

EAHAD Women and Bleeding Disorders Working Group

Terms of Reference

May 2023

1. Purpose and goals

The EAHAD Women and Bleeding Disorders Working Group will continuously work towards a set of objectives agreed in discussion with the EAHAD Executive Committee.

Its objectives are:

- Gather, concentrate, disseminate and provide knowledge among European healthcare providers on the diagnosis and treatment of women with bleeding disorders and evaluate the burden of women-specific bleeding symptoms in inherited bleeding disorders;
- Define research priorities within the European medical society regarding women with inherited bleeding disorders;
- Diminish misdiagnosis and under treatment of women with bleeding disorders in Europe.

2. Membership

- The Working Group will include at least 4 members from at least 3 different European countries and a maximum of 9 members.
- The members must be experts in the management and treatment of women-specific bleeding symptoms in inherited bleeding disorders and able to substantially contribute in the work of the Working Group.
- The Chair will be appointed by the EAHAD Executive Committee. A Vice-Chair can be nominated by the Working Group to provide assistance to the Chair and replace the Chair in their absence.
- The original composition of the Working Group will be decided by the Executive Committee and the Chair of the Working Group.
- The Working Group will include at least one EAHAD Executive Committee member and one patient's representative designated by the EHC.
- When a vacancy arises, or a new need in one or another specific field is identified, a call for applications will be published on the EAHAD website and circulated via EAHAD's networks. Current members will review the applications. Majority agreement within the Working Group is desired for the appointment of a new member. In case of a tie, the Chair has the deciding vote.

- Members of the Working Group will have a term of 2 years and can be re-elected for one more term.

3. Duration of the mandate

- The Working Group will have a fixed term mandate of 2 years. After that period, the mandate term will be re-evaluated by the Executive Committee, based on goals, objectives, and deliverables.

4. Frequency of Meetings

- Maximum of 3 meetings per year. The meetings will be in-person or virtual.
- In-person meetings should, when possible, be organised to coincide with other meetings (e.g. the annual congress, Executive Committee meetings)
- All members are required to actively participate in the work of the Working Group
- At least one staff representative from the EAHAD Office will attend the meetings and help with the preparatory work, the minutes and reporting.

5. Funding

- Meetings and support by the EAHAD Office will be funded by EAHAD with possible external support according to the EAHAD Sponsorship Policy.
- The annual budget is 10,000 EUR.
- The funding will cover in-person meetings, teleconferences, publication fees, IT support, etc.

6. Reporting requirements

- The Working Group will produce reports outlining its progress on agreed objectives. The reports will be submitted to the Executive Committee. A summary will be included in the EAHAD annual report.
- Minutes will be drafted and distributed to Working Group members after the meeting date.

7. Publication acknowledgement

- Publications and other projects should acknowledge that they are produced by the EAHAD Women and Bleeding Disorders Working Group, listing all members.

8. Review of the terms of reference

- The Working Group will review the terms of reference every two (2) years