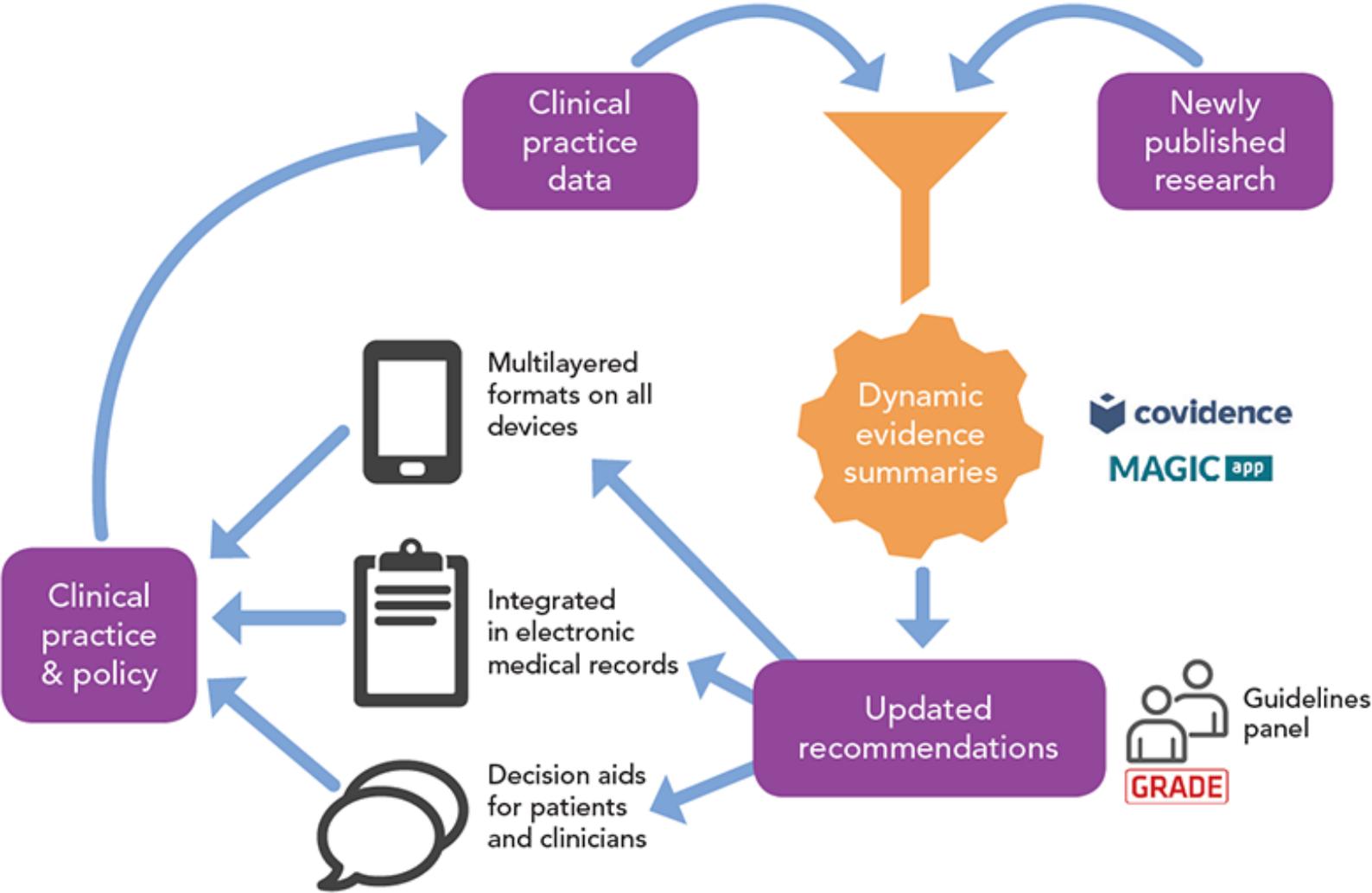
Searches and resources

- The search for new studies retrieved approximately 350 abstracts each month

- 16% potentially relevant to guideline topics

- 2.4% finally included in the guidelines

- The project team - average of 16.8 h per month undertaking screening covering 96 topics.

Hill K et al. J Clin Epidemiol. 2022;142:184-93.

