Guidelines for Developing an AACPDM Care Pathway

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Definition of an AACPDM Care Pathway: *A care pathway is a practical summary, including an algorithm, of evidence-informed guidelines or the best evidence for an aspect of care/services for individuals with childhood-onset disabilities to inform clinical practice. The main goal of care pathways is to provide recommendations that allow users to implement evidence-informed care in clinical practice at the point of care.*

When to create a Care Pathway

A care pathway can be developed in (but not limited to) the following circumstances:

- When there is a need to describe best practice clinical recommendations in an important health condition or setting that individuals with childhood-onset disabilities experience or for a service that they seek.
- When multiple treatment options for a condition exist.
- When a systematic review has been completed recently (meaning the literature search dates are within five years of the initial care pathway application and publication is within three years of the initial application) for the topic of the Care Pathway.

Priority setting for Care Pathway development

Priority setting for topics is directed by the AACPDM Care Pathways Council who may consider input from key advisors. This ensures resources for the AACPDM care pathways are devoted to those areas where recommendations from the AACPDM will provide the greatest benefit.

How to create a care pathway?

Overview of Methodology

Every Care Pathway must begin with a recent systematic review on the topic (within three years). If a systematic review is recently published, this is an excellent starting point for a care pathway. If a systematic review has not yet been completed, the applicants will need to identify or complete a high-quality systematic review published in a peer-reviewed journal prior to applying for a Care Pathway.

Once the evidence base is established through a high-quality systematic review published within the prior three years, care pathway authors can then move from evidence to actionable recommendations. For this process, the AACPDM Care Pathways Council endorses the GRADE (Grading of Recommendations Assessment, Development and Evaluation) methodology. GRADE is a well-developed formal process to assess the quality of scientific evidence in systematic reviews and to develop recommendations for clinical practice that are as evidence-based as possible.

GRADE provides guidance on framing questions, choosing and prioritizing outcomes of interest, evaluating the evidence (including making explicit the risk of various biases), and considering issues of imprecision, inconsistency between studies, and indirectness (i.e., making inferences using evidence from a similar population). Using the 12-step evidence to decision GRADE framework, the available evidence is graded for its probable accuracy (i.e., quality) and the confidence with which it can be used (i.e., strength) for the purpose of making clinical decisions. In arriving at one of four types of possible recommendations, GRADE incorporates evidence about costs, benefits, and harms, and explicitly considers the values and preferences of patients and society at large. GRADE also provides clinicians, patients, and policy makers with a guide to using those recommendations.

It is expected that all Care Pathways be produced using the GRADE framework. The AACPDM Care Pathways Council strongly recommends that key authors be experienced in using GRADE methodology or undertake GRADE training. GRADE training is available at:

1. In North America (provide links)
2. In Australia at the Melbourne GRADE Centre one- or two-day courses

STEP 1: An **application** to request permission to develop a care pathway will be made to the AACPDM Care Pathways Council, through the AACPDM office, by an interested team. The application will include a:

Title

Team roster: The volunteer team should include experts from multiple disciplines relevant to the care pathway. The team should have expertise in the clinical management of the condition and research/methodology knowledge. Prior experience and/or training in GRADE should be described for at least one key team member. A lead should be identified and should be an AACPDM Member. Participants who are non-AACPDM members are considered when representatives of clinical diversity or necessary expertise are not available from within the AACPDM membership. AACPDM Members should approximate at least 50% of the team. Exceptions should be reviewed with the Council and the AACPDM Board as necessary. The team members will declare any potential conflicts of interest, and these will be reviewed by the team lead and the Care Pathways Council. The team must include at least one individual with a childhood-onset disability or family member who does not need to be an AACPDM member. Consumer consultation is expected. The team could be layered in two parts and include a core team that is primarily responsible for developing the 'AACPDM care pathway' and a consultative team that is involved as needed, including reviewing drafts of the care pathway sections.

Statement of objective(s) and a clear description of the health condition/service/care need that will be the area of focus, the intended target population and expected benefit(s) or outcome(s) as well as the target clinical providers of the care pathway.

