Victorian Subacute Childhood Stroke Guidelines

May 2018

Appendices

Contents

Appendix 1: Guideline scope

Aim

To provide an overview of the development of clinical guidelines for the subacute management of childhood stroke.

Guideline title

Victorian Subacute Childhood Stroke Guidelines

Rationale for guideline

- Stroke is among the top ten causes of death in children and more than half of survivors have long term disabilities. 20-40% of children have recurrent strokes, resulting in a need for high quality, specialist sub-acute acute medical and rehabilitation services. Contrary to commonly held views, children do not recover better than adults (1). The lifelong individual, family and societal burden of early stroke is likely to be greater than in adults because children surviving stroke face many more years living with disability. The economic cost of stroke is also substantial, with a U.S. case control study estimating an average five year medical cost of $110,921 per child, representing a 15 fold cost increase compared to controls. Of note, this figure does not include family cost of loss of income, reduced employment, rehabilitation expenses, and psychosocial consequences for child and family. Costs are higher for childhood than for neonatal stroke and higher for haemorrhagic than ischaemic stroke (2). Higher costs correlate with worse impairment, emphasising the importance of rehabilitation to maximise recovery (3).
- The key difference between children and adults is that paediatric stroke results in inability to achieve (rather than lose) functional independence. The extent and severity of physical, cognitive, social and behaviour deficits may not be apparent in the short term following stroke. Therefore the functional, behavioural and social consequences may not be apparent at the time of stroke, particularly in newborns and preschool children, who typically grow into their deficits (4).
- There is substantial evidence that coordinated, individualised, interdisciplinary approaches to stroke management improve outcomes in adults, but no such systems currently exist for paediatric stroke. Further, there are currently no available clinical guidelines for the subacute care of paediatric stroke in Australia. The best available guidelines for subacute care were developed in the UK over 10 years ago. Anecdotal reports from treating clinicians and parent members of StroKidz childhood stroke advocacy/support group) suggest there is currently considerable variation in quality of subacute care.
- The development of evidence-based clinical care guidelines and the standardization of referral and service delivery pathways across the Victorian Paediatric Rehabilitation Service (VPRS) will improve consistency of subacute paediatric stroke care.

The Guideline

Objective

To develop evidence-based guidance on the subacute management of childhood stroke to:

- Reduce variation in subacute care across Victorian paediatric centres.

- Create a list of key quality indicators for the evaluation of clinical care across multiple paediatric rehabilitation services in Victoria.
- Identify key areas of research that will provide the most benefit to reducing disability and improving outcomes post stroke.

Proposed scope

Population	○ Children with stroke (1 month up to 18 years or school exit).	**Main outcomes:** ○ Improvement in the access to, quality of and equity of subacute care. ○ Improvement in outcomes.
Clinical Presentation	○ Arterial ischaemic stroke. ○ Non-traumatic intracranial haemorrhagic stroke.	
Rehabilitation Needs	○ Motor function. ○ Sensory function and pain. ○ Dysphagia and nutrition. ○ Language, speech and communication. ○ Cognitive function. ○ Psychosocial, emotional and behavioural. ○ Activities of daily living. ○ Recreation and participation. ○ Education, learning and vocation. ○ Family function.	
Delivery of Rehabilitation	○ Availability. ○ Appropriate care settings. ○ Health professionals involved. ○ Family involvement. ○ Service organisation (multidisciplinary, interdisciplinary, transdisciplinary). ○ Quality, frequency, intensity and duration. ○ Organisational sector structure (public, private, hospital etc). ○ Transition between paediatric and adult services.	

Groups not covered

- Adult stroke (over 18 years of age or after school exit).
- Perinatal and neonatal stroke.
- Subdural haemorrhage secondary to trauma.
- Spinal stroke syndromes.
- Cerebral venous thrombosis, without infarction.

Setting

Victorian Paediatric Rehabilitation Service

Clinical questions for review

Clinical questions of interest guide review of the literature. These will be drafted with the guideline advisory committee. Clinical questions address only issues covered in the scope and often follow the PICO acronym:

- P: patient group
- I: intervention
- C: comparison
- O: outcome

For example: In children with stroke (P) does patient-centred goal setting (I) compared to no goal setting (C) improve outcome (O).

Alignment with current international and adult stroke guidelines

- 2004 UK Child Stroke Guidelines (RCP currently updating) (5).
- 2015 Canadian Stroke Best Practice Recommendations (6).
- 2017 Clinical Guideline for Stroke Management (NSF currently updating) (7).

Guideline Development Process

The guidelines were developed in line with the following process:

- Scoping document.
- Development of clinical questions and guideline content.
- Literature review.
- Designated leads with clinical expertise to review and approve literature searches, draft recommendations and grade accordingly.
- Drafted guideline to be consulted (externally/publically) prior to finalisation.
- A more detailed process will be developed by the committee.

Target Audience

- Paediatric Neurologists
- Paediatric Rehabilitation Consultants
- Paediatric Rehabilitation Nurses
- Paediatric Physiotherapists
- Paediatric Occupational Therapists
- Paediatric Speech Pathologists
- Paediatric Social Workers
- Paediatric Allied Health Assistants
- Paediatric Educational Consultants
- Paediatric Neuropsychologists
- Paediatric Clinical Psychologists

- Paediatric Play Therapists
- Paediatric Music Therapists

Anticipated Outputs

- Guideline published in peer review journal (author listed as Victorian Subacute Childhood Stroke Committee).

Future outputs (pending further funding)

- Quick reference guide for clinicians to aid implementation.
- Web friendly version for hospital/centres intranet.
- Lay summary and information for families and carers of children admitted with stroke.
- These will be facilitated by a structured dissemination and implementation plan to be developed and approved by the committee.

Appendix 2: Conflict of interest

Name	Conflict of interest declared
Dr Mark Mackay	None
Prof Vicki Anderson	Expert testimony
A/Prof Michael Fahey	Employment with Monash Health and Monash University. Expert testimony
Dr Sarah Knight	None
Dr Adam Scheinberg	None
Dr Jill Rodda	None
Dr Kathleen Bakker	None
Ms Janeen Bower	None
Ms Kim Cartwright	None
Ms Catherine Clancy	None
Dr Therese Clark	None
Dr Ali Crichton	None
Ms Anne Fulton	None
Ms Jane Galvin	Personal payment for lectures/educational tools
Dr Sue Greaves	Consultancy – Allergan Inc. for training in a Botox trial. Personal payment for lectures/educational tools
Ms Lyndal Hickey	None
Dr Brian Hoare	Personal payment for lectures/educational tools
Dr Emily Inceldon	None
Prof Angela Morgan	None
Mrs Kathryn Newton	None
Ms Chloe Noble	None
Miss Clare O'Donnell	None
Mis Jill Steadall	None
Dr Jayasri Srinivasan	None
Ms Renata Winkler	None

Appendix 3: Terms of reference and conflict of interest form

Terms of Reference for the Victorian Subacute Childhood Stroke Advisory Committee and the Murdoch Childrens Research Institute

Name:

Position:

Institution:

Email:

1. Context

The advisory committee has been established under the umbrella of the Royal Children's Hospital, Murdoch Childrens Research Institute, Monash Children's and Victorian Paediatric Rehabilitation Service strategic commitment to give all children the opportunity to have a healthy and fulfilled life. The specific objective of this committee is to **develop evidence-based guidelines on the subacute care of childhood stroke** to:

- Reduce variation in care across Victorian paediatric rehabilitation centres.
- Create a list of key quality indicators for the evaluation of clinical care across multiple paediatric rehabilitation services in Victoria.
- Identify key areas of research likely to provide the most benefit in reducing disability and improving outcomes post stroke.

2. Purpose of the Victorian Subacute Childhood Stroke Advisory Committee

The purpose of the advisory committee will be to:

- Provide advice and guidance on the scope and processes of developing the guideline.
- Develop consensus around the clinical questions to be investigated and review literature.
- Evaluate and consider the latest evidence-based literature and other relevant international adult and paediatric guidelines.
- Contribute to the development of content, recommendations and format of the publication.
- Play key role as implementers within your hospital/institutions.

3. Membership

Membership of the advisory committee will be for the period to develop the clinical guidelines for the subacute care of childhood stroke. We expect the term of your membership to be 12 months.

4. Governance Structure

The committee will function with representation from the Murdoch Childrens Research Institute Clinical Sciences Team and operations include:

- Day to day operations, the guidelines in development and all resulting publications will be managed by the Murdoch Childrens Research Institute's Clinical Sciences Team.
- The Chair will be Dr Mark Mackay.
- Meetings will be via teleconference and where possible face-to-face. The frequency of meetings is proposed as monthly, but may vary based on project commitments.
- Due to gaps in the literature in some areas of childhood stoke, it is likely that the committee will need to develop many recommendations based on expert-opinion. Each member is asked to assist in achieving consensus through active contributions, such as comments on drafted text.
- Due to busy schedules, work between meetings will be required. For example members may be asked to comment on drafts, review evidence and vote on committee decisions.
- Where the committee are unable to reach full consensus on an issue, decisions can be made by a 2/3rd majority. Agendas and minutes from each meeting will be prepared and distributed to members in a timely fashion.

5. Disclosure of Interest

Please declare any conflicts of interest on the form below. Should an interest arise during the development of the guideline please notify mardee.greenham@mrci.edu.au and your form will be updated.