Early assessment and diagnosis (Chapter 2)

https://app.magicapp.org/#/guideline/ojmKvn/section/L0grgj

Transient ischaemic attack 8

Strong recommendation

• All patients with suspected transient ischaemic attack (TIA), i.e. focal neurological symptoms due to focal ischaemia that have fully resolved, should have urgent clinical assessment. (Lavallee et al. 2007 [25]; Rothwell et al. 2007 [26]) *(Refer to the 'Practical Information' section for further useful information)*
• Patients with symptoms that are present or fluctuating at time of initial assessment should be treated as having a stroke and be immediately referred for emergency department and stroke specialist assessment, investigation and reperfusion therapy where appropriate. (Lavallee et al 2007 [25]; Rothwell et al. 2007 [26])
• In pre-hospital settings, high risk indicators (e.g. crescendo TIA, current or suspected AF, current use of anticoagulants, carotid stenosis or high ABCD2 score) can be used to identify patients for urgent specialist assessment. (Lavallee et al. 2007 [25]; Rothwell et al. 2007 [26])

Research evidence (1)   Evidence to decision   Rationale   Practical info   References

Strong recommendation

When TIA patients present to primary care, the use of TIA electronic decision support, when available, is recommended to improve diagnostic and triage decisions. (Ranta et al. 2015 [15])

Research evidence (1)   Evidence to decision   Rationale   Practical info   References

Weak recommendation against

In TIA patients, use of the ABCD2 risk score in isolation to determine the urgency of investigation may delay recognition of atrial fibrillation and symptomatic carotid stenosis in some patients and should be avoided. (Wardlaw et al. 2015 [8])

https://app.magicapp.org/#/guideline/ojmKvn/section/L0grgj

An example

EXTEND trial results published 9 May

Revised guideline released for consultation

Submitted to NHMRC for approval

Dissemination

Window for thrombolysis up to 4.5 hrs after stroke onset

2019   May   July   Aug   Sept   Nov (7th)

Systematic review and individual patient meta-analysis published 22 May

Updated guideline drafted

UPDATED and APPROVED GUIDELINE

Window for thrombolysis up to 9 hrs after stroke onset

4 major guideline updates were released involving 22 new and updated recommendations

Evaluation aims

1. Explore the impact of the LSGs approach on **workload and efficiency** of guideline production *(feasibility)*;

2. Identify **facilitators and barriers** for living guidelines development and production; and

3. Investigate how the LSGs approach influenced **acceptability** of the guideline recommendations among end-users.

Safer Care Victoria

RESEARCH   **Open Access**

Is it possible to make 'living' guidelines? An evaluation of the Australian Living Stroke Guidelines

Louise Wiles[1,2,3], Peter D Hibbert[1,2,3]*, Yvonne Zurynski[1,4], Carolynn L. Smith[1,4], Gaston Arnolda[1], Louise A. Ellis[1,4], Rebecca Lake[1], Brona Nic Giolla Easpaig[1], Charlotte Molloy[1,2,3], Sandy Middleton[5], Jeffrey Braithwaite[1,4], Kelvin Hill[6] and Tari Turner[7]

Methods

- In October 2020, we conducted a mixed-methods (realist paradigm) evaluation

- Sequential quantitative surveys (n=228) and qualitative interviews (n=29) to understand the experience of stakeholders contributing to, or impacted by, living guideline production and implementation.

- Google Analytics data were used to examine access trends over five years.

- Macquarie University Human Research Ethics Committee granted ethics approval (ID: 7918)

Methods - participants

- **Guideline developers**—The Stroke Foundation guideline development group, including the project team, executive, guideline content and methodology experts, people with lived experience of stroke (50 survey respondents, 14 interviews)
- **Guideline users**—stakeholder group members and end-users, including clinicians (156 survey respondents, 15 interviews).

Guideline users surveyed were more likely:

Survey question	%
To have increased trust in the LSGs over previous static versions	69
To follow the recommendations	66
To access the LSGs	63
To use them more frequently	58

"Well look, I think they're working well. As I said, because you do know when you log on that you are getting the most up-to-date information, and you are getting what is the expected standard in Australia." (Guideline user, Interview Participant 12).

Generic guideline principles

"I think what works well is the balancing of medical professional advice with the lived experience of consumers as this does not always mirror the medical advice." (Guideline developer, Survey Participant 32).

"I wonder if there should be an app...I think an app-based option where you then can have a better search function would also be better." (Guideline user, Interview Participant 12).

Development sustainability

| Survey question	%
Processes underpinning the production of LSGs worked well	90
The technology supporting the production of LSGs worked well	71
LSGs process increased their workload	54

- Enthusiasm for ensuring the continuation and embedding of the living guidelines approach. However, concerns about sustainability and ongoing funding were raised.

"How continual is continual for living guidelines?" (Guideline developer; Interview Participant 4).

