International Clinical Practice Guidelines for Cerebral Palsy

2014 REPORT OF THE EACD WORKSHOP & PRESIDENTIAL INTER-ACADEMY MEETINGS OF THE EACD, AACPDM & AusACPDM

This report has been prepared for the Boards and Leadership Representatives of the European Academy of Childhood Disability (EACD), the American Academy of Cerebral Palsy and Developmental Disability (AACPDM) and the Australasian Academy of Cerebral Palsy and Developmental Disability (AusACPDM), and is a compilation of the presentations given, discussions held and agreements made at the EACD Workshop and in the Presidential Meetings of the three academies in Vienna July 2014.

Contributors

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1. Executive Summary

No international agreed upon guidelines, based upon best-available evidence exist for cerebral palsy. The purpose and scope of a workshop and presidential meeting held in Vienna 2014 at the EACD meeting was to explore if agreement existed about the need for such guidelines and whether a process to develop guidelines could be agreed upon. The following agreements were reached:

1. Development of international clinical practice guidelines for cerebral palsy was wanted and perceived as worth doing
2. The guidelines should be underpinned by respect for the individual person and developed using best-available evidence, but present options that consider the cultural and economic implementation contexts
3. The guidelines should be developed using the best-available evidence and best practice for developing guidelines
4. The guidelines should be developed in compliance with the AGREE II tool so as to ensure a quality product
5. The first step in the writing guidelines should be to assess whether or not existing guidelines could be endorsed or updated
6. Guidelines should be developed using web authoring software to enable reading from a smart phone, plus they should be disseminated using infographics
7. Endorsement of the guidelines should be sought from the three academies and other relevant bodies
8. The choice of priority topics and author teams should include people with cerebral palsy and their families
9. An inter-academy steering committee with experience in developing clinical practice guidelines and systematic reviews should be established to progress the work along with appointment of a project officer
10. Priority topics were identified with the highest priority “easy win” topics comprising: participation; active motor training; early diagnosis; and outcome measurement. A Delphi Survey would be the natural next step.

2. Introduction

2.1 Background

Cerebral palsy is a life-long disorder requiring a variety of interventions depending on the location and magnitude of the brain damage, the person's age, the existing environmental barriers and facilitators and the person's individual characteristics. To date, **no international agreed upon guidelines, based upon best-available evidence exist**, about how to best address all the various health and function related problems.

2.2 Purpose and Scope

The purpose and scope of the workshop and meetings were to:

(a) **Explore the preliminary level of agreement** about the call for development of evidence-based clinical guidelines that are needs based – identified either by parents, children or practitioners – that could be implemented internationally appreciating the fact that each nation has different organizations and health policies.

(b) **Define a process** for developing such guidelines and explore the level of agreement about the proposed process and level of interest in collaborating to write the guidelines.

3. Method

Two methodologies were used, an interactive workshop and a follow-up presidential meeting with the workshop organisers.

3.1 Interactive Workshop

The interactive workshop was divided in two halves, the first half setting the background, the second half homing in on what kind of recommendations the delegates wanted to develop and the process to develop them. The full program is outlined in appendix A. The first part was a series of very brief presentations by invited speakers outlining their perspective on important considerations, which were provided to delegates as pre-reading. The second half was two hours of workshop discussions led by Ilona and Iona.

3.2 Presidential Meeting

A meeting was held with the Presidents of the three academies, or the President's representative and the Workshop Organising Committee. Present were:

Presidents and Nominated Representatives

Professor Hans Forssberg, President EACD

Professor Richard Stevenson, President AACPDM

Professor Darcy Fehlings, Incoming President AACPDM

Dr Adam Scheinberg, President Representative and Past President AusACPDM

Organising Committee

Professor Hans Forssberg, Karolinska Institute, Sweden

Professor Ilona Autti Rämö, Research Department, Finland

Professor Diane Damiano, National Institutes of Health, USA

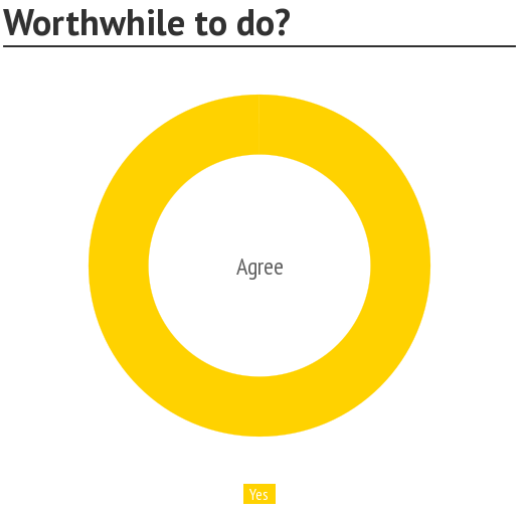
Professor Iona Novak, Cerebral Palsy Alliance, Australia

At the meeting the impressions of the workshop were discussed and a collaborative agreed upon action plan was devised, which is described in the results section of this report.

4. Results

4.1 Worth Doing?

"Gathering expertise and sharing resources to define the best options to improve some aspects of the quality of life of disabled children is right from the start a positive move for their parents" [Dr Alain Chatelin | Parent & Président de La Fondation Motrice]



RECOMMENDATION

There was **unanimous agreement** amongst workshop participants that despite it being a complex and large-scale task, it was worthwhile to collaboratively develop internationally agreed upon clinical practice guidelines for cerebral palsy. **Development of Clinical Practice Guidelines was recommended**.

