NICE National Institute for Health and Care Excellence

NICE advice

UK Achondroplasia Network's consensus guideline for multidisciplinary care of children and young people with achondroplasia: NICE review

NICE review

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Overview

NICE has reviewed the UK Achondroplasia Network's consensus guideline for multidisciplinary care of children and young people with achondroplasia. The UK Achondroplasia Network is part of the Skeletal Dysplasia Group.

This review has been carried out to support improved care and outcomes for children and young people with achondroplasia, and to assist healthcare professionals in their decision making. NICE has chosen to present the strengths and limitations of the guideline because:

- it covers a condition for which there are no NICE guidelines
- it was developed using appropriate processes and methods.

Disclaimer

NICE does not assume responsibility for the content of the reviewed guideline, including its clinical recommendations, accuracy, or its relevance to specific patient circumstances. Healthcare professionals should use clinical judgment and consider local policies, individual patient needs and other relevant guidance before applying any of the clinical recommendations from the reviewed guideline.

NICE commentary

NICE has reviewed the UK Achondroplasia Network's consensus guideline for multidisciplinary care of children and young people with achondroplasia.

Summary of the review

The guideline clearly describes its objectives, its users and the population to whom the recommendations apply. The recommendations are specific and clearly presented, and relevant stakeholders were involved throughout the development process.

No formal systematic review of the literature was undertaken; instead, the recommendations were developed by clinical experts using consensus methodology and reviewed by patient representatives. The consensus methodology and the process for formulating the recommendations are clearly described. The guideline has been endorsed by relevant professional organisations.

Although the guideline does not address the implementation of the recommendations or their resource impact, it is clear that the recommendations were developed within the context of UK clinical practice. Future updates could explicitly outline the impact of the recommendations on UK practice to improve clarity and usability.

Review process

NICE has reviewed the guideline using AGREE II assessments. This is a structured approach to evaluating the quality of clinical guidelines.

Strengths of the guideline

- The guideline was developed by specialist clinicians from across the UK and was reviewed by patient advocacy groups, parents and clinicians from all the major UK units that care for people with achondroplasia. The guideline was also peer reviewed before publication in Archives of Disease in Childhood.
- The guideline clearly describes its objectives, its users and the population to whom

the recommendations apply. The supplementary material supports this by providing details of the healthcare professionals that should be included in the achondroplasia multidisciplinary team.

- A modified Delphi process was used to formulate the recommendations. This is clearly described. The supplementary material provides further details of the voting process and its outcomes, and a summary of the expert commentary on the draft statements used.
- The recommendations are specific and clearly presented. The guideline has separate sections for different age groups, each with sub-sections on different aspects of care. The guideline provides rationales for the recommendations and presents options of care. Recommendations are easy to identify through the use of flowcharts, coloured boxes and tables.
- The guideline clearly states that a biotechnology company provided logistics funding for the meeting to agree the Delphi statements and funding for medical writing support, but the guideline was developed independently without any input from the funder. The guideline is endorsed by professional societies.

Limitations of the guideline

- There are inherent challenges in developing guidance for rare diseases, such as limited published evidence.
- The guideline did not include a literature review or a systematic review, and no review questions were specified.
- A non-systematic search for evidence was used to inform the framework for the guideline.
- Although the guideline includes references to literature used to inform the recommendations, there is limited information on the process used to select or assess this evidence.
- In addition, there is no discussion of the strengths and weaknesses of the cited evidence. Consideration of health benefits and risks was noted for some recommendations, but it is unclear if these were considered across all recommendations.

Other observations

- Some of the recommendations are included as part of supplementary material, and this may mean some users overlook them.
- There is no information on how the guideline will be updated.
- There is limited information on the applicability of the guideline according to AGREE II criteria. No cost or resource analysis was carried out and there is little detail on facilitators and barriers to implementation. There are no specific implementation tools and no audit or monitoring criteria.

Users should be aware that this is not NICE guidance and that the development does not follow NICE's published processes and methods.

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