A copy of at least one published systematic review (preferably with meta-analysis where possible) on the topic of the care pathway. This/these systematic review(s) must include a literature search conducted within the prior five years and be published within the prior three years. The systematic review(s) should be of adequate quality (such as would be determined by AMSTAR).

Planned methods to develop the care pathway.

STEP 2: The AACPDM Care Pathways Council will **review** the application and the systematic review(s) to determine appropriateness for a care pathway. The Council may make suggestions back to the care pathway development team. Additional team members may be suggested to ensure all relevant perspectives are represented. If the AACPDM Care Pathways Council approves the application, the team will be asked to submit a project plan outlining key elements of the care pathway development steps with a particular focus on what is in/out of scope in the pathway, assumptions, and deliverables. The team lead will be expected to attend Care Pathways Council meetings and provide regular (at least quarterly) updates with an anticipated submission of the candidate care pathway (STEP 6) no later than two years following application approval.

STEP 3: Based on the relevant systematic reviews, the expert team will formulate clinical recommendations with specific formatting following the 12-step evidence to decision framework. As noted, GRADE methodology must be used to go from evidence (systematic review) to recommendations. Teams are encouraged to utilize GRADE Pro for this process https://gradepro.org/.

Evidence summaries are required for each comparison of treatment strategies (including no treatment or usual care). These are presented by tables that list the primary studies and their Risk of Bias assessments (shown as red for high, green for low, and yellow for some or moderate), reported effects and effect sizes, and diagrams displaying statistical (e.g., forest plot) or non-statistical (e.g., combining P-values) syntheses of quantitative intervention effects.

Syntheses of evidence are presented in two formats: Evidence Profiles and Summary of Findings Tables. Both types of syntheses are organized by the outcomes designated as critical or important, including evidence about harmful effects. Contents differ based on the intended audience. GRADE Evidence profiles (or Evidence to Decision Frameworks) provide a detailed understanding of the judgments determining the certainty in the evidence for each outcome; as such, they are essential for consideration by groups when developing their recommendations. Summary of Findings tables, based on the Evidence Profiles, are useful for a broader audience, including end users of care pathways. These findings may be formulated such that they are appropriate to include as practical tools in the care pathway.

STEP 4: Once recommendations have been agreed upon by the team, **supporting documentation** will be developed. This includes Section I (Evidence summary), Section II (active links to the published Clinical Practice Guideline and published Systematic Review(s), Section III Practical Tools (for Clinicians to implement the Care Pathway including a lay summary for families), and Section IV Acknowledgements (Care Pathway/CPG members, Community Advisory Group, External Consultation)

Section I Evidence Summary (in keeping with website format)
The expert team will develop the Evidence Summary which consists of the following sections.

A. **Title and Contributors**

The care pathway title should concisely describe the topic. The authors will include all core contributors. The pathway lead will be listed first, with "(lead)" indicated beside their name.

B. **Introduction to the Topic**

This section can include working definitions, why the topic is important for childhood-onset disabilities, the target population for the Care Pathway, and the target clinical providers.

C. Assessment and Diagnosis (when appropriate for the topic)

For this section, the team should briefly comment on the psychometric properties of relevant screening and diagnostic tools. If available, cite systematic reviews on assessment (clinimetric SRs) or diagnostic accuracy (STARD/STARD-T criteria). Recommendations should reflect best practices based on measurement properties and clinical expertise. Refer to NINDS/AACPDM Common Data Elements for CP when applicable.

D. **Summary of the Care Pathway/Clinical Practice Guideline.**

This section will include the care pathway/clinical practice recommendations (often in table format) and reference the published CPG and published systematic review(s). This step will also include the algorithm (see step 5).

E. A**lgorithm**

An algorithm will be constructed in a flow chart format utilizing any preferred software (e.g. MS PowerPoint®, MS Visio®, LucidChart,) and saved as a pdf or jpg file for uploading. The structure or format of the algorithm will be dependent on the condition and the suggestions from the expert team. The box should include the core components required by the health professional for making treatment decisions (e.g. GMFCS level, contraindications). The maximum page length for the algorithm is ideally two pages (embedded links will be allowed). Please note that once an algorithm is finalized, it can be formatted by the AACPDM pathway team support person (office staff).