"Children worldwide have very different possibilities in their access to diagnostic and therapeutic facilities. The resources are not used wisely, some out-dated and possibly harmful methods are being used and unrealistic demands and expectations are being set both on families and professionals. It's clear that there is currently a need of recommendations especially on the clinically relevant issues that: (a) demand time, money or resources; (b) have the potential to change the life course of the child with CP; (c) include risks; (d) require expertise and training; and (e) can be tackled with various options (with special relevance to LMIC)" [Professor Ilona Autti-Ramo | The Social Insurance Institution Finland]

4.2 Agreed Underpinning Principles

There was agreement that internationally-agreed upon clinical practice guidelines (CPGs) for cerebral palsy should be framed by the following underpinning principles:

(a) The **lived experience** of people with cerebral palsy and the **WHO's ICF-CY** framework for considering functional difficulties, environmental barriers and facilitators, and individual values and preferences;

(b) **Individualisation of intervention** based upon the person and families' self-identified needs and priorities;

(c) Guidelines should be developed using **best-available evidence**;

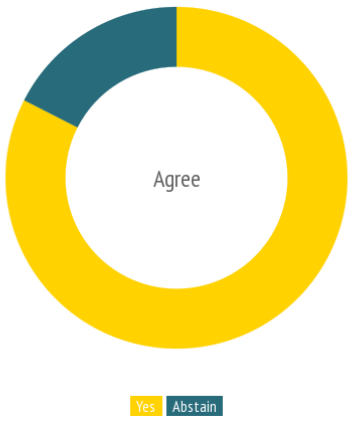
(d) Guidelines must respect **patient values, clinical experience and research evidence**; and

(e) Guidelines should consider the **transferability of evidence into different international contexts and provide a continuum of options**.

4.3 PROCESS RECOMMENDATION: Use Best-Available Evidence for Developing Clinical Practice Guidelines

Background: Substantial evidence exists about what to do and what not to do when writing clinical practice guidelines (CPGs). CPGs can be both effective and ineffective depending on how they are written and disseminated it is therefore important to consider international best practice for writing CPGs. How to write CPGs evidence has been generated and implemented by research groups with enormous international repute including the BMJ, the GRADE group, COCHRANE, the National Guideline Clearinghouse (NGC), NICE, the DECIDE group and could be used to inform the development of international CPGs for cerebral palsy.

Guidelines should be developed using best-avialable evidence for developing clinical guidelines?



RECOMMENDATION

There was **strong agreement and recommendation** amongst workshop participants, that international clinical practice guidelines for cerebral palsy should be developed using the best available evidence for developing clinical practice guidelines.

Evidence Summary: Multiple systematic reviews show that clinical practice guidelines (CPGs) effectively bridge the know-do research-practice gap if the knowledge gap is simple BUT they *do not* work if the knowledge gap to bridge is highly complex– we therefore must be strategic in the choice of questions and topics.

CPGs are highly effective for promoting change when they consider the local factors, and are ACTIVELY disseminated using active education and patient reminders. They should also describe the what, who, when, where and how to promote effective behaviour change consistent with the behavioural literature (Grilli 1994; Davis 1997; Grimshaw 2001, 2004 Michie 2004; Thomas 2009).

Best Practice Summary: The Institute of Medicine Standards recently published guidelines about what constitutes a trustworthy clinical guideline. Here are the basic features:

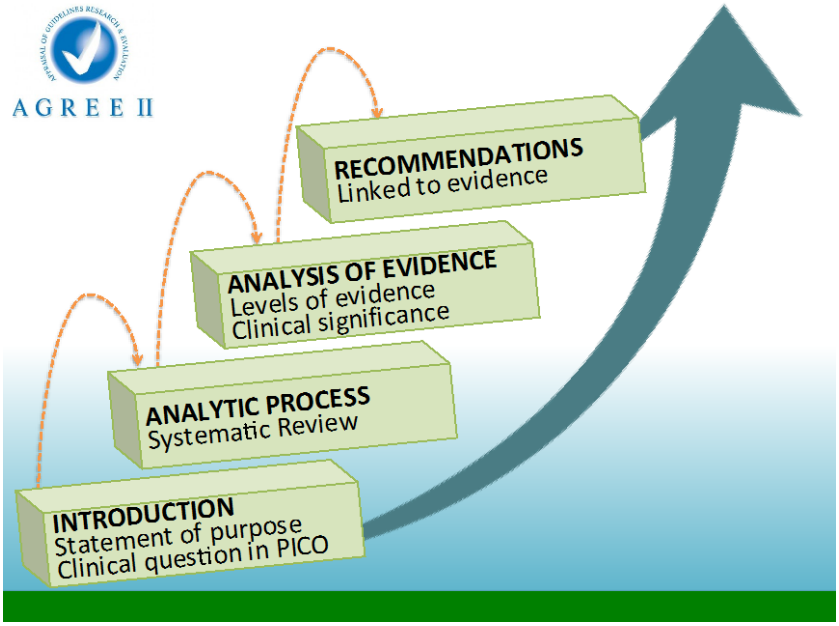
WHAT:

- Based on systematic reviews
- Include evidence quality ratings & strength of recommendations

- Discuss alternatives (e.g. consider a hierarchy of recommended alternatives when the cultural and financial context for implementation does not allow for the best-available evidence to be implemented)
- Consider patient subgroups & preferences
- Revised with new evidence
- Integrate expert opinion when evidence is not available (and clearly identify this integration in the CPG)

WHO: written by multidisciplinary experts + patients

HOW: use transparent process to minimise bias & conflict of interest (Institute of Medicine Standards, Laine 2011; Tappenden 2013)