6. Confidentiality Obligations

If a Committee member shares Confidential Information (of their employer organisation or of a third party) during their membership, they must make it clear that the information being shared is confidential.

No Committee member may disclose any Confidential Information of another Committee member to any third party or use any Confidential Information other than for the purpose of collaborating and developing the guideline, except for disclosures:

- required by law or government authorities;
- to employees, students or financial or legal advisers on a need to know basis and provided they agree to be bound by obligations of confidentiality; or
- with the prior written consent of the other party.

For the purposes of this section 6, Confidential Information means any information or knowledge, in any form or media relating to or representing the intellectual property or other confidential information of a party other than information which:

- was in the public domain at the time of its disclosure or subsequently comes into the public domain otherwise than through breach by the receiving party;
- came into the hands of the receiving party by lawful means and without breach of any obligation of confidentiality by any third party; or

- was in fact known to the receiving party prior to its disclosure to that party.

In parallel any personal information, terms of reference and conflicts provided to the Murdoch Childrens Research Institute by Committee members will be held in confidence and not shared without consent from the member, unless required by applicable law.

7. Intellectual Property

Each member acknowledges and agrees that a member's background (pre-existing) intellectual property will remain the property of the member who provided it.

Members acknowledge and agree that any new intellectual property in material created or produced during the conduct of advisory committee will be owned jointly (and in equal shares) by all members.

All members are granted a non-exclusive, perpetual, royalty-free licence to use all new intellectual property in material created or produced during the conduct of advisory committee for their internal research and education purposes. No member may commercialise the material created or produced during the conduct of advisory committee without prior written consent from all members.

8. Acknowledgment

All members must acknowledge the Murdoch Childrens Research Institute and the Victorian Stroke Clinical Network when internally and externally referring to the final developed guidelines.

9. Publication

The publication process and procedure will be agreed on and documented in the minutes of the first Committee meeting. In any published form the authorship will be awarded to the Victorian Subacute Childhood Stroke Advisory Committee and all efforts will be made to list and acknowledge all committee members and their institutions.

10. Liability

Each member (and their employer organisation) is liable for their member's acts and omissions in relation to their conduct and work on the Committee.

Please sign and return via email to Mardee Greenham (mardee.greenham@mcri.edu.au)

_____

Name

_____

Signature

_____

Date

Conflict of Interest for the Victorian Subacute Childhood Stroke Advisory Committee

Name:

Position:

Institution:

Email:

The purpose of this form is to identify any potential duality of interest in the context of membership of the Victorian Subacute Childhood Stroke Advisory Committee for the development of the clinical guideline entitled "The Victorian Subacute Childhood Stroke Guidelines".

Please note that this information will be kept confidently at the Murdoch Childrens Research Institute to be used for the purposes of declaring conflict of interests as relevant to the development of the guideline.

What to declare

Declaring conflicts is a member's responsibility. A conflict can arise in any situation in which member's interest, or appear to influence, the independent performance of the responsibilities in developing the guidelines.

Some examples of what should be disclosed are:

- *Interactions* with entities relevant to the advisory committee's work. For example, any participation with other guideline development groups, publications and editorial invites in the area of paediatric or adult stroke, or work with other organisations that have positions/recommendations on the diagnostic or therapeutic strategies in stroke.

- *Sources of revenues* paid or relevant financial relationships with entities that could be perceived to influence what is to be incorporated into the guideline. If you have any question/doubt, it is usually better to disclose a relationship than not to do so. *For grants received for your other work, you only need to disclose support from entities perceived to be affected financially by the published work*. For example, drug companies and or foundations perceived to have a financial stake in the outcome of the developed recommendations. Public funding sources, such as government agencies, charitable foundations or academic institutions **do not** need to be disclosed.

Please place a cross (not the amount) in the appropriate boxes to indicate financial relationships where relevant to paediatric or adult stroke.

Type of relationship	Money paid to you (Y/N)	Money paid to your institution (Y/N)	Details/Comments
Board memberships			
Memberships			
Consultancy			
Employment			
Expert testimony			
Payment for lectures educational tools			
Payment for manuscript preparation			
Patents (planned/pending)			
Potential income from recommendations			
Other			

Please sign and return via email to Mardee Greenham (mardee.greenham@mcri.edu.au)

_____

Name

_____

Signature

_____

Date

Appendix 4: Search strategies

Question 1: What is the appropriate framework for providing rehabilitation to children with stroke?

Database: MEDLINE

(Date searched: January 2001 – November 2016)

#	Searches
1	exp *Stroke/rh [Rehabilitation]
2	(pre-school* or preschool* or child* or adolescen* or pediatric*).mp. or paediatric*.af.
3	1 and 2
4	limit 3 to (english language and humans and yr="2001 - 2016")

Database: Embase

(Date searched: January 2001 – November 2016)

#	Searches
1	exp *Stroke/rh
2	(pre-school* or preschool* or child* or adolescen* or pediatric*).mp. or paediatric*.af.
3	1 and 2
4	limit 3 to (english language and humans and yr="2001 - 2016")

Database: Cochrane

(Date searched: January 2001 – November 2016)

#	Searches
1	exp Stroke/
2	exp child/
3	exp child, preschool/
4	exp adolescent/
5	exp rehabilitation/
6	limit to “2001 - 2016")
7	#1 and (#2 or #3 or #4) and #5

Question 2: In children with stroke and motor difficulties, which interventions improve outcome?

Database: MEDLINE

(Date searched: January 2001 – March 2017)

#	Searches
1	exp *Stroke/
2	exp *Brain Ischemia/
3	(pre-school* or preschool* or child* or adolescen* or pediatric*).mp. or paediatric*.af.
4	exp *Motor Skills/
5	exp *Motor Disorders/
6	exp *Mobility Limitation/
7	exp *Upper Extremity/
8	exp *Lower Extremity/
9	exp *Gait/
10	exp *Muscle Spasticity/
11	exp *Contracture/
12	exp *Paresis/
13	exp *Physical Therapy Modalities/
14	exp *Hemiplegia/
15	exp *Exercise Therapy/
16	exp *Occupational Therapy/
17	exp *Recovery of Function/
18	exp *Treatment Outcome/
19	1 or 2
20	4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18
21	3 and 19 and 20
22	limit 21 to (english language and humans and yr="2001 - 2017")

Database: Embase

(Date searched: January 2001 – March 201)

#	Searches
1	exp *Stroke/
2	exp *Brain Ischemia/
3	(pre-school* or preschool* or child* or adolescen* or pediatric*).mp. or paediatric*.af.
4	exp *Motor Skills/
5	exp *Motor Disorders/
6	exp *Mobility Limitation/
7	exp *Upper Extremity/
8	exp *Lower Extremity/
9	exp *Gait/
10	exp *Muscle Spasticity/
11	exp *Contracture/
12	exp *Paresis/
13	exp *Physical Therapy Modalities/
14	exp *Hemiplegia/
15	exp *Exercise Therapy/
16	exp *Occupational Therapy/

17	exp *Recovery of Function/
18	exp *Treatment Outcome/
19	1 or 2
20	4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18
21	3 and 19 and 20
22	limit 21 to (english language and humans and yr="2001 - 2017")

Database: Cochrane

(Date searched: January 2001 – March 2017)

#	Searches
1	exp stroke
2	exp child
3	exp child, preschool
4	exp adolescent
5	exp motor skills
6	exp motor disorder
7	exp upper extremity
8	exp lower extremity
9	exp gait
10	exp muscle spasticity
11	exp contracture
12	#1 and (#2 or #3 or #4) and (#5 or #6 or #7 or #8 or #9 or #10 or #11)
13	limit to english language and yr="2001 - 2017"

Question 3: In children with stroke and sensory deficits, which interventions improve outcome?

Database: MEDLINE

(Date searched: January 2001 – December 2016)

#	Searches
1	exp *Stroke/
2	(pre-school* or preschool* or child* or adolescen* or pediatric*).mp. or paediatric*.af.
3	exp *Sensation Disorders/ or exp *Sensation/
4	exp *Paresthesia/
5	exp *Somatosensory Disorders/
6	3 or 4 or 5
7	1 and 2 and 6
8	limit 7 to (english language and humans and yr="2001 - 2016")

Database: Embase

(Date searched: January 2001 – December 2016)

#	Searches
1	exp *cerebrovascular accident/
2	(pre-school* or preschool* or child* or adolescen* or pediatric*).mp. or paediatric*.af.
3	exp *sensation/
4	exp *sensory dysfunction/
5	exp *paresthesia/
6	exp *somatosensory disorders/
7	3 or 4 or 5 or 6
8	1 and 2 and 7
9	limit 8 to (english language and humans and yr="2001 - 2016")

Database: Cochrane

(Date searched: January 2001 – December 2016)

#	Searches
1	exp stroke
2	exp child
3	exp child, preschool
4	exp adolescent
5	exp sensation
6	exp sensation disorder
7	exp paresthesia
8	exp somatosensory disorders
9	#1 and (#2 or #3 or #4) and (#5 or #6 or #7 or #8)
10	limit to english language and yr="2001 - 2016"

Question 4: In children with stroke and pain, which interventions improve outcome?