F. Footnote

A footnote at the bottom of the evidence summary should include the following statement "The purpose of this document is to provide health care professionals with key facts and recommendations for the assessment and treatment of individuals with childhood-onset disabilities (can insert the topic area as well). This evidence summary is based on a peer-reviewed systematic review. However, health care professionals should continue to use their own clinical judgement and consider additional relevant factors and context. The AACPDM is not liable for any damages, claims, liabilities, or cost arising from the use of these recommendations including loss or damages arising from any claims made by a third party." A copyright should also be included with the date of finalizing the Care Pathway, AACPDM Care Pathways.

Section II Published Evidence

This section includes active links to the published care pathway/Clinical Practice Guideline and published Systematic Review(s). It can also include a '**New Literature Summary'** if relevant**.** A summary of new literature published since the last systematic review must be systematically

searched, compiled, and posted in Section II. This may be submitted as a journal manuscript or uploaded as a Word document.

Section III Practical Tools to Implement the Care Pathway
This section consists of links to relevant clinical tools for Clinicians to implement the Care Pathway and should include a lay summary for families.

Section IV Acknowledgements
This section should list the: i) Clinical Practice Guideline/Care Pathway team members with the lead listed first. It should include their name, institution, geographical location and specialty expertise ii) Consumer Group, iii) Evidence and Administration Group, iv Participants in the External Review Process of the CPG/Care Pathway.

STEP 5: All materials should be circulated to an advisory group for **review**. The advisory group will be identified by the pathway team and should be representative of individuals with childhood-onset disabilities, families/caregivers, and community clinician experts. This representative external advisory group will provide feedback including on the feasibility, acceptability, and cultural sensitivity of the pathway. A teleconference call will be organized by the AACPDM Care Pathways Council with the expert team and the advisory group to review the pathway (evidence summary with algorithm) to provide input and suggestions and where appropriate the pathway will be revised thereafter.

STEP 6: The expert team will finalize the **content** items for Sections I-IV that will be posted online on the AACPDM Care Pathways website and will submit to the AACPDM Care Pathway Council for review.

STEP 7: The Care Pathway Council will review the submitted documents and provide feedback. Once feedback from the Council has been addressed by the care pathway team, the materials will go to the Board of Directors for review and **initial acceptance**.

STEP 8: Following initial acceptance by the Board of Directors, the pathway will be posted for **public comment** on the AACPDM website for 30 days. After this time period, the pathway will be removed pending final revisions and final acceptance.

STEP 9: The AACPDM office team will summarize and provide the feedback to the Care Pathway team. Following any revisions by the Care Pathway expert team that arise from public comment, the Care Pathway Council will review, approve and forward the pathway to the Board for **final acceptance**. A disclaimer will be added to the pathway and the AACPDM staff will post the pathway on the website. The expert team will verify the functionality of the online care pathway and approve the website live date included on the pathway. Copyright of the 'AACPDM Care Pathway' will be assigned to the AACPDM.

The final care pathway/clinical practice guideline should be submitted for peer-reviewed publication. DMCN is the official journal of the AACPDM, and is the preferred journal for

publication, but it is not mandated as the journal of choice. Authors should notify the AACPDM office if a journal outside of DMCN is targeted. Outputs that become part of the Care Pathway include the peer-reviewed and published Clinical Practice Guideline and the AACPDM Care Pathway website sections including: Section I (Evidence summary with algorithm and recommendations[see below]),Section II (active links to the published systematic review, the published Clinical Practice Guideline), Section III (practical tools to aid clinicians in using the Care Pathway), and Section IV (acknowledgements).

STEP 10: A blast email will be circulated to the AACPDM membership and networks that a new pathway has been posted. The AACPDM will allow for ongoing feedback on the Care Pathway at which point any comments/feedback with regards to the pathway will be distributed to the pathway team for a direct response. The AACPDM office will forward the emails received to the pathway team leader on a monthly basis for the first three months and then every 6 months. The pathway team lead or delegate is encouraged to respond to the inquiry and consider any potential revision to the pathway process based on feedback.

