

ERIN Summit Selection Criteria

This document sets out the selection criteria for participants attending the ERIN Summit. This criteria aims to balance continuity and representation of people affected by haemophilia with inhibitors, whose needs remain largely unmet, with a stronger inclusion of new community members and individuals affected by extremely rare bleeding disorders.

Guiding Principles

These selection criteria are based on the following principles:

- Inclusivity: Creating more space for new participants and underrepresented communities, particularly people with extremely rare bleeding disorders.
- Continuity and expertise: Maintaining meaningful representation of people affected by haemophilia with inhibitors, whose lived experience remains highly valuable to the ERIN community.
- Fair access: Ensuring balanced geographical and community representation through National Member Organisations (NMOs).
- Renewal of participation: Encouraging rotation of delegates to allow broader community engagement over time.

Overall Capacity and Allocation

The ERIN Summit has a maximum capacity of 100 participants.

Approximately 20 places are expected to be occupied by:

- ERIN Committee members
- Speakers
- EHC staff
- Conference Organiser staff

This leaves **80 available slots** to be allocated to patient delegates and their family members.

Allocation of Delegate Slots

The distribution of the 80 available slots (including patients and accompanying family members) will be done as follows:

- **10 slots** for delegates affected by **haemophilia A with inhibitors**
- **20 slots** for delegates affected by **haemophilia B with inhibitors**
- **50 slots** for delegates diagnosed with **extremely rare bleeding disorders**

This allocation reflects the intention to increase participation of people with rare bleeding disorders while preserving strong representation of haemophilia with inhibitors.

National Member Organisation (NMO) Nominations

- Each NMO may propose **up to four (4) delegates**.
- Exceptions to this limit may be granted by the EHC on a case-by-case basis (e.g. families with more than four members).
- If an NMO submits more than four delegate nominations, it must clearly indicate:
 - Which delegates are considered **priority**, and
 - Which delegates should be placed on a **waiting list**.

Delegates on the waiting list may be invited if additional slots remain available after the application process has closed.

Encouraging New Participation while supporting Continuity

NMOs are strongly encouraged to nominate new participants, while also supporting continuity where appropriate.

- To support community building and continuity, delegates may attend the ERIN Summit for **up to two consecutive years**. After attending for two consecutive years, delegates are required to skip at least one edition before reapplying.
- The EHC reserves the right to give **priority to applicants who did not attend the previous edition(s)** of the Summit, in order to ensure broad participation, wider community engagement, and effective knowledge sharing.

Conclusion

The selection framework supports a fair, inclusive, and sustainable approach to participant selection for the ERIN Summit. It allows for greater diversity of voices while safeguarding the continued involvement of communities whose experiences remain central to ERIN's mission.

EHC ERIN Committee

