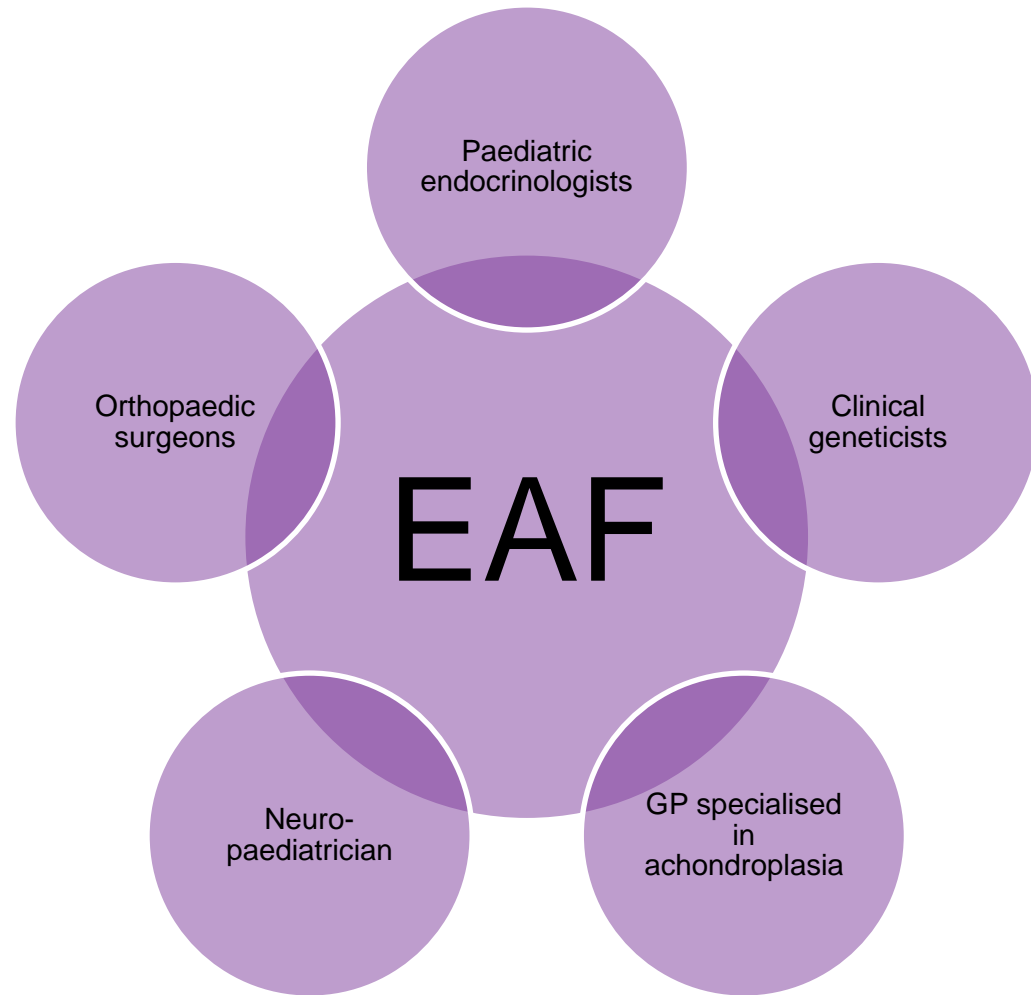




European Achondroplasia Forum

## THE FIRST EUROPEAN CONSENSUS ON PRINCIPLES OF MANAGEMENT FOR ACHONDROPLASIA

# The European Achondroplasia Forum



- Representative of the specialities managing achondroplasia, from:
  - Belgium
  - France
  - Germany
  - Italy
  - Kingdom of Saudi Arabia
  - Norway
  - Portugal
  - Qatar
  - Spain
  - UK