Database: MEDLINE

(Date searched: January 2001 – October 2016)

#	Searches
1	exp *Stroke/
2	(pre-school* or preschool* or child* or adolescen* or pediatric*).mp. or paediatric*.af.
3	exp *Pain
4	1 and 2 and 3
5	limit 4 to (english language and humans and yr="2001 - 2016")

Database: Embase

(Date searched: January 2001 – October 2016)

#	Searches
1	exp *cerebrovascular accident/
2	(pre-school* or preschool* or child* or adolescen* or pediatric*).mp. or paediatric*.af.
3	exp *pain
4	1 and 2 and 3
5	limit 4 to (abstracts and english language and r="2001 - 2016")

Database: Cochrane

(Date searched: January 2001 – October 2016)

#	Searches
1	exp stroke
2	exp child
3	exp child, preschool
4	exp adolescent
5	exp pain
7	#1 and (#2 or #3 or #4) and #5
6	limit to “2001 - 2016")

Question 5: In children with stroke and dysphagia or poor nutrition status, which interventions improve outcome?

Database: MEDLINE

(Date searched: January 2001 – December 2016)

#	Searches
1	exp *Stroke/
2	(pre-school* or preschool* or child* or adolescen* or pediatric*).mp. or paediatric*.af.
3	exp *Deglutition Disorders/
4	exp *Deglutition/
5	exp *Nutritional Status/
6	exp *Respiratory Aspiration/
7	exp *Eating/
8	3 or 4 or 5 or 6 or 7
9	1 and 2 and 8
10	limit 9 to (english language and humans and yr="2001 - 2016")

Database: Embase

(Date searched: January 2001 – December 2016)

#	Searches
1	exp *cerebrovascular accident/
2	(pre-school* or preschool* or child* or adolescen* or pediatric*).mp. or paediatric*.af.
3	exp *dysphagia/
4	exp *swallowing/
5	exp *nutritional status/
6	exp *eating/
7	3 or 4 or 5 or 6
8	1 and 2 and 7
9	limit 8 to (abstracts and english language and yr="2001 - 2016")

Database: Cochrane

(Date searched: January 2001 – December 2016)

#	Searches
1	exp stroke
2	exp child
3	exp child, preschool
4	exp adolescent
5	exp deglutition
6	exp deglutition disorders
7	exp nutritional status
8	exp respiratory aspiration
9	exp eating
10	#1 and (#2 or #3 or #4) and (#5 or #6 or #7 or #8 or #9)
11	limit to “2001 - 2016"

Question 6: In children with stroke and speech, language or communication difficulties, which interventions improve outcome?

Database: MEDLINE

(Date searched: January 2001 – October 2016)

#	Searches
1	exp *Stroke/
2	(pre-school* or preschool* or child* or adolescen* or pediatric*).mp. or paediatric*.af.
3	exp *Communication Disorders/
4	exp *Vocal Cord Paralysis/
5	exp *Apraxias/
6	3 or 4 or 5
7	1 and 2 and 6
8	limit 7 to (english language and humans and yr="2001 - 2016")

Database: Embase

(Date searched: January 2001 – October 2016)

#	Searches
1	exp *cerebrovascular accident/
2	(pre-school* or preschool* or child* or adolescen* or pediatric*).mp. or paediatric*.af.
3	exp *communication disorder/
4	exp *vocal cord paralysis/
5	exp *apraxia/
6	3 or 4 or 5
7	1 and 2 and 6
8	limit 7 to (english language and humans and yr="2001 - 2016")

Database: Cochrane

(Date searched: January 2001 – October 2016)

#	Searches
1	exp stroke
2	exp child
3	exp child, preschool
4	exp adolescent
5	exp communication disorders
6	exp vocal cord paralysis
7	exp apraxias
8	#1 and (#2 or #3 or #4) and (#5 or #6 or #7)
9	limit to “2001 - 2016"

Question 7: In children with stroke and cognitive difficulties, which interventions improve outcome?

Database: MEDLINE

(Date searched: January 2001 – December 2016)

#	Searches
1	exp *Stroke/
2	(pre-school* or preschool* or child* or adolescen* or pediatric*).mp. or paediatric*.af.
3	exp *Cognition/
4	exp *Cognition Disorders/
5	exp *Attention/
6	exp *Executive Function/
7	exp *Memory/
8	exp *Problem Solving/
9	exp *Fatigue/
10	3 or 4 or 5 or 6 or 7 or 8 or 9
11	1 and 2 and 10
12	limit 11 to (english language and humans and yr="2001 - 2016")

Database: Embase

(Date searched: January 2001 – December 2016)

#	Searches
1	exp * Cerebrovascular Accidents/
2	(pre-school* or preschool* or child* or adolescen* or pediatric*).mp. or paediatric*.af.
3	exp *Cognition/
4	exp *Cognition impairment/
5	exp *Attention/
6	exp *Executive Function/
7	exp *Memory/
8	exp *Problem Solving/
9	exp *Fatigue/
10	3 or 4 or 5 or 6 or 7 or 8 or 9
11	1 and 2 and 10
12	limit 11 to (english language and humans and yr="2001 - 2016")

Database: PsycINFO

(Date searched: January 2001 – December 2016)

#	Searches
1	exp * Cerebrovascular Accidents/
2	(pre-school* or preschool* or child* or adolescen* or pediatric*).mp. or paediatric*.af.
3	exp *Cognition/
4	exp *Cognition impairment/
5	exp *Attention/
6	exp *Executive Function/
7	exp *Memory/
8	exp *Problem Solving/
9	exp *Fatigue/
10	3 or 4 or 5 or 6 or 7 or 8 or 9

11	1 and 2 and 10
12	limit 11 to (english language and humans and yr="2001 - 2016")

Database: Cochrane

(Date searched: January 2001 – December 2016)

#	Searches
1	exp Stroke
2	exp child
3	exp child, preschool
4	exp adolescent
5	exp cognition
6	exp cognitive disorders
7	exp attention
8	exp executive function
9	exp memory
10	exp problem solving
11	exp fatigue
12	#1 and (#2 or #3 or #4) and (#5 or #6 or #7 or #8 or #9 or #10 or #11)
13	limit to “2001 - 2016"

Question 8: In children with stroke and psychosocial, emotional or behavioural difficulties, which interventions improve outcome?

Database: MEDLINE

(Date searched: January 2001 –November 2016)

#	Searches
1	exp *Stroke/
2	(pre-school* or preschool* or child* or adolescen* or pediatric*).mp. or paediatric*.af.
3	exp *behavior/
4	exp *emotions/
5	exp *emotional adjustment /
6	exp *mental disorders/
7	exp *psychopathology/
8	exp *mental health/
9	3 or 4 or 5 or 6 or 7 or 8
10	1 and 2 and 9
11	limit 10 to (english language and humans and yr="2001 - 2016")

Database: Embase

(Date searched: January 2001 –November 2016)

#	Searches
1	exp *Stroke/
2	(pre-school* or preschool* or child* or adolescen* or pediatric*).mp. or paediatric*.af.
3	exp *behavior/
4	exp *emotions/
5	exp *emotional adjustment /
6	exp *mental disorders/
7	exp *psychopathology/
8	exp *mental health/
9	3 or 4 or 5 or 6 or 7 or 8
10	1 and 2 and 9
11	limit 10 to (english language and humans and yr="2001 - 2016")

Database: PsycINFO

(Date searched: January 2001 –November 2016)

#	Searches
1	exp *Stroke/
2	(pre-school* or preschool* or child* or adolescen* or pediatric*).mp. or paediatric*.af.
3	exp *behavior/
4	exp *emotions/
5	exp *emotional adjustment /
6	exp *mental disorders/
7	exp *psychopathology/
8	exp *mental health/
9	3 or 4 or 5 or 6 or 7 or 8
10	1 and 2 and 9
11	limit 10 to (english language and humans and yr="2001 - 2016")

Database: Cochrane

(Date searched: January 2001 –November 2016)

#	Searches
1	exp stroke
2	exp child
3	exp child, preschool
4	exp adolescent
5	exp behavior
6	exp emotions
8	exp mental disorders
9	exp psychopathology
10	exp mental health
11	#1 and (#2 or #3 or #4) and (#5 or #6 or #7 or #8 or #9)
12	limit to “2001 - 2016"

Question 9: In children with stroke and difficulties with activities of daily living, which interventions improve outcome?

Database: MEDLINE

(Date searched: January 2001 –October 2016)

#	Searches
1	exp *Stroke/
2	(pre-school* or preschool* or child* or adolescen* or pediatric*).mp. or paediatric*.af.
3	exp *activities of daily living/
4	exp *self care/
5	3 or 4
6	1 and 2 and 5
7	limit 6 to (english language and humans and yr="2001 - 2016")

Database: Embase

(Date searched: January 2001 –October 2016)

#	Searches
1	exp *cerebrovascular accident/
2	(pre-school* or preschool* or child* or adolescen* or pediatric*).mp. or paediatric*.af.
3	exp *activities of daily living/
4	exp *self care/
5	3 or 4
6	1 and 2 and 5
7	limit 6 to (english language and humans and yr="2001 - 2016")

Database: Cochrane

(Date searched: January 2001 –October 2016)

#	Searches
1	exp stroke
2	exp child
3	exp child, preschool
4	exp adolescent
5	exp activities of daily living
6	exp self care
7	#1 and (#2 or #3 or #4) and (#5 or #6)
9	limit to “2001 - 2016"

Question 10: In children with stroke and reduced participation in recreation or leisure activities, which interventions improve outcome?