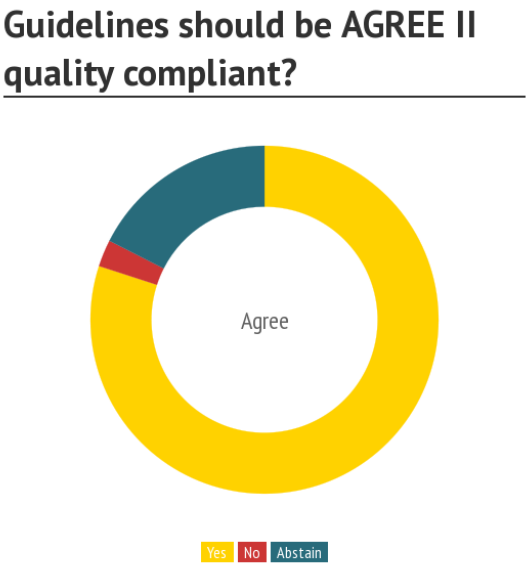
This is a synopsis of what the process for developing a trustworthy CPG looks like when following best practice.

4.4 PROCESS RECOMMENDATION: Use Quality Tools during Development

Multiple recommendations exist for essential features to include within a quality CPG. The AGREE II tool is the gold-standard tool for assessing the quality of the finished product (Brouwers et al, 2010). An examination of key recommendations about how to develop quality CPGs (from the continents represented; see Appendix B for an example CPG) were summarised and compared to the AGREE II tool. This data were summarised in the table below.

	AGREE II	NHMRC	NICE	BMJ	NGC
Scope & Purpose					
1. Objective is specified	Y	Y	Y	P	Y
2. Health question is specified [PICO format]	Y	Y	Y	P	Y
3. Intended population described in depth	Y	Y	Y	P	Y
Stakeholder Involvement					
4. Multidisciplinary group	Y	Y	Y	Y	N
5. Opinions of consumers are sought	Y	Y	Y	N	N
6. Target users of guideline are specified	Y	Y	Y	N	Y
Rigor of Development					
7. Systematic review methodology	Y	Y	Y	Y	Y
8. Evidence inclusion & exclusion criteria	Y	Y	Y	Y	Y
9. Evidence strengths & limitations described	Y	Y	Y	Y	Y
10. Methods for recommendations described	Y	Y	Y	P	N
11. Benefits, side effects & risks specified	Y	Y	Y	Y	Y
12. Evidence & recommendations linked	Y	Y	Y	Y	Y
13. Externally reviewed	Y	Y	P	Y	Y
14. Updating procedure	Y	Y	Y	Y	N
Clarity of Presentation					
15. Specific unambiguous recommendations	Y	Y	Y	N	Y
16. Range of management options	Y	N	Y	N	N
17. Key recommendations identifiable	Y	Y	Y	Y	Y
Applicability					
18. Facilitators & barriers to implementation	Y	Y	Y	N	N
19. Provides implementation advice	Y	Y	Y	N	Y
20. Implementation resource implications	Y	Y	Y	Y	N
21. Implementation monitoring criteria	Y	Y	Y	N	N
Editorial Independence					
22. No funding conflicts of interest	Y	Y	Y	N	Y
23. Competing interests described	Y	Y	Y	N	Y
Other					
24. Statement of best available evidence	N	Y	N	N	N
25. Legal disclaimer	N	Y	Y	N	N
26. Economic evaluation of guideline process	N	Y	N	N	N
27. Initial scoping to find existing guidelines	N	N	Y	N	N

28. Consideration of equality issues	**N**	**N**	**Y**	**N**	**N**
29. Signed contributor code of conduct	**N**	**N**	**Y**	**N**	**N**
30. Search includes economic evaluations	**N**	**N**	**Y**	**N**	**N**
31. Includes strength of recommendations	**N**	**Y**	**Y**	**Y**	**Y**



RECOMMENDATION

Given the comprehensive nature of the AGREE II tool and international acceptability with respect to standards of excellence: there was **good agreement and recommendation** amongst workshop participants, that international clinical practice guidelines for cerebral palsy should be developed in compliance with the AGREE II tool features.

4.5 PROCESS RECOMMENDATION: Don't Reinvent the Wheel

> *"We urgently need to become more involved and partner with global efforts and resources that already exist e.g. WHO global disability action plan" [Professor Diane Damiano | NIH USA]*

A preliminary literature search revealed that a number of clinical guidelines for cerebral palsy already exist in the published literature or public domain. These include but are not limited to:

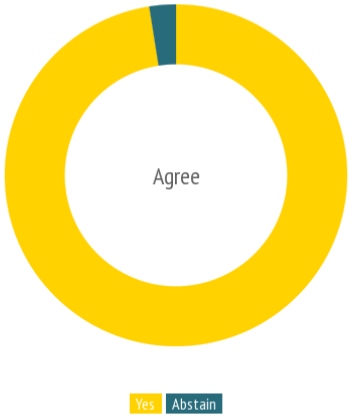
GUIDELINE	AUTHOR
Aquatic with land based physiotherapy	NGC
Aquatic therapy	NGC
Behavioral & oral motor feeding	NGC
Biofeedback in hemiplegia	NGC
Bone Density	Holland Bloorview

Botulinum toxin for neurological disorders (x7)	EJN
Cerebral Palsy (in progress)	NICE
Diagnostic Assessment	AAN
Diagnostic Assessment	Pediatrics
Hip Surveillance	AusACPDM
Lower extremity orthoses	NGC
Lower limb casting	NGC
Pediatric CIMT	NGC
Pharmacological Treatment Spasticity	AAN
SDR	NICE
Spasticity	NICE
Strengthening	NGC
Supported treadmill	NGC
Wheelchair delivery	NGC

In addition, a number of reputable groups host websites with guideline-like documents that could be reviewed. These include but are not limited to:

- CanChild | Keeping Current
- Cerebral Palsy Alliance | CP Decision
- MacGill University | CP Engine
- MacGill University | Childhood Disability Link
- Peninsula Cerebra Research Unit (PenCRU)
- Sunnyhill Rehabilitation | E_4P

Guideline development group should first consider whether all the existing guidelines could be used or updated?



