

Patient Surveys as an Advocacy Tool: Highlighting Unmet Needs of Cancer Patients in Finland

INTRODUCTION & AIMS

Cancer Patients Finland conducts national surveys to gather real-life experiences from patients across different cancer types.

For rare and chronic cancers like MPN, patient voices are often underrepresented in healthcare planning.

Aims:

- To amplify the voice of cancer patients as a basis for advocacy.
- To identify unmet needs particularly relevant for rare cancer patients, such as those with MPN.
- To use survey results as evidence to drive improvements in healthcare systems and policies.

"Without patient advocacy, diagnostic delays, insufficient support and lack of information would remain invisible."

RESULTS

Key findings relevant to patients:

- 50% felt symptoms were not taken seriously before diagnosis.
- 33% experienced diagnostic delay.
- 97% reported strong adherence to treatment.
- 33% felt they had insufficient information about medication efficacy and safety.
- 90% experienced side effects from medication.
- 70% felt included in shared decision-making with healthcare professionals.
- 38% discussed work-related issues with their doctor.

CONCLUSIONS

Survey results show that patient perspectives are essential in shaping better healthcare for patients.

Key advocacy messages:

- Early diagnosis requires raising awareness of non-specific symptoms.
- Long-term treatment needs better communication and coordinated care.
- Side effects and psychosocial challenges must be addressed in care pathways.
- Patient voice is not optional – it is central to building sustainable, patient-centered cancer care.

"Patient advocacy transforms survey findings into real change – without it, unmet needs remain unheard."

METHODOLOGY

2023

2024

2025

Several surveys were conducted in 2023–2025, including:

- *Cancer and Work*
- *Adherence to cancer medication*
- *Diagnosis, treatment and follow-up*
- *Rare cancer care pathways*

Approach:

- Online questionnaires distributed nationally
- Input from patient networks and healthcare experts
- Analysis used for advocacy, communication, and policy work

Evaluation:

Survey findings are turned into advocacy messages for policymakers, healthcare professionals, and the public.

ADVOCACY HIGHLIGHTS



Patient voice = change driver



Survey data = advocacy evidence



Advocacy improves diagnosis, treatment & support



Without advocacy, unmet needs stay invisible

REFERENCE & CONTACT INFORMATION



Cancer Patients Finland

Patient survey reports 2023–2025
Emma Andersson, Advocacy Specialist
emma.andersson@syopapotilaat.fi
www.syopapotilaat.fi

MPN Horizons 10–12 October
Beyond Boundaries Marrakesh, Morocco
10th International Conference

2025