STEP 11: Ongoing **review** of each Care Pathway is required periodically.
The options for the Care Pathway after review are to retire, reaffirm, update, or revise the pathway:

- -If **no update** is required, the website will reflect that the Care Pathway was reaffirmed.
- -If **minor update**s are required that do not substantially affect Care Pathway recommendations, the website will reflect that the Care Pathway was reaffirmed with minor updates (noted with a brief summary of the results of the literature search).
- -If more **substantial revisions** to the Care Pathway are required (meriting an updated systematic review and updated recommendations), a message indicating the pathway is under revision will be posted on the AACPDM website, typically while permitting the initial Care Pathway to remain available.
- -A **retired** Care Pathway will be clearly marked as retired on the website. A brief statement will be provided indicating the team and the Council's views regarding the validity of the retired Care Pathway (indicating, for example, whether it is outdated because substantial evidence was not included or because methodological standards have changed).

If it is not already underway, the AACPDM staff will automatically reach out to the expert team four years after publication to begin planning a review. The team will be asked to assess the scope of the required update, to establish a plan for the review before year 5. An earlier review may be requested at any time by the Care Pathway team lead or by the Care Pathway Council (e.g., in the event of the emergence of substantial new evidence or the emergence of controversy regarding best practices).

At the time of review, the team (whether consisting of its original members or including new recruited members) is asked to perform an updated preliminary literature search and to make a recommendation for the next course of action. The team will present its recommendations via a

presentation to the Care Pathway Council who will make final decisions regarding updates or revisions and, if an update or revision is recommended, oversee its completion with updates during regular Care Pathway Council meetings. Final Care Pathway updates or revisions will also be reviewed by the Care Pathway Council with standard processes.

RESOURCES

GRADE

(1) Some papers in the Journal of Clinical Epidemiology contain detailed background information and instructions for every step of GRADE (See Appendix I, pages 15-17, for complete reference list).

(2) GRADE Handbook: https://gdt.gradepro.org/app/handbook/handbook.html

(3) GRADEpro GDT software: https://gradepro.org/

(4) The GRADE Working group website has links to tutorials and presentations and annual comprehensive courses on GRADE: http://www.gradeworkinggroup.org/.

Terminology

https://cebgrade.mcmaster.ca/checklistglossaryprintable.pdf (From the Grade Centre at McMaster University, this is a glossary of terms and acronyms appearing throughout the GDC checklist.)

https://bestpractice.bmj.com/info/toolkit/ebm-toolbox/a-glossary-of-ebm-terms/ (From British Medical Journal Best Practice)

https://gdt.gradepro.org/app/handbook/handbook.html GRADE Handbook GRADE guidance with extensive discussion of each topic.

Tools

1. Guidelines International Network (GIN) - McMaster Guideline Development Checklist (GDC). Available at: https://heigrade.mcmaster.ca/guideline-development/using-checklist

2. AGREE II (Appraisal of guidelines for research and evaluation). Available at: https://www.agreetrust.org/resource-centre/agree-ii/
AGREE II was developed to address the issue of variability in the quality of Clinical Practice Guidelines. It can help guideline developers and users assess the methodological quality of full CPG guidelines.

3. AMSTAR 2 (Measurement Tool to Assess quality of Systematic Reviews). Available at: https://amstar.ca/Amstar_Checklist.php

AMSTAR (2007) was developed to address the variation in quality and empirical validation of systematic reviews of randomized controlled trials. AMSTAR 2 (2017) is an updated version of AMSTAR which enables appraisal of systematic reviews of both randomized and non-randomized studies of healthcare interventions.

4. ROBIS (Tool to assess risk of bias in systematic reviews). Available at: www.robis-tool.info.

ROBIS assesses the risk of bias of studies included in a systematic review. It can be used to evaluate studies of intervention, etiology, diagnostic, and prognostic systematic reviews.