RECOMMENDATION

Given the scope of the project: there was **strong agreement and recommendation** amongst workshop participants, that the NICE recommendation of reviewing whether or not **existing guidelines** could be used, modified, updated or endorsed, should be the **first step** in the guideline development process. A **thorough search of the published and grey literature** should be conducted, aiming to retrieve existing reviews. Groups who have already written guidelines should be invited into the team.

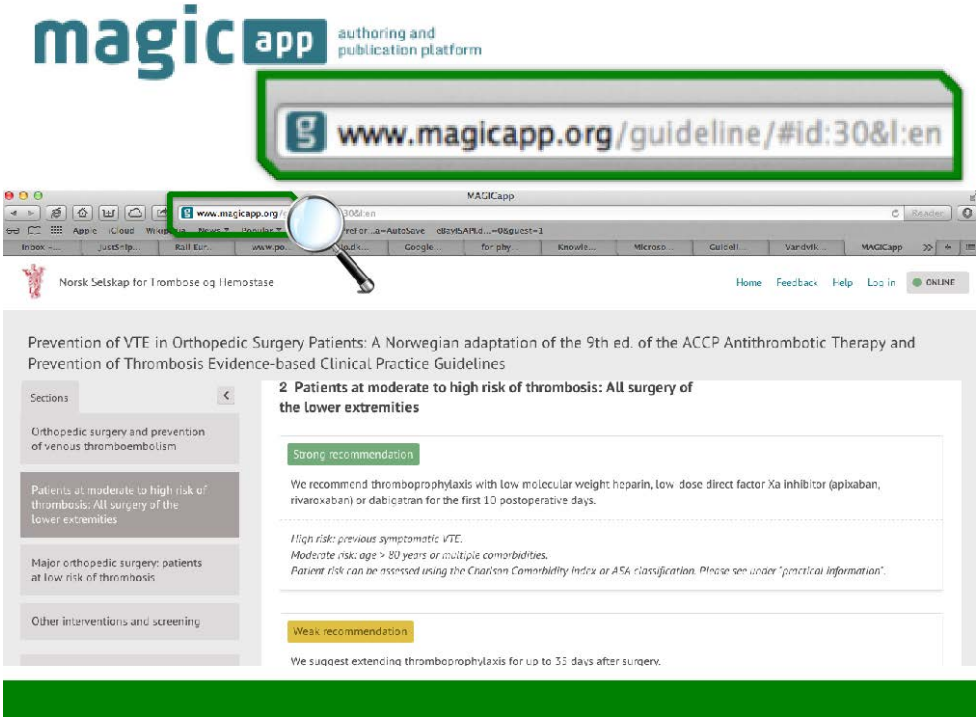
4.6 PROCESS RECOMMENDATION: Develop and Disseminate using Technology & Infographics

Evidence suggests CPGs are more likely to be used if they are available at the time of decision-making (Austin et al 1994; Balas et al, 1996; Bero et al, 1998; Buntinx et al 1993; Grimshaw et al, 2001; Grol & Grimshaw, 2003; Haines et al, 2004; Hunt et al 1998; Shea et al 1996; Sullivan & Mitchell 1995; Yano et al, 1995). Technological solutions are required to make CPGs available at the time of decision-making, but are expensive to develop and require compatibility and agreed security of IT systems.

MAGIC is an innovative new app for writing, authoring, updating and disseminating guidelines [http://www.magicproject.org]. MAGIC was developed by the GRADE group and is being tested by the DECIDE group (a 5yr project to

advance the dissemination of CPGs), which are two of the biggest CPG developer groups worldwide.

MAGIC App Example



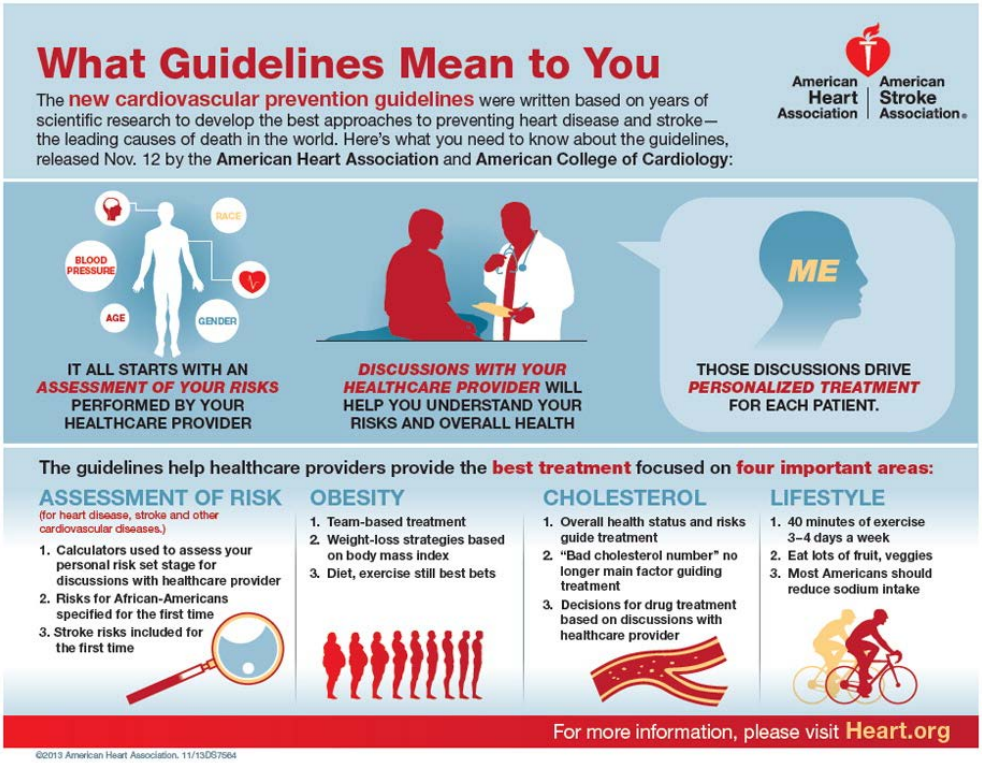
The major advantages of the International CPG for Cerebral Palsy group using MAGIC include:

