

SWG Networking Hub Meeting Report Template

1. Meeting Overview

SWG Name: Quality of Life and Symptoms

Date & Location: 7-8 November 2025, Reggio Calabria, Italy

Chair(s): Edward Laane, Esther Natalie Oliva, Sam Salek

Participants: Robert Klaassen, Yana Stepanishyna, Lena von Bahr, Priya Sriskandarajah, Vibor Milunović, Elena Crisa, Bruno Fattizzo, Tatiana Ionova. Volodymyr Lotushko

Purpose of Meeting: (Brief summary)

The purpose of the Networking Hub meeting was to have a possibility to meet each other in person as well as via Zoom, and to deliver the results and achievements of previous and ongoing SWG projects, especially EHA Evidence-Based "Guidelines on patient-reported outcomes measurement in Hematology" to new members, to discuss SWG session program at EHA2026 Congress and to envisage future plans, future research strategy and expansion of the SWG.

Furthermore, SWG members learned about the new EHA goals and strategic plans, "EHA Agenda 2030", Borderless Hematology.

2. Executive Summary

- Key outcomes and decisions

The development of a Treatment-Related Patient-Reported Outcome measure (HM-PRO) in hematological malignancies for use in clinical practice and research (2013-2018) was presented and training in clinical case scenarios and scenarios of trial design was provided. The HM-PRO has been developed with the involvement of all the stakeholders and regulatory guidelines (FDA and EMA), in particular strong involvement of patients, clinicians, and other relevant stakeholders and, therefore, it should become standard of care in clinical practice, as well as the instrument of choice in clinical trials.

The SWG session program for EHA2026 Congress was unanimously endorsed.

The status of the “EHA Evidence-Based Guidelines on use and reporting of patient-reported outcomes measurement in Hematology” was presented and discussed. The Guidelines are focused on malignant hematology, adult patients and clinical trials. The Guidelines are developed in collaboration with Patient Advocacy and respective EHA SWGs representatives. Published results were disseminated:

- 1) The Reporting, Use, and Validity of Patient-Reported Outcomes in Multiple Myeloma in Clinical Trials: A Systematic Literature Review (Cancers 2022)
- 2) Guidelines for the Use and Reporting of Patient-Reported Outcomes in Multiple Myeloma Clinical Trials (Cancers 2023)
- 3) Patient-reported outcomes in Hodgkin lymphoma trials: a systematic review (Front Haematolog 2023)

The EHA Strategy 2030 was acknowledged by all participants.

The Palliative Care in Hematology was proposed by the members as an expansion of the SWG’s focus moving forward. This agreed unanimously and carried.

Main priorities identified for the next 3–5 years

The future focus is on the following disorders:

- chronic myeloproliferative neoplasms
- non-malignant hematology as paroxysmal nocturnal hemolysis and immune thrombocytopenia, autoimmune disorders
- B-cell neoplasms

Pediatric hematology, both benign and malignant, will be considered

Palliative care will be included into SWG structure.

The main priority is to advertise the use of Quality of Life and Patient Reported Outcome tools in day-to-day practice to influence clinical and treatment decision-making. The HM-PRO will be considered to achieve this goal.

3. Alignment with EHA Strategy 2030

For each ambition below, briefly describe how your SWG's planned activities contribute. Please note that you do not need to fill out all aspirations. You can select only a few of them based on the SWG capacity.

1) *Nurturing Knowledge for Collective Growth*

- a) Planned educational programs, mentorship, and knowledge-sharing initiatives

- EHA Patient Advocacy Sessions within EHA Congress
- Educational sessions on PRO in hematology within EHA Congress
- Scientific sessions on PRO in hematology within EHA Congress.

- b) How will you mobilize professionals and expand impact within the ecosystem?

The SWG educational activities in PRO assessment in hematology and collaboration with other SWGs and societies to promote PRO research in hematology:

- Patient, Family and Donor Day within EBMT Congress
- Educational sessions on PRO in hematology within International Society of Quality of Life Research (ISOQOL) Congress.

2) *Fostering an Innovative Environment*

- a) New technologies or methods to be adopted

- b) Plans for collaborative, cross-disciplinary projects

- To publish a palliative care position paper on the use and reporting of PROs and quality of life instruments
- To establish collaboration with other EHA SWGs in palliative care topic.

- c) Approaches to disseminate and make innovations accessible

- The SWG has historically been research active and has published extensively on different aspects of PROs and quality of life both as awareness pieces as well as research outcomes in scientific journals. Such activities will continue as part of the SWG's strategic plan for the next three years.
- The SWG will continue to use its dedicated session at the annual EHA congress to disseminate innovations accessible.

3) *Advancing Research for Significant Breakthroughs*

- a) Research priorities and planned projects (including clinical, translational, and fundamental research)

- To complete EHA Evidence-Based Guidelines on patient-reported outcomes measurement in Hematological malignancy.