5. PRIOR (Preferred Reporting Items for Overviews of Reviews)

Overviews of reviews (sometimes referred to as "overviews of systematic reviews," "reviews of reviews," "reviews of systematic reviews," or "umbrella reviews") analyze the results of multiple related systematic reviews. PRIOR is a reporting guideline for overviews of reviews of healthcare interventions that is currently in development. For guidance until the final tool is available, please refer to:

Lunny C, Brennan SE, McDonald S, McKenzie JE. Toward a comprehensive evidence map of overview of systematic review methods: paper 1 –purpose, eligibility, search and data extraction. Syst Rev. 2017;6(1):231.

Lunny C, Brennan SE, McDonald S, McKenzie JE. Toward a comprehensive evidence map of overview of systematic review methods: paper 2 — risk of bias assessment; synthesis, presentation and summary of the findings; and assessment of the certainty of the evidence. Syst Rev. 2018;7(1):159

6. PRISMA (Preferred Reporting Items for Systematic Review and Meta-Analysis) Available at: http://annals.org/aim/fullarticle/744698/prisma-statement-reporting-systematic- reviews-meta-analyses-studies-evaluate-health

The original PRISMA checklist was developed in 2009 to ensure all the critical methodological components of a systematic review are reported. There are currently over 400 PRISMA guidelines housed on the Enhancing the QUAlity and Transparency Of health Research (EQUATOR) Network's Website. PRISMA extensions relevant to Care Pathways include:

- 2018 PRISMA-ScR Checklist for reporting scoping reviews
- PRISMA-C Checklist for reporting systematic reviews for children, In progress
- PRISMA-PC Protocol for systematic reviews for children, in progress

7. Critical appraisal tools for primary research studies

Two specific tools are recommended by GRADE: Cochrane Risk of Bias Tool (RoB2) for randomized controlled trials, and ROBINS-1 for all types of observational study designs. See Cochrane Handbook for additional information and links to tools.

- Links to Cochrane Risk of Bias 2 tool training, webinars and information

https://methods.cochrane.org/risk-bias-2

- Link to RoB2, BOBINS-I, ROBINS-E, ROB-ME, robvis tools

https://www.riskofbias.info/welcome/rob-2-0-tool

8. Equator Network (Repository of reporting guidelines)
https://www.equator-network.org

Other standardized, credible tools may be used to appraise other study designs (e.g., qualitative, single subject). Suggestions for appraisal tools for other study designs include:
-Johanna Briggs Institute (JBI) Checklists for Analytical Cross Sectional Studies, Case Reports, Case Series, Diagnostic Test Accuracy Studies, Economic Evaluations, Prevalence Studies, Qualitative Research and scoping reviews.
https://urldefense.proofpoint.com/v2/url?u=https-3A joannabriggs.org_ebp_critical-5Fappraisal-5Ftools&d=DwIFAg&c=yzGiX0CSJAqkDTmENO9LmP6KfPQitNABR9M66gsTb5w&r=KUNAV1nA0lCR_1Hze-At2zmbo98saAAmV848HmLmIIE&m=8Lee-YBAnlb-1fb8dNt67cAfMqrnobSXjobTXw6Rm18&s=Hfizf9ARIdm_ilwmx1oaO8nLwwoT0s1VUwU7eht9iTM&e=

-Critical Appraisal Skills Programme (CASP) Checklist for qualitative research
https://urldefense.proofpoint.com/v2/url?u=https-3A casp-2Duk.net_wp-2Dcontent_uploads_2018_01_CASP-2DQualitative-2DChecklist-2D2018.pdf&d=DwIFAg&c=yzGiX0CSJAqkDTmENO9LmP6KfPQitNABR9M66gsTb5w&r=KUNAV1nA0lCR_1Hze-At2zmbo98saAAmV848HmLmIIE&m=8Lee-YBAnlb-1fb8dNt67cAfMqrnobSXjobTXw6Rm18&s=iJQK3Z5-PnjkgeI2YrTww6hjHF3vQEU05Ttdj5uD8zY&e=

-Mixed Method Appraisal Tool (MMAT) Version 2018
http://mixedmethodsappraisaltoolpublic.pbworks.com/