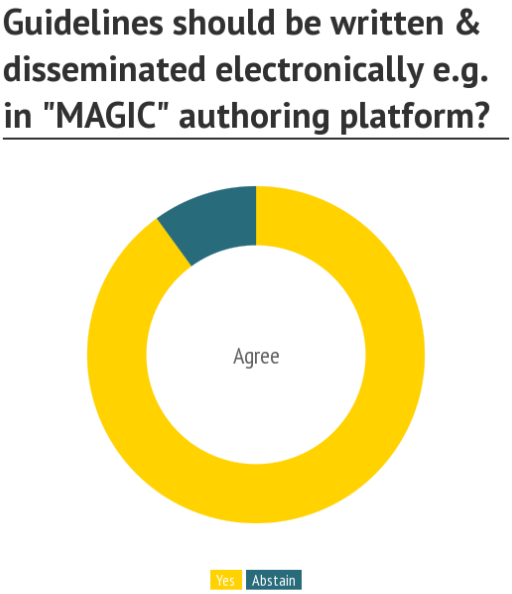
- The ease in which the group could develop guidelines without the need for a shared IT system
- The ease in which the group could update the guideline from any location worldwide
- The guideline/s would be disseminated on a smart phone, which are very often available in low to middle income countries (LMIC)
- The guideline would always be up-to-date as paper-copies do not exist

Evidence also suggests that patients can also influence the uptake of evidence, because they are the most interested in receiving high quality effective services (Bero et al, 1998; Grimshaw et al 2004; Grol & Grimshaw, 2003; Haines et al, 2004). If CPGs are disseminated in patient-friendly formats, patients are known to

influence the uptake of evidence, by seeking from their practitioner evidence-based services complying with guidelines.

Infographic Example



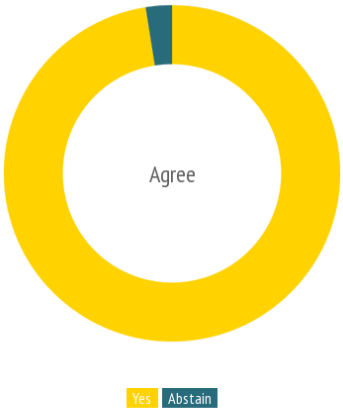


RECOMMENDATION

There was **strong agreement and recommendation** amongst workshop participants, that the clinical practice guidelines should be developed and disseminated **using an electronic system such as MAGIC**. Furthermore it was also agreed that **family-friendly infographics summaries** of the clinical practice guidelines should be developed, as evidence suggests patients can influence professionals to use best-available evidence.

4.7 PROCESS RECOMMENDATION: Endorsement should be sought

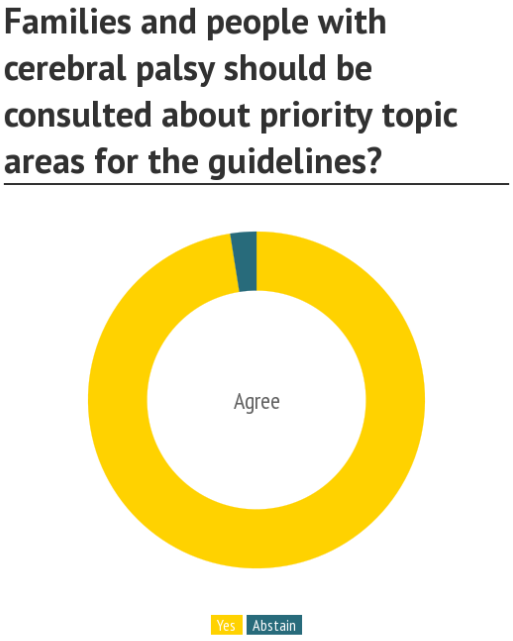
Guidelines endorsement should be sought from EACD, AACPDM, AusACPDM & other relevant bodies?



RECOMMENDATION

To assist with bridging the evidence-practice gap: there was **strong agreement and recommendation** amongst workshop participants, that all CPGs developed by the collaboration should be submitted to the EACD, AACPDM, AusACPDM and other relevant bodies for endorsement.

