

EAHAD Artificial Intelligence and Machine Learning Working Group

Terms of Reference

1. Purpose and goals

Artificial Intelligence (AI) and Machine Learning (ML) are transforming healthcare research and clinical care by enabling advanced data analysis, risk prediction and personalised treatment strategies. In haemophilia and other inherited bleeding disorders, where large high-quality datasets exist but remain under-analysed, AI offers particular potential to improve diagnosis, stratification and outcome prediction. Systematic reviews confirm the expanding role of AI in healthcare while emphasising the need for robust methodology, governance and ethics.

EAHAD is uniquely positioned to lead in this area through its clinical expertise, collaborative networks and access to multinational data.

The purpose of this Working Group (WG) is to advance scientifically rigorous, ethically responsible AI/ML research in haemophilia and other inherited bleeding disorders in Europe.

The key objectives are to:

- Build a multidisciplinary European network of clinicians, data scientists, mathematicians and ethicists.
- Identify priority haemophilia research questions suitable for AI/ML approaches.
- Design and launch a flagship multicentre AI-driven research project.
- Develop competitive European funding applications
- Signpost high-quality educational resources to improve AI literacy within EAHAD.

Illustrative research themes include:

- Phenotype clustering in Bleeding Disorder of Unknown Cause (BDUC).
- Automated interpretation of complex haemostasis laboratory data.
- In silico simulation models to support rare disease trial design.
- Predictive models for complications and treatment response.

The broader literature highlights that responsible implementation requires transparency, fairness, strong data governance and meaningful patient involvement. At the same time, high-impact reporting illustrates the accelerating integration of AI into predictive medicine, reinforcing the need for domain-specific leadership in specialised fields such as haemophilia. Ethical aspects will be taken into consideration.

All WG activities will comply with GDPR principles and established standards for trustworthy AI.

2. Membership

The WG will comprise 6–10 members:

- 1 Chair or Co-Chair with collaborative research leadership experience. The Chair or co-chair will be appointed by the EAHAD Executive Committee. In the absence of a co-

chair, a Vice-Chair can be nominated by the Working Group to provide assistance to the Chair and replace the Chair in their absence.

- 3 haemophilia clinical experts.
- 1 mathematician or data scientist with AI/ML expertise.
- 1 clinical scientist in haemostasis diagnostics.
- 1 ethics and data governance expert.
- 1 junior member (early career researcher).
- 1 patient representative.
- 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.
- 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.
- External experts in mathematics or computer science may be recruited to ensure technical excellence. Members will be selected via an open call with transparent criteria based on expertise, diversity and commitment. Inclusion of ethics and patient representation aligns with best-practice recommendations for trustworthy healthcare AI.

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 conferences).

All members are required to actively participate in the work of the Working Group and attend at least 50% of the meetings organised

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 15,000 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 Working Group, listing all members unless a different arrangement has been decided.

8. Review of the terms of reference

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

September 2026