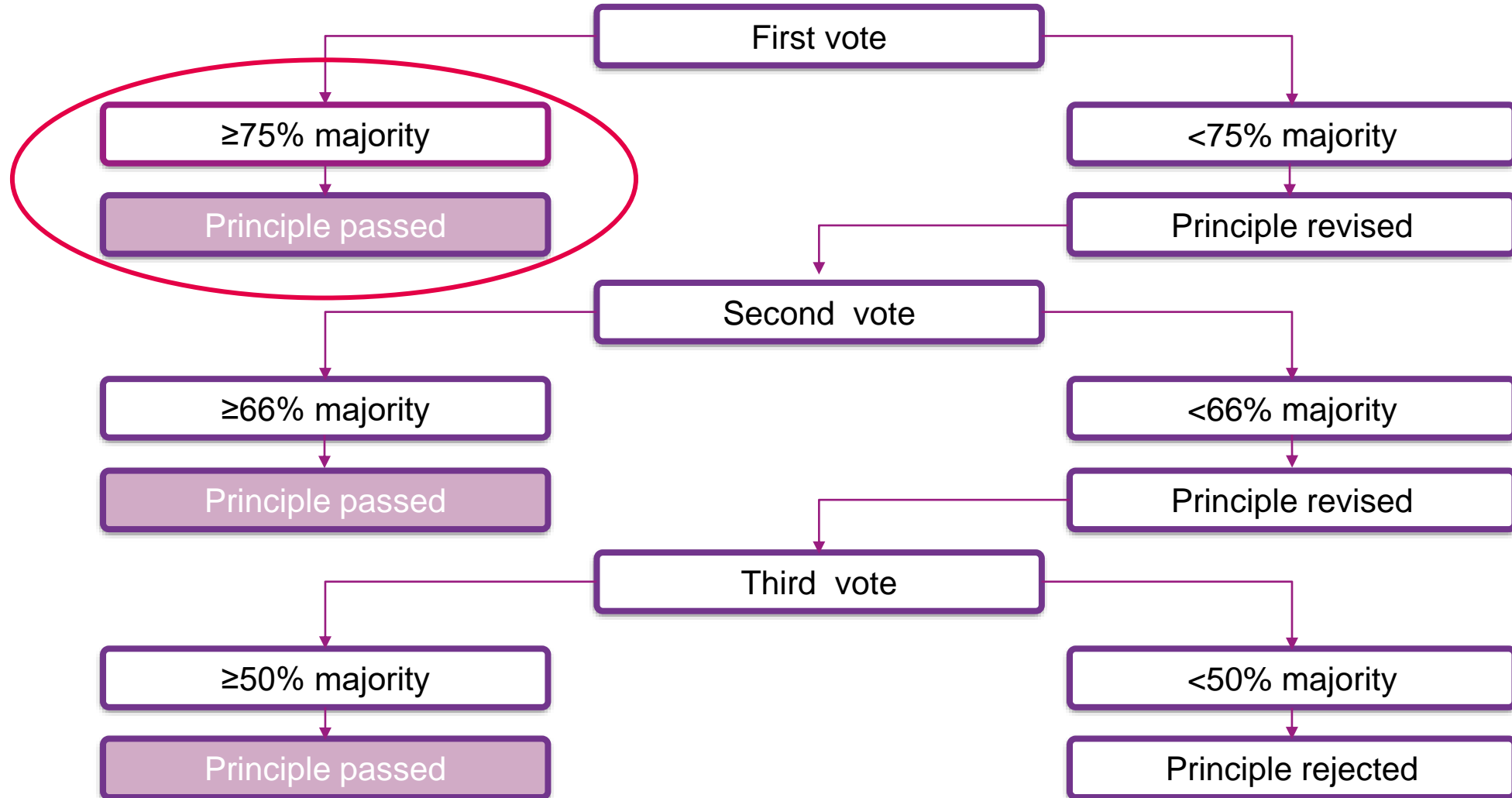


# The Process of Defining Guiding Principles



# Voting Process

## All Principles Achieved 75% Majority on First Vote



# The 2020 EAF Guiding Principles of Management for Achondroplasia

Item	Guiding principle	Vote (%)	Agreement (mean; range)
A	Achondroplasia is a lifelong condition requiring lifelong management by an experienced MDT, led by physicians/clinicians experienced in achondroplasia management. Close monitoring during the first two years of life is critical	92	8.9 (8–10)
B	When a diagnosis of achondroplasia is made or suspected, either in utero or after birth, the family should be referred as soon as possible to a physician experienced in achondroplasia to discuss the prognosis and management of the condition	100	9.3 (8–10)
C	Decisions around management should be made in the MDT setting jointly with the person with achondroplasia and/or their family	100	9.6 (7–10)
D	The primary goals of management are to enable anticipation, identification and treatment of problems, provide education and support to encourage a healthy lifestyle, positive self-esteem and mental health, autonomy and independence	100	9.2 (8–10)
E	Patients should have access to a variety of adaptive measures, support to ensure proper usage and access to approved treatment options as they become available	91	8.5 (5–10)
F	Regular monitoring in adolescence and adulthood should continue under an MDT with expertise in achondroplasia management. Care should include genetic counselling, transition to adulthood, psychosexual well-being and management of pregnancy	100	9.3 (8–10)



# Conclusions

- Guiding principles cover lifelong care for people with achondroplasia
- Guiding principles of management can be implemented in any healthcare system
- Implementation will provide a basis for developing optimal care
- There is ongoing collaboration to scrutinise individual aspects of care
- Principles of management for achondroplasia will be reviewed in 3–4 years, or when there are developments in the field that may change clinical practice