4.8 PROCESS RECOMMENDATION: Include people with cerebral palsy

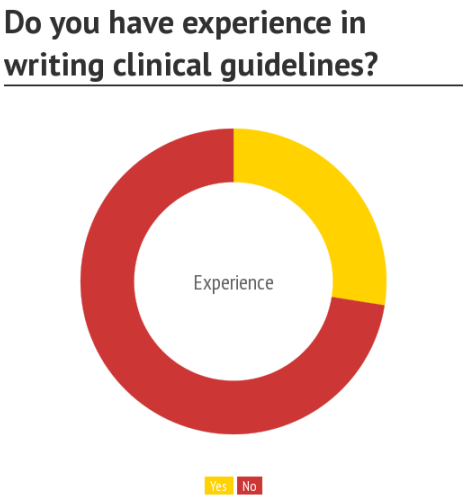


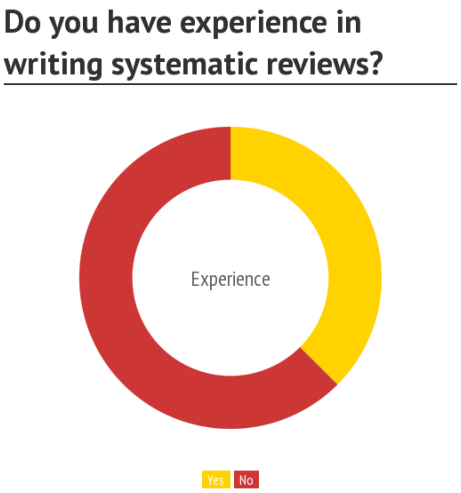
RECOMMENDATION

As per best-available evidence for developing CPGs and the agreed guiding principles: there was **strong agreement and recommendation** amongst workshop participants, that people with cerebral palsy and their families be consulted about priority topics for developing guidelines. The Delphi survey methodology was recommended. Furthermore, people with cerebral palsy and their families should be included as equal members in author teams.

4.9 PROCESS RECOMMENDATION: Establish a Steering Committee with Experience

Delegates at the workshop had a diverse range of interests and skills in relation to the development of CPGs and systematic reviews.



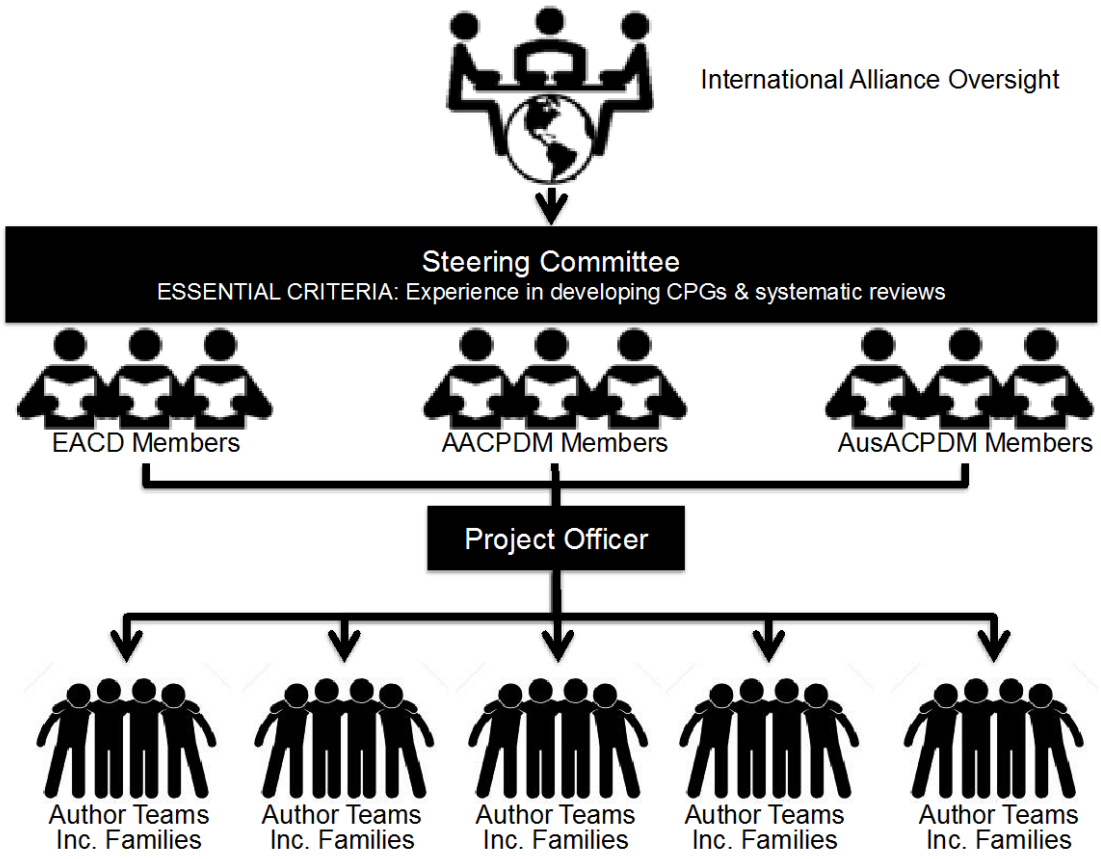


NOTE: There was some difference in interpretation of the question about experience in developing CPGs, i.e. some delegates answered no if they had not developed CPGs exactly as per best-available evidence for developing CPGs, whereas others answered yes if they had developed any type of CPG. Regardless of the accuracy of this data, the recommendation remains the same.

RECOMMENDATION: Develop a steering committee with **representatives from each academy** that have **experience in developing CPGs and systematic reviews**. The steering committee would be selected and auspiced by the International Alliance of Academies after ratification of the proposed Memorandum of Understanding (MOU) between the academies. The steering committee would then recruit, and provide leadership and support to voluntary multidisciplinary authorship groups that also include patient representatives. A list should be circulated to academy members inviting voluntary contributions and recommending potential collaborators to connect with.

It was also **recommended that a project officer be appointed** to coordinate the quality, timely and uniform delivery of the guidelines. This would need to either be a paid full time role or a PhD student specifically recruited for this purpose, where their doctoral studies were one integral and unique component of the wider guideline development project.