Barriers and facilitators to development of LSGs

Barriers	Facilitators
Lack of integration between software platforms and collaborative tools	Technical platforms and e-support
Potential bias/lack of consensus between agencies	Collaborative and sustained input from diverse stakeholders
Lack of transparency around potential conflicts of interest, decision-making on recommendation inclusion	Acknowledgement of contributions
Unpredictable workload	

Wiles et al BMC HSR 2024

Google analytics data

Wiles et al BMC HSR 2024
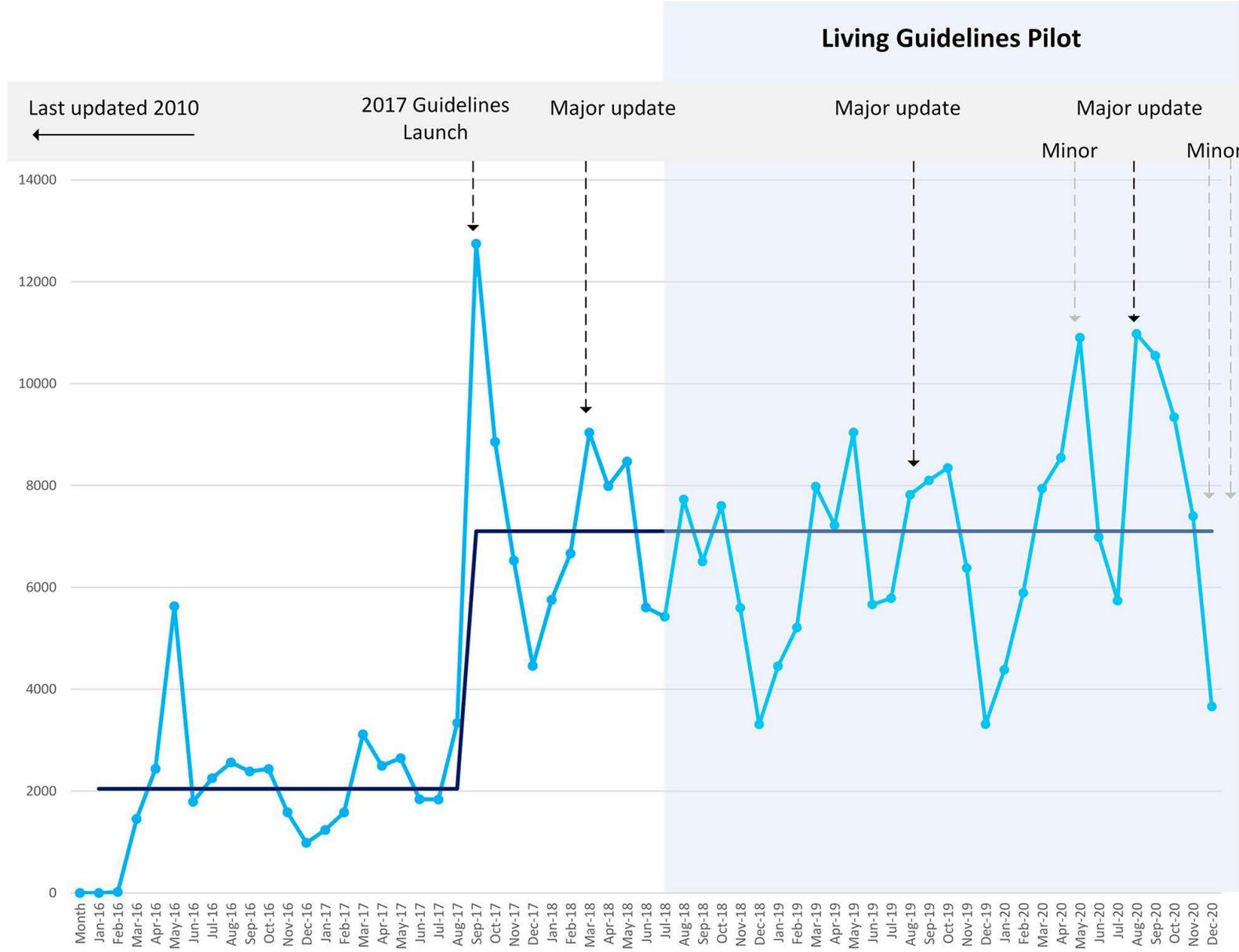
Summary

- Living Stroke Guidelines were largely feasible and acceptable for a relatively well resourced agency

- Enabled continual updating of recommendations in line with new evidence

- Optimal frequency of updates is unknown

- Multi-d involvement including living stroke survivors highly valued

- Marginally increased trust and credibility

- Conditions with a high burden of disease and rapidly changing evidence should be prioritised.

- Work should also be guided by organisations that have well-established relationships with clinicians and people with lived experience.

- Effective communication strategies and provision of resources to support living guideline adoption as recommendations change need to be embedded in the design early to support evidence-based care.

- May benefit from an international collaboration.

Wiles et al BMC HSR 2024

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Kelvin Hill

Thank you

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