

Patient Involvement in the Swedish National Care Programme (Vårdprogrammet), for Myeloproliferative Neoplasms (MPN)

INTRODUCTION

In 2023, Blodcancerforum was invited to participate in the development of the Swedish national clinical guidelines for Myeloproliferative Neoplasms (Vårdprogrammet för MPN).

This initiative aimed to ensure that the patient perspective is integrated into evidence-based decision making, covering areas such as symptom burden, quality of life, and equitable access to care across Sweden.

AIMS:

- Strengthen patient involvement in guideline development.
- Contribute to more patient centered recommendations.
- Demonstrate the value of collaboration between patients, clinicians and health care providers.

METHODOLOGY

Target audience

- Swedish clinicians, healthcare decisionmakers, and MPN patients.

Tactics employed:

- Direct participation in guideline working groups.
- Patient review and feedback on draft documents.
- Consultation with the wider patient community

Resources required:

- Patient advocate expertise (Blodcancerforum and Lise-lott Eriksson).
- Organizational support from Blodcancerforum.
- Collaboration with RCC (Regionala Cancercentrum).

Evaluation strategy:

- Compare the inclusion of patient relevant aspects in earlier versus updated versions of the guidelines (2023-2024).
- Gather feedback from both clinicians and patients regarding clarity and usefulness.

RESULTS

- First time real inclusion of patient advocates in the official Swedish MPN Care Programme.
- Patient perspectives on fatigue, quality of life, and communication needs were incorporated.
- Blodcancerforum established as a recognized partner in national cancer policy development.
- Positive feedback received from clinical experts and patient representatives.

CONCLUSIONS

- Collaboration between clinicians and patients is feasible and impactful.
- Structured patient input ensures a balance between clinical outcomes and real-life experiences.
- Key lessons - early involvement and clear roles are crucial for meaningful collaboration.
- Next step - the model of collaboration is extended to other hematological malignancies in Sweden.

REFERENCES

Swedish National Care Programme for MPN (Vårdprogrammet för MPN): <https://kunskapsbanken.cancercentrum.se/diagnoser/myeloproliferativ-neoplasi/varprogram/>