- b) Strategies for collaboration (internal and external)
 - Collaboration with QOL-ONE on global surveys including patients' advocacy group
 - Study project on home delivered treatment in acute myeloid leukemia in Sweden
 - Collaboration with COST Action CA24124 project Neutro-NARPS.
- c) Funding and grant opportunities to be pursued
 - The membership will be encouraged to apply for suitable EHA grants
 - The SWG will identify external source of funding including pharmaceutical industry for its short and long-term research projects.

4) Pursuing Equitable Access to Enhance Patient Care

- a) Actions to improve access, standardize care, and reduce disparities
 - Dissemination and translation of the HM-PRO to facilitate QoL assessment in clinical trials and clinical practice in order to improve evidence-based practice.
- b) Patient and public engagement plans
 - The SWG considers patients in the center of its activities, as information providers, advisors, reviewers, research partners, research subjects and driving force
 - Further strengthen cooperation, partnership and co-creation with patient advocacy.

5) Empowering a Thriving Hematology Community

- a) Community-building, diversity, and inclusion initiatives
 - The SWG will be as part of its strategic plan, intensifying its outreach activities to embrace diverse hematology groups including rare diseases and initiate inclusiveness environment within the SWG as such that all diverse communities be able to cultivate their novel ideas and flourish.
- b) Sustainability and governance practices
 - As part of its strategic plan, the SWG will be initiating more frequent Business Meetings during both the EHA annual Congresses as well as virtual meetings. This practice will allow continuous improvement of governance and sustainability of growth.

4. SWG Framework Compliance

Confirmation that planned activities align with SWG objectives and structure

- Membership engagement and recruitment strategies
 - Currently, the SWG consists of 18 members as of December 2025. The recent Networking Hub meeting demonstrated membership engagement and cohesiveness.
 - As part of the SWG's strategic outreach plan it is envisaged that the membership recruitment will be securing a further 12 new members in the next three years.

5. 3–5 Year Working Plan & Milestones

Year 1:

- Key activities
 - To continue development of the EHA's Evidence-Based Guidelines on the use and reporting of patient-reported outcomes measurement in adult hematological malignancy clinical trials.
- Milestones and deliverables
 - Guidelines on the use and reporting of PROs in Hodgkin Lymphoma, non-Hodgkin Lymphoma, Chronic Myeloproliferative Neoplasms, Chronic Lymphocytic Leukemia and Chronic Myeloid Leukemia clinical trials have been published.

Year 2:

- Key activities
 - To conclude the development of the EHA Evidence-Based Guidelines on the use and reporting of patient-reported outcomes measurement in adult Hematological malignancy clinical trials development
 - To initiate conceptualization of a global survey in selected hematological malignancy in collaboration with respective patient advocacy groups.
- Milestones and deliverables
 - Publication of the remaining EHA Guidelines on the use and reporting of PROs in adult clinical trials such as Myelodysplastic

Syndrome, Acute Myeloid Leukemia and Acute Lymphoblastic Leukemia clinical trials.

Year 3:

- Key activities
 - Finalizing the global surveys' protocols and securing funding for its roll out
 - Development of the embryonic outline for development of the SWG's position paper on the incorporate of palliative care activities. It is hoped that publication of this position paper would be acting as an awareness tool for the hematology palliative care community.
- Milestones and deliverables
 - Publication of the Palliative care position paper

Years 4–5 (Optional):

- Longer-term objectives and flexible targets
 - Roll out of the global surveys.

6. Concrete Steps & Action Items

- List of agreed actions, responsible persons, and deadlines
The new leadership of the SWG will be elected by 2026
- Steps for implementation and follow-up
 - A steering committee will be set up from the membership to monitor implementation of the SWG strategic plan and follow up the deliverables.
- Mechanisms for monitoring progress (KPIs, feedback, surveys)
 - From time to time a "task and finish group" from the membership will be set up monitor the progress and engage with the rest of membership and outreach communities to collect feedback regarding the SWG's activities through appropriate surveys.

7. Collaboration & Networking

- Plans for joint activities with other SWGs, EHA committees, or external partners

- As part of its strategic plan, the SWG will be engaging with other EHA SWGs as well as the local European Hematology Associations such as the British Society for Haematology (BSH) for provision of Education and Development events.
- Opportunities for community growth, engagement, and impact
 - Initiating widespread advertisement of the SWG sessions during the EHA Congresses by the EHA
 - Establishment of a “public relation” sub-committee.

8. Feedback & Suggestions (if applicable)

- Member feedback on the meeting and their priorities should be routinely collected during the SWG Business meeting
- Suggestions for improving future meetings and for the SWG processes should be coordinated with the EHA SWG liaison.