Database: MEDLINE

(Date searched: January 2001 –December 2016)

#	Searches
1	exp *Stroke/
2	(pre-school* or preschool* or child* or adolescen* or pediatric*).mp. or paediatric*.af.
3	exp *leisure activities/
4	exp *fatigue/
5	exp *life style/
6	3 or 4 or 5
7	1 and 2 and 6
8	limit 7 to (english language and humans and yr="2001 - 2016")

Database: Embase

(Date searched: January 2001 –December 2016)

#	Searches
1	exp *cerebrovascular accident/
2	(pre-school* or preschool* or child* or adolescen* or pediatric*).mp. or paediatric*.af.
3	exp *leisure/
4	exp *recreation/
5	exp *sport/
6	exp *play
7	exp *fatigue/
8	exp *lifestyle/
9	3 or 4 or 5 or 6 or 7 or 8
10	1 and 2 and 9
11	limit 10 to (english language and humans and yr="2001 - 2016")

Database: Cochrane

(Date searched: January 2001 –December 2016)

#	Searches
1	exp stroke
2	exp child
3	exp child, preschool
4	exp adolescent
5	exp leisure activities
6	exp fatigue
7	exp lifestyle
8	#1 and (#2 or #3 or #4) and (#5 or #6 or #7)
9	limit to “2001 - 2016"

Question 11: In children with stroke, which interventions improve education, learning and vocation outcomes?

Database: MEDLINE

(Date searched: January 2001 –October 2016)

#	Searches
1	exp *Stroke/
2	(pre-school* or preschool* or child* or adolescen* or pediatric*).mp. or paediatric*.af.
3	exp *education/
4	exp *learning/
5	exp *occupations/
6	exp *work/
7	3 or 4 or 5 or 6
8	1 and 2 and 7
9	limit 8 to (english language and humans and yr="2001 - 2016")

Database: Embase

(Date searched: January 2001 –October 2016)

#	Searches
1	exp *cerebrovascular accident/
2	(pre-school* or preschool* or child* or adolescen* or pediatric*).mp. or paediatric*.af.
3	exp *education/
4	exp *learning/
5	exp *occupations/
6	exp *work/
7	3 or 4 or 5 or 6
8	1 and 2 and 7
9	limit 8 to (english language and humans and yr="2001 - 2016")

Database: Cochrane

(Date searched: January 2001 –October 2016)

#	Searches
1	exp stroke
2	exp child
3	exp child, preschool
4	exp adolescent
5	exp education
6	exp learning
7	exp occupations
8	exp work
9	#1 and (#2 or #3 or #4) and (#5 or #6 or #7 or #8)
10	limit to “2001 - 2016"

Question 12: In children with stroke, which interventions improve family function?

Database: MEDLINE

(Date searched: January 2001 –December 2016)

#	Searches
1	exp *stroke/
2	(pre-school* or preschool* or child* or adolescen* or pediatric*).mp. or paediatric*.af.
3	exp *parents/
4	exp *family/
5	exp *siblings/
6	exp *caregivers/
7	exp *social support/
8	exp *social adjustment/
9	exp *mental health/
10	exp *emotional adjustment/
11	3 or 4 or 5 or 6 or 7 or 8 or 9 or 10
12	1 and 2 and 11
13	limit 12 to (english language and humans and yr="2001 - 2016")

Database: MEDLINE

(Date searched: January 2001 –December 2016)

#	Searches
1	exp *cerebrovascular accident/
2	(pre-school* or preschool* or child* or adolescen* or pediatric*).mp. or paediatric*.af.
3	exp *parent/
4	exp *family/ or exp *family functioning/
5	exp *sibling/
6	exp *caregiver/
7	exp *social support/
8	exp *mental health/
9	exp *psychological adjustment/
10	3 or 4 or 5 or 6 or 7 or 8 or 9
11	1 and 2 and 11
12	limit 11 to (english language and humans and yr="2001 - 2016")

Database: Cochrane

(Date searched: January 2001 –December 2016)

#	Searches
1	exp stroke
2	exp child
3	exp child, preschool
4	exp adolescent
5	exp family
6	exp sibling
7	exp caregiver
8	exp social support
9	exp mental health

10	exp emotional adjustment
11	#1 and (#2 or #3 or #4) and (#5 or #6 or #7 or #8 or #9 or #10)
12	limit to “2001 - 2016"

Appendix 5: NHMRC Level of Evidence Matrix

Level	Intervention	Diagnostic accuracy	Prognosis	Aetiology	Screening Intervention
I	A systematic review of level II studies	A systematic review of level II studies	A systematic review of level II studies	A systematic review of level II studies	A systematic review of level II studies
II	A randomised controlled trial	A study of test accuracy with: an independent, blinded comparison with a valid reference standard, among consecutive persons with a defined clinical presentation	A prospective cohort study	A prospective cohort study	A randomised controlled trial
III-1	A pseudorandomised controlled trial (i.e. alternate allocation or some other method)	A study of test accuracy with: an independent, blinded comparison with a valid reference standard, among non-consecutive persons with a defined clinical presentation	All or none	All or none	A pseudorandomised controlled trial (i.e. alternate allocation or some other method)
III-2	A comparative study with concurrent controls: Non-randomised, experimental trial ▪ Cohort study ▪ Case-control study ▪ Interrupted time series with a control group	A comparison with reference standard that does not meet the criteria required for Level II and III-1 evidence	A retrospective cohort study		A comparative study with concurrent controls: Non-randomised, experimental trial ▪ Cohort study ▪ Case-control study
III-3	A comparative study without concurrent controls: ▪ Historical control study ▪ Two or more single arm study ▪ Interrupted time series without a parallel control group	Diagnostic case-control study	A retrospective cohort study	A case-control study	A comparative study without concurrent controls: ▪ Historical control study ▪ Two or more single arm study
IV	Case series with either post-test or pre-test/post-test outcomes	Study of diagnostic yield (no reference standard)	Case series, or cohort study of persons at different stages of disease	A cross-sectional study or case series	Case series

Appendix 6: Evidence Tables

Motor Function

Author (date)	Evidence level/Study design	Participants	Intervention	Control group	Outcome measure	Length of follow-up	Findings
Kirton et al (2008)	Level II Randomised Controlled Trial	10 children and young adults aged 8-20 years (6 male); 2-13 years post-childhood onset subcortical AIS (mean 6.33 years since stroke)	Contralesional, inhibitory repetitive transcranial magnetic stimulation (rTMS) was provided daily for eight days. Treatment parameters: intensity that was 100% of the rest motor threshold on the non-lesioned side; frequency of 1 Hz; and duration of 20 min (1200 stimuli, with the Magstim SuperRapid, Magstim, Wales, UK).	Yes. rTMS set up as per the intervention group, except that the coil was placed perpendicular to the skull so only the top of the coil touched the scalp and magnetic fields were directed posteriorly so as not to deliver measurable brain stimuli. Both methods produce auditory and	Melbourne Assessment of Upper Extremity Function (MAUEF) Grip strength, via hand dynamometer	1 week post-treatment	Benefits of rTMS only statistically significant in relation to grip strength of impaired upper limb. Trend to improvements in upper extremity function not statistically significant.

				physical scalp sensations.			
Gordon et al (2007)	Level IV Case Series	6 children aged 6-15 years (1 male); at least 1 year post-childhood onset AIS	Modified Constraint Induced Movement Therapy (mCIMT) 2 hours per day, 5 days per week for 4 weeks	no	Modified Ashworth Scale; Melbourne Assessment of Unilateral Upper Limb Function; Sensorimotor impairment and active grasp ability assessment. Goal Attainment Scaling of functional goals. Child and parent interview.	4 weeks	no significant improvements in sensorimotor function nor quality of upper limb movement. Improvements noted in individual functional goal attainment. Children and parents were positive about mCIT, indicating feasibility and tolerability of the intervention.
Khalid et al (2015)	Level III Pseudorandomised Controlled Trial	50 children aged 0-15 years (no other details provided)	Proprioceptive Neuromuscular Facilitation (PNF) technique of physical therapy. This included infrared application (dry heat) for 10 minutes, warm up	Yes. Passive range of movement exercises only	Muscle power as measured by Medical Research council scale. Five grades described (0=unable to move to 5=move under	1, 2 and 3 months post-baseline	PNF significantly improved muscle strength at 1, 2 and 3 months post-baseline.