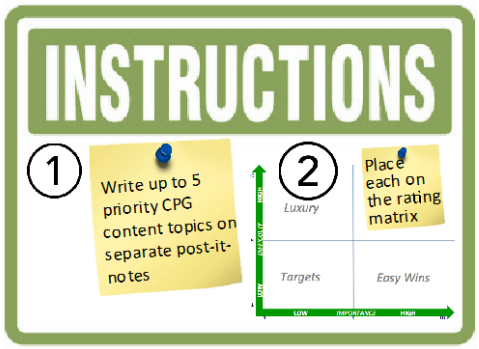
Recommended Governance

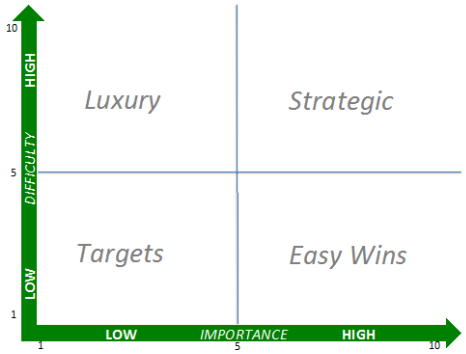


4.10 CONTENT RECOMMENDATION: Priority Topics

> *"There is a need to develop new strategies to improve health and well-being of children and youth with disabilities around the globe, mainly on the participation level but also on the functional and activity levels" [Professor Hans Forssberg | President of EACD]*

A voting system was used to elicit delegate-perceived priority areas for CPG content development. Each delegate could identify up to 5 priority areas, then assigned an importance rating out of 10 (10 highest priority, 1 lowest priority); and assigned a difficulty rating out of 10 (10 highest priority, 1 lowest priority). They then place their priority ratings on a matrix.





Below is the priority content topic areas developed and the corresponding ratings. Topics above the horizontal green line were suggested as priority topics by more than one delegate; items below the green line were raised by one delegate. Items are reported in their ranked order of importance, with the most important priorities first. An interquartile range of 2 or less indicates very high agreement amongst delegates.

Topic	Number of votes	Importance Median	Interquartile Range	Difficulty Median	Interquartile Range	Rating
Participation	10	10	5	4	2	Easy win
Active motor training / goal directed training	7	10	2	4	4	Easy win
Early Diagnosis*	6	10	0	3.5	5	Easy win
Outcome measurement and follow-up	6	10	2	3	2	Easy win
Attitude to disability	2	9.5	-	2.5	-	Easy win
Communication interventions	2	9.5	-	5	-	Easy win
Goal setting based on family & child unmet need	9	9	3	4	4	Easy win
Cultural & contextual considerations	3	9	-	7	-	Strategic
Transitions (to adolescence & adulthood)	2	9	-	2	-	Easy win
Pain Assessment & Management	9	8	4	3	2	Easy win
Nutrition management	5	8	2	5	5	Strategic
Early intervention*	3	8	-	8	-	Strategic
Prevention of CP	3	8	-	2	-	Easy win
Walking aides (including LMIC contexts)	2	8	-	6	-	Strategic
Prevention of secondary impairments	6	7.5	2	8	5	Strategic
Hip Surveillance (including non-surgical)	2	7.5	-	3.5	-	Easy win
Tone management (Spasticity & Dystonia)	4	7	4	4.5	2	Easy win
Oral feeding & gastrostomy	2	7	-	4	-	Easy win
Vision and visual motor	2	6.5	-	3	-	Easy win
Cognitive rehabilitation	2	6	-	7	-	Strategic
Orthotic/bracing interventions	2	6	-	2	-	Easy win

Adult CP	1	10	-	2		Easy win
Intensity of therapy for hemiplegia	1	10	-	1	-	Easy win
Obstetric care improvements in LMIC (infection)	1	10	-	10	-	Strategic
Policy Recommendations	1	10	-	2	-	Easy win
Drooling interventions	1	8	-	3	-	Easy win
Registration	1	8	-	4	-	Easy win
Research methodologies other than RCTs	1	8	-	6	-	Strategic
Interventions for specific sub-groups of CP	1	7	-	1	-	Easy win
Management algorithms	1	7	-	8	-	Strategic
Respiratory rehabilitation	1	7	-	5	-	Strategic
Classification tools (GMFCS, MACS, CFCS)	1	6	-	6	-	Strategic
Community rehabilitation	1	6	-	7	-	Strategic
Educational materials	1	6	-	8	-	Strategic
Mental health	1	6	-	3	-	Easy win
Occupational therapy for diplegia	1	6	-	6	-	Strategic
Quality of Life	1	6	-	4	-	Easy win
Sleep	1	6	-	2	-	Easy win
Terminology (common language)	1	6	-	5	-	Strategic
Wheelchair provision	1	6	-	3	-	Easy win
Burn out	1	5	-	3	-	Targets
SDR (best candidates)	1	5	-	5	-	Luxury

** CPGs for these topics are already in development*

> *"[In low to middle income countries there is the] necessity to increase public awareness of CP, underscore the value of early identification and initiation of culturally appropriate intervention services" [Dr Angela Kakooza-Mwesige | Makerere University Uganda]*

RECOMMENDATION: A Delphi Survey would help to gain consensus on priority topic areas to begin with. The aforementioned identified priority items could form round one Delphi survey, coupled with surveying the AACPDM, AusACPDM and consumers about their perceived prioirites.

