

European Achondroplasia Forum Standard Operating Procedure

Document no. 101	Title Developing Guiding Principles/Recommendations	
Version no. 1.0	Prepared by EAF Steering Committee	Date prepared 16 February 2022
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Policy

Developing Guiding Principles/Recommendations

Background

The protocol for this SOP was developed by the EAF Steering Committee with advice from Professor Chris Edwards. The protocol was adopted, endorsed, and used by the EAF Steering Committee at a meeting held on 10th December 2020. This SOP formalises the protocol used and has been approved in its current form by the EAF Co-Chairs, with endorsement from the Steering Committee via online vote held on 8th July 2022.

Purpose

To define the European Achondroplasia Forum's (EAF) policy for developing and reaching consensus on recommendations for management of achondroplasia

Scope

To be used in all projects requiring consensus on proposed principles/recommendations that influence clinical practice.

Responsibilities

EAF Steering Committee

1. Assess projects brought to their attention for policy development with fair, unbiased consideration
2. Review and consideration of proposed guiding principles/recommendations
3. Anonymous voting on proposed guiding principles/recommendations and level of agreement

Moderator

1. Fair, inclusive collation of proposed guiding principles/recommendations in collaboration with EAF Project Lead/EAF Chair(s)
2. Preparation of materials to enable Steering Committee discussion and anonymous voting
3. Collation of voting results and report back to EAF Steering Committee

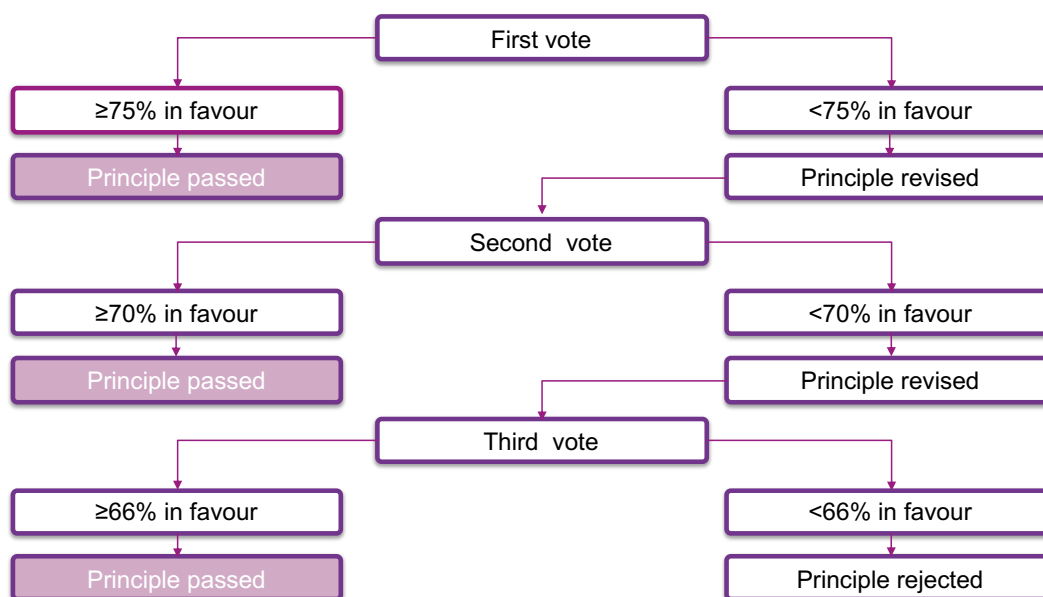
Definitions

Guiding Principles

Overarching considerations for the management of achondroplasia that can be applied within individual systems of management to support healthcare professionals, patient advocacy groups, and policy makers providing services for people with achondroplasia

Procedure

1. Projects to define recommendations/guiding principles seeking EAF endorsement should be brought to the EAF Steering Committee
2. Proposals for recommendations/guiding principles to be submitted to moderator
3. Moderator to compile group recommendations/guiding principles in preparation for discussion
4. A meeting of the EAF Steering Committee and invited experts to be convened to discuss the proposals in detail; for content, support from the literature or collective expert opinion, and wording
5. 2/3 (two thirds) of the Steering Committee must be present for a valid vote; if <2/3 of the Steering Committee are available, the vote must be postponed
6. Anonymous voting to be held to accept or reject each proposal as follows:
 - Vote 1: For a principle to be accepted, a majority of 75% in favour is needed
 - Vote 2: Should 75% not be reached, text should be revised, and a subsequent ballot held requiring a majority of 70% in favour to pass
 - Vote 3: Should 70% not be reached, text should be revised, and a subsequent ballot held requiring a majority of 66% in favour to pass, or proposal is rejected
7. On reaching a vote to pass a proposal, anonymous voting to be held on level of agreement, ranging from 1, no agreement at all, to 10, strong agreement



Cormier-Daire V et al. Orphanet J Rare Dis 2021;16:333.

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References

van der Heijde D, Aletaha D, Carmona L, et al 2014 Update of the EULAR standardised operating procedures for EULAR-endorsed recommendations. *Annals of the Rheumatic Diseases* 2015;74:8-13.