			ROM exercises for 5 minutes, daily stretching and ROM exercises to improve flexibility, isometric exercises to improve strength, and isotonic exercises. Maximum of 2 days per week.		maximum resistance). Did not say which muscles were measured		

Cognitive function

Author (date)	Evidence level/Study design	Participants	Intervention	Control group	Outcome measure	Length of follow-up	Results
Yerys et al (2003)	Level III Case-control Study	6 African-American children aged 11-15 years (3 male) with sickle-cell disease related infarcts affecting frontal lobes	3 children received tutoring for 40 minutes and extra specific learning and memory strategies for 20 minutes (silent rehearsal/semantic clustering). The other 3 children received academic tutoring for 1 hour. 6 weekly sessions of 1 hour,	Yes. Academic tutoring without specific learning and memory strategies.	Children's Memory Scale	Immediate post intervention only.	Short term memory (digit span) improved 'markedly' (no p value) in the intervention group (n=2). Strategy training intervention group were able to learn and use semantic

		or related brain regions.	plus pre- and post-intervention assessments.				clustering strategies to organize information but performed at similar level to group without strategy training on free recall.
Eve et al (2016)	Level IV Case Series	7 children aged 10-16 years (4 male); 4-10 years post-stroke (mean 7.3 years since stroke)	Cogmed working memory training; 25 30-minute to 40-minute sessions during a 5- to 7-week period	No	-Working Memory Test Battery for Children -TEA-Ch -WRAT-4	1-2 weeks and 12 months post intervention	Significant improvement in one aspect of (untrained) working memory (phonological loop) apparent at 1-2 week follow-up but no longer term improvements. No significant improvements in other aspects of (untrained) WM, or in attention or maths skills.
King et al (2007)	Level III Case-control Study	9 children ages 8-16 years (4 male) with sickle cell disease related	-Academic tutoring + memory rehabilitation training (silent rehearsal and semantic clustering)	Yes. -Academic tutoring only (60 mins) -1 hour session/week for	- Wechsler Abbreviated Scale of Intelligence -California Verbal	2 years	Significant improvement in 'delayed cued recall' as measured by the CVLT-C (p=0.02).

		infarcts and memory impairment; 5 intervention, 4 controls	+ task preparation strategies -40 mins Tutoring, 20 mins memory rehabilitation strategies -1 hour session/week for 1 year duration (first year) -2 x 1 hour session/week for 1 year duration (second year)	1 year duration (first year) -2 x 1 hour session/week for 1 year duration(second year)	Learning Test – Children's Version (CVLT-C) -Digit Span subtest from Children's Memory Scale -Reading, math and spelling subtest from Wechsler Individual Achievements Tests – Second edition		Participants in intervention group did not show any relative benefit on academic outcomes (reading, spelling, maths).

Education

Author (date)	Evidence level/Study design	Participants	Intervention	Control group	Outcome measure	Length of follow-up	Results
Yerys et al (2003)	Level III Case-control Study	6 African-American children aged 11-15 years (3 male) with sickle-cell disease related	3 children received tutoring for 40 minutes and extra specific learning and memory strategies for 20 minutes (silent rehearsal/semantic clustering). The other	Yes. Academic tutoring without specific learning and memory strategies.	Children's Memory Scale	Immediate post intervention only.	Short term memory (digit span) improved 'markedly' (no p value) in the intervention group (n=2). Strategy training

		infarcts affecting frontal lobes or related brain regions.	3 children received academic tutoring for 1 hour. 6 weekly sessions of 1 hour, plus pre- and post-intervention assessments.				intervention group were able to learn and use semantic clustering strategies to organize information but performed at similar level to group without strategy training on free recall.
King et al (2007)	Level III Case-control Study	9 children ages 8-16 years (4 male) with sickle cell disease related infarcts and memory impairment; 5 intervention, 4 controls	-Academic tutoring + memory rehabilitation training (silent rehearsal and semantic clustering) + task preparation strategies -40 mins Tutoring, 20 mins memory rehabilitation strategies -1 hour session/week for 1 year duration (first year) -2 x 1 hour session/week for 1 year duration (second year)	Yes. -Academic tutoring only (60 mins) -1 hour session/week for 1 year duration (first year) -2 x 1 hour session/week for 1 year duration(second year)	- Wechsler Abbreviated Scale of Intelligence -California Verbal Learning Test – Children's Version (CVLT-C) -Digit Span subtest from Children's Memory Scale -Reading, math and spelling subtest from Wechsler Individual Achievements	2 years	Significant improvement in 'delayed cued recall' as measured by the CVLT-C (p=0.02). Participants in intervention group did not show any relative benefit on academic outcomes (reading, spelling, maths).

					Tests – Second edition		

Appendix 7: Evidence Statement Forms

Clinical question 2: In children with stroke and motor difficulties, which interventions improve outcome?		
1. Evidence base (*number of studies, level of evidence and risk of bias in the included studies*)		
The evidence base consisted of three studies: • One randomized controlled trial (Level II) with moderate risk of bias • One case series (Level IV) with high risk of bias • One pseudorandomised controlled trial (Level III) with high risk of bias	A	Several level I or II studies with low risk of bias
	B	One or two level II studies with low risk of bias or SR/multiple III studies with low risk of bias
	C	Level III studies with low risk of bias or Level I or II studies with moderate risk of bias
	D	Level IV studies or Level I to III studies with high risk of bias
2. Consistency (*if only on study was available, rank this component as 'not applicable'*)		
There is no consistency amongst the three studies as they are all investigating different aspects of motor interventions.	A	All studies consistent
	B	Most studies consistent and inconsistency can be explained
	C	Some inconsistency, reflecting genuine uncertainty around question
	D	Evidence is inconsistent
	NA	Not applicable (one study only)
3. Clinical impact (*indicate if the study results varied according to some unknown factor (not simply study quality or sample size) and thus the clinical impact of the intervention could not be determined*)		
Repetitive TMS shows promise for feasibility, improvements in grip strength and upper limb function. Modified Constraint Induced Movement Therapy shows promise for individual upper limb goal attainment.	A	Very large
	B	Moderate
	C	Slight
	D	Restricted
4. Generalisability (*how well does the body of evidence match the population and clinical settings being targeted by the Guideline?*)		
• Findings from two of the studies can be generalised (Kirton et al (2008), Gordon et al 2007))	A	Evidence directly generalisable to target population
	B	Evidence directly generalisable to target population with some caveats

• The third study did not describe the population in enough detail to allow generalizability (Khalid et al (2015))	C	Evidence not directly generalisable to the target population but could be sensibly applied
	D	Evidence not directly generalisable to target population and hard to judge whether it is
5. Applicability (*is the body of evidence relevant to the Australian healthcare context in terms of health services/delivery of care and cultural factors?*)		
The studies are applicable to the way in which subacute care is delivered in Australia.	A	Evidence directly applicable to Australian healthcare context
	B	Evidence applicable to Australian healthcare context with few caveats
	C	Evidence probably applicable to Australian healthcare context with some caveats
	D	Evidence not applicable to Australian healthcare context
Other factors *(Indicate here any other factors that you took into account when assessing the evidence base (for example, issues that might cause the group to downgrade or upgrade the recommendation))*		

EVIDENCE STATEMENT MATRIX

Please summarise the development group's synthesis of the evidence relating to the key question, taking all the above factors into account.

Component	Rating	Description
1. Evidence base	D	One randomized controlled trial (Level II) with moderate risk of bias, one case series (Level IV) with high risk of bias, and one pseudorandomised controlled trial (Level III) with high risk of bias
2. Consistency	D	No consistency amongst the three studies, all investigating different aspects of motor interventions
3. Clinical impact	D	Repetitive TMS shows promise for feasibility, improvements in grip strength and upper limb function. Modified Constraint Induced Movement Therapy shows promise for individual upper limb goal attainment
4. Generalisability	C	Two studies can be generalised, once did not describe participants adequately
5. Applicability	C	The studies are applicable to the way in which subacute care is delivered in Australia

Indicate any dissenting opinions

RECOMMENDATION *What recommendation(s) does the guideline development group draw from this evidence? Use action statements where possible*	**GRADE OF RECOMMENDATION**	NA
No recommendations could be made due to the low level of evidence.		
IMPLEMENTATION OF RECOMMENDATION		

Please indicate yes or no to the following questions. Where the answer is yes please provide explanatory information about this. This information will be used to develop the implementation plan for the guidelines.	
Will this recommendation result in changes in usual care?	NA
Are there any resource implications associated with implementing this recommendation?	NA
Will the implementation of this recommendation require changes in the way care is currently organised?	NA
Are the guideline development group aware of any barriers to the implementation of this recommendation?	NA

Clinical question 7: In children with stroke and cognitive difficulties, which interventions improve outcome?		
!. Evidence base (*number of studies, level of evidence and risk of bias in the included studies*)		
The evidence base consisted of three studies: • Two case-control studies (Level III) with moderate risk of bias • One case series (Level IV) with high risk of bias	A	Several level I or II studies with low risk of bias
	B	One or two level II studies with low risk of bias or SR/multiple III studies with low risk of bias
	C	Level III studies with low risk of bias or Level I or II studies with moderate risk of bias
	D	Level IV studies or Level I to III studies with high risk of bias
2. Consistency (*if only on study was available, rank this component as 'not applicable'*)		
• All studies employed working memory or memory training strategies • All studies reported beneficial results from the intervention to aspects of working memory and memory • Some consistency in outcome measures used. • Inconsistency across type of intervention – face to face vs online/computerised • Inconsistency in approaches to cognitive rehabilitation interventions – direct re-training vs compensatory approach • There is a lack of consistency in outcome measures and therefore ability to generalise findings • There are inconsistencies in the duration (2 years; 5-7 weeks) and intensity of interventions (daily vs weekly). • Diagnostics groups differed between SCD vs ischaemic stroke • Age groups consistent across studies (upper primary and secondary cohort)	A	All studies consistent
	B	Most studies consistent and inconsistency can be explained
	C	Some inconsistency, reflecting genuine uncertainty around question
	D	Evidence is inconsistent
	NA	Not applicable (one study only)
3. Clinical impact (*indicate if the study results varied according to some unknown factor (not simply study quality or sample size) and thus the clinical impact of the intervention could not be determined*)		
• Specific cognitive domains may demonstrate benefit from cognitive strategy training (compensatory techniques) and to lesser extent cognitive retraining.	A	Very large
	B	Moderate