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Appendix

Appendix A: EACD Workshop Program

Developing Global Guidelines for Professionals, Families and Communities to Enhance Functioning in Children with Cerebral Palsy

Venue: Schubert classroom, Reed Messe Congress Center

Time: 08.00 – 12.00, Thursday 3 July, 2014

Organisers: Ilona Autti Rämö, Iona Novak, Diane Damiano, Hans Forssberg

Programme

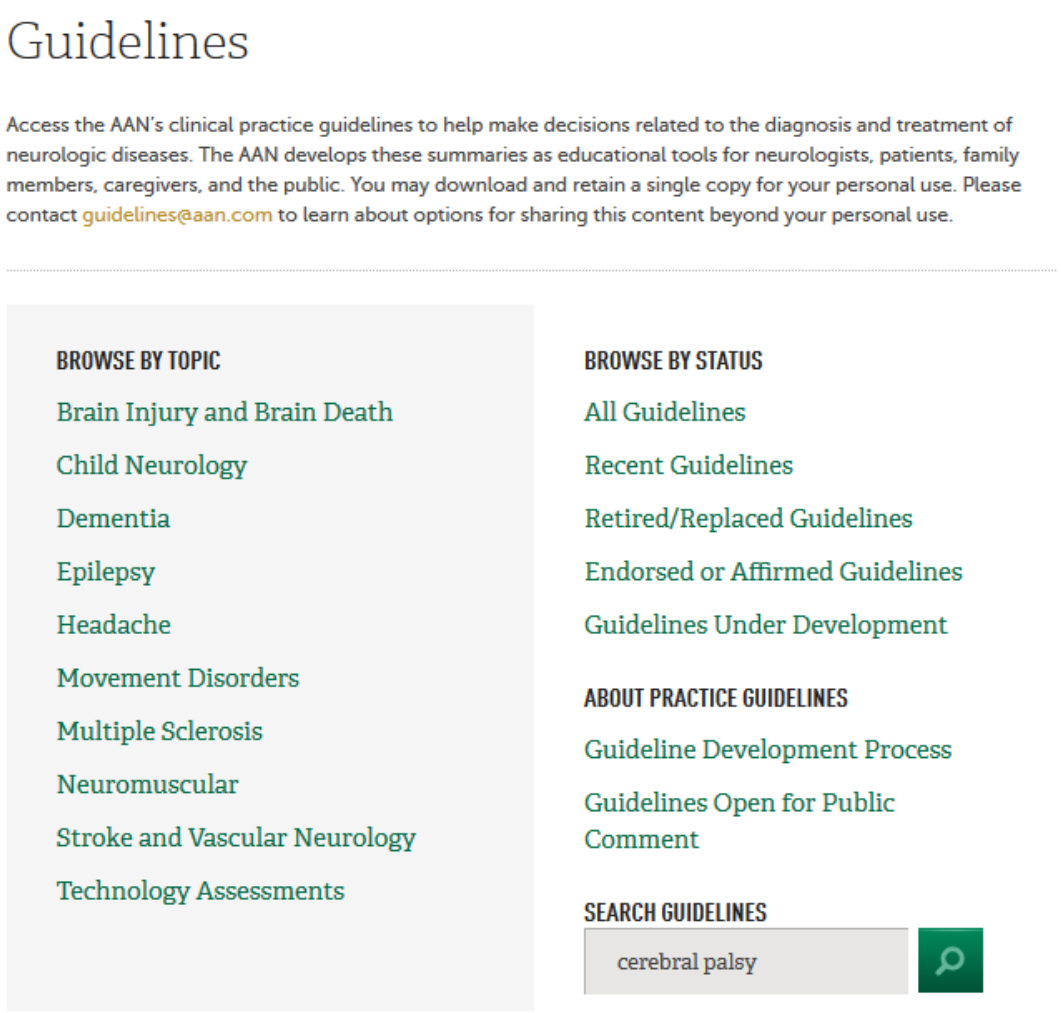
08.00- 08.20	**Introduction** Goals for an international professional network. Why we need global recommendations. Goals of the workshop.	Hans Forssberg
08.20-08.40	**Fundamental concepts** to build recommendations on (UNICEF report, WHO Europe report, Azov workshop (key principles))	Diane Damiano
Perspectives Panel		
08.40-08.50	**LMIC perspective on CP**. What kind of information is needed to develop intervention programs	Angelina Kakooza
08.50-09.00	**Family's perspective** on CP recommendations	Alain Chatelain
09.00-09.10	**Clinicians perspective** on CP recommendations	Giovanni Cioni
09.10-09.20	**Collaborations** between clinicians, researchers, children and families	Richard Stevenson
09.20-09.30	**Evidence based perspective** on CP recommendations	Iona Novak
09.30-09.40	**Societal, organizational and payers**	Ilona Autti

	perspective	Rämö
9:40-10:00	**Discussion** Summarize commonalities/ differences in perspectives	Hans Forssberg/ Diane Damiano
Coffee		
10.30-11-00	How could **key principles** of global recommendations/framework for CP management be constructed in a way that they can be transferred to various countries, cultures, and organizations	Ilona Autti Rämö
11.15-12.00	How can we proceed in order to develop such recommendations/framework? Suggestions for an **action plan** to the IAACD	Iona Novak

Appendix B: Example of Clinical Practice Guidelines

American Academy of Neurology

Website: www.aan.com/Guidelines



Guidelines

Access the AAN's clinical practice guidelines to help make decisions related to the diagnosis and treatment of neurologic diseases. The AAN develops these summaries as educational tools for neurologists, patients, family members, caregivers, and the public. You may download and retain a single copy for your personal use. Please contact guidelines@aan.com to learn about options for sharing this content beyond your personal use.

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Child Neurology
Dementia
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Headache
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Stroke and Vascular Neurology
Technology Assessments

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cerebral palsy