These domains were working memory, short term memory and recall. However, the particular populations and population characteristics (age, time since stroke etc.) that would benefit most from these interventions is unclear given the small sample size and the limited number of studies conducted. • The magnitude of any potential benefit or effect of the interventions cannot be determined form the current studies and larger trials are needed. • Two of the studies addressed the relative benefit of cognitive strategy training when paired with tutoring relative to tutoring alone and found beneficial effects. • Interventions varied in method (face-to-face, computer) and location (home, school-based) of delivery) and personnel involved in services delivery (rehabilitation professionals, community services providers, education personnel, families). • There was significant variability in the duration (2 years; 5-7 weeks) and intensity of interventions (daily vs weekly). Dosage of treatment required to gain benefit relative to time and resource cost of intervention was not examined. For cognitive retraining there is evidence in other populations that are relevant for dosage. • No harms identified other than cost, time	C	Slight
	D	Restricted
4. Generalisability (*how well does the body of evidence match the population and clinical settings being targeted by the Guideline?*)		
• It is difficult to generalise results from the limited population studied, in particular the age cohort was limited to middle childhood so genralisability to younger or older children is unknown. • Children with SCD were represented in 2/3 studies and it is unclear if those findings can be generalized to a broader stroke population or varying etiology. • As the studies focus on limited cognitive domains, it is difficult to generalize to strategy training or cognitive retraining in a broader sense.	A	Evidence directly generalisable to target population
	B	Evidence directly generalisable to target population with some caveats
	C	Evidence not directly generalisable to the target population but could be sensibly applied
	D	Evidence not directly generalisable to target population and hard to judge whether it is
5. Applicability (*is the body of evidence relevant to the Australian healthcare context in terms of health services/delivery of care and cultural factors?*)		
	A	Evidence directly applicable to Australian healthcare context

Broadly speaking strategy training and cognitive retraining is applicable to the current Australian model of service delivery. Current practices in Australia allows for the assessment of cognitive function and the addition of more standardized implementation of strategy training or cognitive retraining if feasible. It may require additional resources dependent on intensity and duration of intervention and additional links with other services providers and educational personnel. Cognitive retraining as studied used a licensed product and costs associated with this programs use may effect possible implementation.	B	Evidence applicable to Australian healthcare context with few caveats
	C	Evidence probably applicable to Australian healthcare context with some caveats
	D	Evidence not applicable to Australian healthcare context

Other factors *(Indicate here any other factors that you took into account when assessing the evidence base (for example, issues that might cause the group to downgrade or upgrade the recommendation))*

EVIDENCE STATEMENT MATRIX

Please summarise the development group's synthesis of the evidence relating to the key question, taking all the above factors into account.

Component	Rating	Description
1. Evidence base	D	Two case-control studies (Level III) with moderate risk of bias and one case series (Level IV) with high risk of bias
2. Consistency	D	All studies employed working memory and memory training strategies, but there were inconsistencies in the types and approaches to intervention, duration and intensity of intervention and diagnostic groups
3. Clinical impact	D	The magnitude of any potential benefit or effect of the interventions cannot be determined form the current studies and larger trials are needed
4. Generalisability	D	It is difficult to generalise results from the limited population studied
5. Applicability	C	Broadly speaking strategy training and cognitive retraining is applicable to the current Australian model of service delivery

Indicate any dissenting opinions

RECOMMENDATION *What recommendation(s) does the guideline development group draw from this evidence? Use action statements where possible*	**GRADE OF RECOMMENDATION**	D

Strategy training interventions may improve aspects of memory (short term memory and delayed cued recall) after childhood stroke.

IMPLEMENTATION OF RECOMMENDATION

Please indicate yes or no to the following questions. Where the answer is yes please provide explanatory information about this. This information will be used to develop the implementation plan for the guidelines.

Will this recommendation result in changes in usual care?	No
Are there any resource implications associated with implementing this recommendation?	No
Will the implementation of this recommendation require changes in the way care is currently organised?	No
Are the guideline development group aware of any barriers to the implementation of this recommendation?	No

<table>
<tr><td colspan="3">Clinical question 11: In children with stroke, which interventions improve education, learning and vocation outcomes?</td></tr>
<tr><td colspan="3">!. Evidence base (number of studies, level of evidence and risk of bias in the included studies)</td></tr>
<tr><td rowspan="4">The evidence base consisted of two studies:
• Two case-control studies (Level III) with moderate risk of bias</td><td>A</td><td>Several level I or II studies with low risk of bias</td></tr>
<tr><td>B</td><td>One or two level II studies with low risk of bias or SR/multiple III studies with low risk of bias</td></tr>
<tr><td>C</td><td>Level III studies with low risk of bias or Level I or II studies with moderate risk of bias</td></tr>
<tr><td>D</td><td>Level IV studies or Level I to III studies with high risk of bias</td></tr>
<tr><td colspan="3">2. Consistency (if only on study was available, rank this component as ‘not applicable’)</td></tr>
<tr><td rowspan="5">• Both studies employed memory training strategies
• Both studies reported beneficial results from the intervention to aspects of memory
• There is a lack of consistency in outcome measures and therefore ability to generalise findings
• Very small sample sizes in both studies make it difficult to generalise results
• There are inconsistencies in the duration of interventions (2 years; 6 weeks)</td><td>A</td><td>All studies consistent</td></tr>
<tr><td>B</td><td>Most studies consistent and inconsistency can be explained</td></tr>
<tr><td>C</td><td>Some inconsistency, reflecting genuine uncertainty around question</td></tr>
<tr><td>D</td><td>Evidence is inconsistent</td></tr>
<tr><td>NA</td><td>Not applicable (one study only)</td></tr>
<tr><td colspan="3">3. Clinical impact (indicate if the study results varied according to some unknown factor (not simply study quality or sample size) and thus the clinical impact of the intervention could not be determined)</td></tr>
<tr><td rowspan="4">• Both included studies report on memory training for children with SCD and associated infarcts. A different population to the sub-acute stroke population these guidelines are designed for.
• The interventions facilitated by teachers/tutors not health professionals
• King et al (2007) reported the intervention occurred weekly for 2 years. This may not be practical for a sub-acute rehabilitation service. High resource implications due to extended duration of intervention.</td><td>A</td><td>Very large</td></tr>
<tr><td>B</td><td>Moderate</td></tr>
<tr><td>C</td><td>Slight</td></tr>
<tr><td>D</td><td>Restricted</td></tr>
</table>

• Level of skill and training of intervention facilitators not detailed in either of the included studies. • King et al (2007) report a significant effect in 'delayed cued recall' (p=0.02). Both groups in the study improved in 'backward recall' however the intervention group showed a greater improvement (p=0.04). Both groups also improved in the Digit Span Forwards tests but there was no significance between groups. Both groups improved on academic achievement tests but there was no overall statistical significance between the two groups. • Potential harms = decreased academic potential/not maximizing academic outcomes. Suggests a need for follow up and intervention beyond duration of hospital admission.		
4. Generalisability (*how well does the body of evidence match the population and clinical settings being targeted by the Guideline?*)		
• Difficult to generalize with very low participant numbers • Both studies report on SCD cohort, therefore difficult to generalize to general stroke population • Yerys et al study cannot generalize finding outside racial/cultural/ethnic group • Yerys et al only include participants with frontal or related brain regions stroke, therefore difficult to generalise • Majority of participants in both included studies high school aged, cannot generalize to younger age groups • Time post stroke not detailed	A	Evidence directly generalisable to target population
	B	Evidence directly generalisable to target population with some caveats
	C	Evidence not directly generalisable to the target population but could be sensibly applied
	D	Evidence not directly generalisable to target population and hard to judge whether it is
5. Applicability (*is the body of evidence relevant to the Australian healthcare context in terms of health services/delivery of care and cultural factors?*)		
• Memory training strategies applicable to the way care is delivered in Australian paediatric sub-acute rehabilitation • Follow up required in schools	A	Evidence directly applicable to Australian healthcare context
	B	Evidence applicable to Australian healthcare context with few caveats

• Memory training strategies implemented in these studies may not be not applicable to pre-school aged or younger school aged children. There is insufficient detail to determine this.	C	Evidence probably applicable to Australian healthcare context with some caveats
	D	Evidence not applicable to Australian healthcare context

Other factors *(Indicate here any other factors that you took into account when assessing the evidence base (for example, issues that might cause the group to downgrade or upgrade the recommendation))*

EVIDENCE STATEMENT MATRIX

Please summarise the development group's synthesis of the evidence relating to the key question, taking all the above factors into account.

Component	Rating	Description
• Evidence base	C	Two case-control studies (Level III) with moderate risk of bias
6. Consistency	C	Both studies employed memory training strategies, but there were inconsistencies in the duration and intensity of intervention and outcome measures
7. Clinical impact	D	The magnitude of any potential benefit or effect of the interventions cannot be determined form the current studies and larger trials are needed
8. Generalisability	D	It is difficult to generalise results from the limited population studied
9. Applicability	C	Memory training strategies applicable to the way care is delivered in Australian paediatric sub-acute rehabilitation

Indicate any dissenting opinions

RECOMMENDATION *What recommendation(s) does the guideline development group draw from this evidence? Use action statements where possible*	**GRADE OF RECOMMENDATION**	D

Strategy training interventions may improve aspects of memory (short term memory and delayed cued recall) after childhood stroke.

IMPLEMENTATION OF RECOMMENDATION

Please indicate yes or no to the following questions. Where the answer is yes please provide explanatory information about this. This information will be used to develop the implementation plan for the guidelines.

Will this recommendation result in changes in usual care?	No
Are there any resource implications associated with implementing this recommendation?	No
Will the implementation of this recommendation require changes in the way care is currently organised?	No

Are the guideline development group aware of any barriers to the implementation of this recommendation?	No

Appendix 8: NHMRC Grades for Recommendations

Grade	Description
A	Body of evidence can be trusted to guide practice
B	Body of evidence can be trusted to guide practice in most situations
C	Body of evidence provides some support for recommendation(s) but care should be taken in its application
D	Body of evidence is weak and recommendation must be applied with caution

Appendix 9: Delphi Survey

We aimed to develop recommendations for Australian health professionals to guide the subacute rehabilitation of children with stroke. We addressed questions relating to the framework of rehabilitation service delivery, as well as treatment strategies targeting specific domain of function.

Methods

A multidisciplinary guideline development committee (GDC) was convened to oversee the development of the CPGs. The GDC consisted of a steering committee (MM-Chair, SK, MG, JR, AS, MF, VA) and an advisory group of health professionals (n=19). Members of the advisory group were recruited through an Expression of Interest process advertised through the Victorian Paediatric Rehabilitation Service networks. Health professionals were eligible if they had clinical expertise in the rehabilitation of children with stroke. Purposeful sampling was used to ensure there was a representation of all disciplines involved in the rehabilitation of childhood stroke and across service location (metropolitan/regional) on the advisory group. The final advisory group included 1 rehabilitation physician, 5 occupational therapists, 4 speech pathologists, 3 neuropsychologists, 2 physiotherapists, 1 clinical psychologist, 1 social worker, 1 education advisor and 1 music therapist from 5 different institutions across Victoria. The GDC developed the purpose, scope and clinical questions for the CPG.

Developing evidence-based recommendations

The GDC was divided into working parties, based on area of expertise, which then developed clinical questions in PICO format (Population, Intervention, Comparison, Outcome), as well as well as key terms for the literature search. Extensive literature reviews were conducted. The search strategies used to identify publications are detailed in Appendix 1. The literature search was conducted on MEDLINE, Embase, Cochrane Library and PsycInfo. Searches were limited to English language. Studies were included if they: i) referred to children aged between 29 days and 18 years diagnosed with stroke; ii) examined rehabilitation treatment strategies following childhood stroke; and iii) were published after 2001. All titles abstracts were screened independently by two reviewers and disagreement was resolved by discussion with a third reviewer. Full texts were obtained when eligibility criteria were met or when they could not be determined from the abstract. The included studies were appraised for methodological quality using critical appraisal checklists developed by the Scottish Intercollegiate Guidelines Network (SIGN)(8) and an NHMRC level of evidence(9) was applied to each study.

Where sufficient evidence was available, evidence based-recommendations were formed by the relevant working committee, then reviewed by the steering committee. Evidence-based recommendations were developed using the NHMRC evidence statement form(10). The form was used to assess the body of evidence for each clinical question. The body of evidence was evaluated according to the evidence base (e.g., number and quality of studies, level of evidence), consistency of results, clinical impact, generalisability and applicability. Evidence-based recommendations were assigned an NHMRC grade(9) based on the quality of evidence.

Developing consensus-based recommendations

Consensus-based recommendations were developed for clinical questions when the literature review did not identify studies meeting inclusion criteria or when only low-quality evidence was available. A modified Delphi method was used for developing consensus-based recommendations(11). The purpose of the modified Delphi method is to develop consensus through a series of sequential questionnaires known as 'rounds', interspersed with controlled feedback of results(11). This method is widely used for solving problems in health and medicine and allows elicitation of expert opinion in an iterative and systematic manner(11). Existing CPGs for childhood stroke rehabilitation (12, 13) were reviewed to inform question development.

Due to the multidisciplinary nature of stroke rehabilitation, a large number of health professionals were recruited to an expert panel of health professionals for the modified Delphi survey. This was to ensure that there was sufficient representation within each clinical area of expertise (e.g., speech, motor function) to establish expert consensus. Health professionals were eligible if they had clinical expertise in the rehabilitation of children with stroke. An invitation to participate in the expert panel was advertised through the Victorian Paediatric Rehabilitation Service. Invitations to participate in the expert panel were also sent to 18 national or international experts in childhood stroke rehabilitation known to the GDC.

Questionnaires were delivered over three rounds between September 2017 and March 2018. The survey was administered online using the RedCAP data capture tool(14). For each round, a link to the survey was emailed to participants, with a two-week period to submit their responses. At Day 7 and Day 11 of this two-week period, reminder emails were sent to those who had yet to complete the survey. Non-completion of a preceding round did not preclude panellists from contributing to subsequent rounds. Each survey took approximately 20 minutes to complete, and demographics were collected at each round. Each round of the survey included two sections: Part A. Rehabilitation

framework and Part B. Rehabilitation treatment strategies. Questions in Round 1 were developed by the steering committee using results from the evidence review, as well as existing CPGs that address childhood stroke rehabilitation(12, 13). An option was included for panellists to opt out of responding to questions that were not within their area of expertise. Each questionnaire was piloted by three members of the steering committee, and minor changes were made to improve clarity. Pre-determined consensus criteria for each round was item selection by ≥75% of participating panellists. At the completion of each round, data was exported into SPSS for Windows(15) to calculate basic descriptive statistics. Free-text was analysed using a content analysis approach.

Round 1. In the first round, members were asked to complete a combination of multiple-choice and open-ended questions. For each multiple-choice question, the panellists were asked to select their preferred answer or make another suggestion under the response "other". A free-text option was included at the end of each multiple-choice question. Consensus was achieved if a response was selected by ≥75% of respondents. For the open-ended questions, the free text responses were analysed using a content analysis approach. Similar responses were conflated, and unique responses were included as statements in Round 2. Statements were reviewed by the steering committee to confirm they were appropriate

Round 2. In the second round, members were provided with a summary of the results from Round 1. Members could also provide a free-text response to each question. A statement reached consensus in Round 2 if it was selected by ≥75% of panellists. For statements not reaching consensus, a maximum of four of the most frequently endorsed statements in each domain were included in Round 3 (i.e., less than four were included if statements in the domain had reached consensus in Round 2).

Round 3. In the third round, members were provided with a summary of the results from Round 2 and were asked to rate each statement on a 5-point scale according to their level of agreement with the statement (1=Strongly Disagree, 2=Disagree, 3=Neither Agree or Disagree, 4=Agree, 5=Strongly Agree). Statements reached consensus if ≥75% of members responded with Agree or Strongly Agree.

Results

The 12 clinical questions developed by the GDG can be viewed in Figure 1.

Evidence-based recommendations

Overall, systematic searches yielded a lack of, or low-quality, evidence across the 12 clinical questions investigated, precluding the development of evidence-based recommendations in most areas. Evidence summaries from the systematic searches can be viewed in Appendix 2. Systematic searches only yielded evidence of sufficient quality to develop one evidence-based recommendation. This evidence-based recommendation related to treatment strategies for cognitive difficulties for children with stroke and was as follows: "Strategy training interventions may improve aspects of memory (short term memory and delayed cued recall) after childhood stroke". This evidence-based recommendation was based on 3 studies (2 Level II evidence(16, 17), 1 Level III evidence(18) according to NHMRC Levels of Evidence grading system(9)).

Consensus-based recommendations

Delphi Panellist characteristics

The final expert panel comprised of 99 health professionals (85 from the Victorian Paediatric Rehabilitation Service and 14 national or international experts) who completed at least one round of the modified Delphi survey. Median years of experience working with children with stroke in a rehabilitation setting was 18 years (IQR 10-26 years). Table 1 shows the representation of disciplines. Across the three rounds, there were 69 (70%), 63 (64%) and 66 respondents (67%), respectively. Thirty-two panellists completed all three rounds. Table 2 includes the number of panellists in each round who endorsed the question topic as within their area of expertise and subsequently completed the question.

Delphi results

Overall, 119 statements reached consensus. These statements were rephrased and/or conflated into 30 consensus-based recommendations. The final list of consensus-based recommendations can be viewed in Tables 3 and 4. Specific statements commented on below are those where consensus was not achieved, and which were informed by free text from panellists. The questions that did not reach consensus are summarised in Tables 5 and 6.

Rehabilitation framework

Overall, 68 statements focussing on rehabilitation framework reached consensus across the three rounds (Table 3). These were conflated into single recommendations where appropriate by the steering committee, resulting in a total of 16 consensus-based recommendations. The recommendations covered the following eight areas of rehabilitation care: i) setting for rehabilitation service delivery; ii) family involvement; iii) team format; iv) funding structure; v) transfer of care; vi) Individual/group therapy; vii) transition to adult services; and viii) measurement of service quality. There was a high level of agreement amongst the panellists for the statements that reached consensus (median=90%, IQR=84-95%). The areas where consensus was not reached are discussed below.

Timing of involvement of rehabilitation team in child's care. Consensus was not reached for statements relating to the stage at which the specialist rehabilitation team should become involved in a child's care (Table 5). In Round 1, panellists were asked when specialist rehabilitation services should become involved in the care of a child with stroke. The two most frequently selected responses were "as soon as diagnosis is established" and "once medically stable". This question was rephrased and asked again in Round 2 and consensus was still not reached, with the panellists' responses split 56% "as soon as diagnosis is established" and 42% "once medically stable". Free text responses by those endorsing "as soon as diagnosis is established" included that "early consultation with rehabilitation is important to establish relationships with the family and an understanding of what rehabilitation involves". Several panellists also suggested that a representative from the multidisciplinary rehabilitation team could meet the family as soon as diagnosis was confirmed to explain the rehabilitation service and what it could offer. Free text responses by those endorsing once medically stable included "families are vulnerable and can be overwhelmed with too much information. When the child is medically stable the family is more likely to be able to contemplate the future". Consensus was, however, reached concerning the criteria for transfer from acute to rehabilitation services. These included: (i) The child is medically stable, or any medical instability is able to be managed by the rehabilitation team; (ii) Rehabilitation goals have been identified; and (iii) The child has change in function that could benefit from rehabilitation.

Parental access to medical records. In Round 1, consensus was achieved on most statements relating to family involvement, including the creation of care plans, goal setting using the Canadian Occupational Performance Measure (COPM), attendance at family meetings, and active involvement in therapy sessions. It was also agreed that families should be copied into all correspondence. The only statement that did not reach consensus related to caregiver access to their child's medical

record. In Round 2, panellists were asked if caregivers are given access to their child's medical record, should they be given full or partial access. This question did not reach consensus either with panellists split almost equally between full or partial access. Free text responses for those selecting "full access" included the following themes: i) information should be transparent; ii) families should be entitled to access/legal right to access health information; and iii) improves collaborative care. For those selecting partial access, free-text responses addressed: i) language used in medical record not appropriate/not easily understood/prone to misinterpretation by parents; and ii) sensitivity/confidentiality of psychosocial information in medical record.

Funding. In Round 1, almost all panellists agreed (97%) that subacute rehabilitation for children with stroke should be funded through the public health system. However, over half of panellists (58%) also indicated that subacute rehabilitation should be funded through the National Disability Insurance Scheme (NDIS). In Round 2, there was consensus that the following should be funded through NDIS: care coordination, carers, equipment, and home modifications. However, therapy for functional goals did not reach consensus.

Setting for rehabilitation following the subacute phase of rehabilitation. Most panellists agreed (88%) that following the subacute phase of rehabilitation for children with stroke, their ongoing rehabilitation is best managed in the community setting (e.g., home, school). However, a high proportion of panellists also selected the "hospital setting" and in a "community centre/facility". Free text responses indicated that the setting for ongoing rehabilitation following the subacute phase of rehabilitation depended on the individual goals, needs, and wants of the child and family, and the resources required. However, consensus was reached on the criteria for transfer from rehabilitation to long-term community care and these were as follows: i) Current goals are better addressed in the community or are more community-based (e.g., return to school), b) Safety of the child in the community and home has been achieved, c) Therapy needs have decreased to a level that they can be confidently met in the community setting, and d) Family feels capable and ready to care for the child at home.

Rehabilitation treatment strategies

Overall, 51 statements regarding rehabilitation treatment strategies reached consensus across the three rounds (Table 4). These were conflated into single recommendations by the steering

committee, resulting in a total of 14 consensus-based recommendations across 11 clinical areas. Overall, there was a high level of agreement amongst the panellists for the statements reaching consensus (median=89%, IQR=84-96%).

A number of treatment strategies suggested by panellists in free-text in Round 1 did not reach consensus in subsequent rounds (Table 6). Several panellists indicated in free-text responses in Round 2 that the type of treatment strategy depended on a number of factors including the age of the child, the nature and severity of injury, the time since treatment, and family needs and preferences.

Discussion

Developing CPGs is critical to improving quality of rehabilitation for children with stroke. The development and implementation of CPGs in adults with stroke has resulted in improvements in quality of rehabilitation practices over time in Australia(19). We aimed to develop Australian CPGs for the subacute rehabilitation of children with stroke. As high-quality evidence was not available for all but two of the clinical questions, consensus-based recommendations were developed by an expert panel using modified Delphi methodology for the vast majority of the clinical areas. One evidence-based recommendation and 30 consensus-based recommendations were developed in this project.

Rehabilitation framework

A high level of agreement was achieved for most questions addressing aspects of rehabilitation framework. Consensus was not reached regarding the timing of initial involvement of the rehabilitation team in a child's care following stroke diagnosis. Approximately half of panellists agreed that the rehabilitation team should be involved at the time of diagnosis; however, the other half felt that this may not be appropriate until after a child is medically stable. Panellists suggested early contact by a representative of the rehabilitation team may be appropriate to provide information about the rehabilitation service to families. Further, client-focused research to understand family preferences regarding this issue will be important in guiding clinical decision making in this area. It was pleasing that consensus was reached concerning the criteria for transfer from acute to rehabilitation services. These included: (i) the child is medically stable, or any medical instability is able to be managed by the rehabilitation team; (ii) rehabilitation goals have been identified; and (iii) the child has change in function that could benefit from rehabilitation. This is an important area as timely and equitable access to rehabilitation care has been shown to be inconsistent across a range of health conditions requiring rehabilitation, with a complex array of factors influencing the process of decision-making surrounding the referral(20). Future research is required to better understand this decision-making process for children with stroke and whether the criteria for transfer to rehabilitation developed in this project are associated with improved equity in timing and access to care.

There was strong agreement surrounding family involvement in most aspects of rehabilitation care. Agreement was not reached regarding full or partial parental access to child medical record with concerns being raised regarding confidentiality and sensitivity of information and the intelligibility of complex medical information for parents. Those supporting full access to the medical records

indicated that this would allow for transparency, is an entitlement/legal right, and that it would support collaborative care. It is not surprising the consensus was not reached in this area, as this represents a broader, contentious issue, particularly now that most medical records are electronic, supporting the greater ease of access to information(21). Family or parent portals to electronic medical records are being increasingly adopted by health services to provide parents with timely, transparent access to health care information and to engage them in the care process(22, 23). While this method holds promise, ongoing evaluation of its potential to optimise usability for families is required(23).

Rehabilitation treatment strategies

A number of treatment strategies suggested by panellists in free-text in Round 1 did not reach consensus in subsequent rounds (Table 6). Several panellists indicated in free-text responses in Round 2 that the type of treatment strategy depended on a number of factors including the age of the child, the nature and severity of injury, the time since treatment, and family needs and preferences. While these statements did not reach consensus as key treatment strategies for children with stroke in the current study, it is possible that many of these factors may be important to consider as rehabilitation practices for children with stroke. Further research is necessary to determine the appropriateness of these treatment approaches for children with stroke.

Strengths and limitations

The current study has a number of strengths: a large expert panel was recruited; the sample of panellists covered a range of disciplines with a spread of practice locations across the State; the response rate remained high across all three rounds, and we achieved a high level of support for the final set of statements. We acknowledge the limitation that no consumers were involved in the Delphi panel. To help address this, the consensus-based recommendations will be reviewed by consumers as part of targeted consultation for the full CPG.

The transferability of our recommendations may be limited in some respects because most panellists were from the Victorian public health care setting. Our panel consisted of a large group of interdisciplinary experts in childhood stroke rehabilitation. While the responses may have differed slightly with a different panel composition, we believe that our composition was large enough to provide a representative sample. Furthermore, although most were from Victoria, the panellists had a diverse background of hospital and community experience and many had worked in different settings and states, highlighting the potential applicability across most settings in Australia.

The inclusion of large proportion of panellists from this particular setting was deliberate and formed part of an integrated clinical implementation strategy for the state of Victoria. It is well-known that implementation of CPGs is complex and often unsuccessful. However, active involvement of stakeholders and clinical decision-makers in the development of CPGs may increase the likelihood of implementation into daily clinical practice in their particular settings(13, 24). While a small number of key stakeholders were involved from other states of Australia, as well as internationally, future targeted work will be required to explore the potential for implementation of these CPGs in a broader Australian health care setting.

Future directions

There has been increasing research into interventions for children with stroke over recent years. Despite this, the evidence reviewed in the current study demonstrated the number of studies, and quality of evidence generated from available studies, remains low. This is in contrast to the research literature for adults with stroke where there is a greater amount of high quality evidence to guide clinical practice(25). This study demonstrates a need for higher-quality research for children with stroke in the rehabilitation setting. Further, the lack of health professional consensus in some areas identified by this study represent important target areas to guide research into understanding the preferences of professionals, children and families. Multisite collaborations will be important to ensure sufficiently sized samples to explore this further.

In conclusion, this project has produced 31 clinical practice recommendations for the subacute rehabilitation of children with stroke. Future work is required to support the implementation of these recommendations into practice and the evaluation of clinicians' adherence to ensure that all children with stroke have access to high quality care.

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Conflict of interest

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