MPN Unmet Needs Assessment preview

The ***2024 MPN Patient and Caregiver Unmet Needs Assessment*** was conducted by MPN Research Foundation to better understand the challenges faced by individuals living with myeloproliferative neoplasms (MPNs) and their caregivers. By gathering insights directly from the MPN community, this assessment identified key gaps in patient education, access to specialized care, symptom management, and clinical trial awareness.

These insights will help shape future research and resources that address the most pressing gaps in MPN care. By prioritizing the needs of patients and caregivers, MPN Research Foundation ensures that their voices remain at the heart of MPN research and advocacy.

Who participated:

The assessment collected **627 total responses** between October 14 and November 11, 2024. Participants included those speaking from one or several different perspectives:

- Patients: **87%**
- Family/Friend/Caregivers: **6%**
- Patient Advocacy Representatives: **3%**
- Researchers: **2%**
- Healthcare Providers: **2%**
- Other: **1%**

Which MPN(s) have you or your loved one been impacted by? *(Select all that apply)*

MPN DIAGNOSIS	#	%
Essential thrombocythemia (ET)	**314**	**46%**
Polycythemia vera (PV)	**273**	**40%**
Primary myelofibrosis (pMF)	**63**	**9%**
Secondary myelofibrosis (sMF)	**75**	**11%**
Post-MPN Acute Myeloid Leukemia (AML)	**3**	**1%**
Other	**13**	**2%**

Global representation:

Participants represented **31 countries**, with the top 5 being:

- United States *(45 states, with highest participation from California, Florida, New York, Pennsylvania, Washington)*
- United Kingdom
- Canada
- Australia
- New Zealand

Treatment location:

Where patients receive their MPN treatment and care:

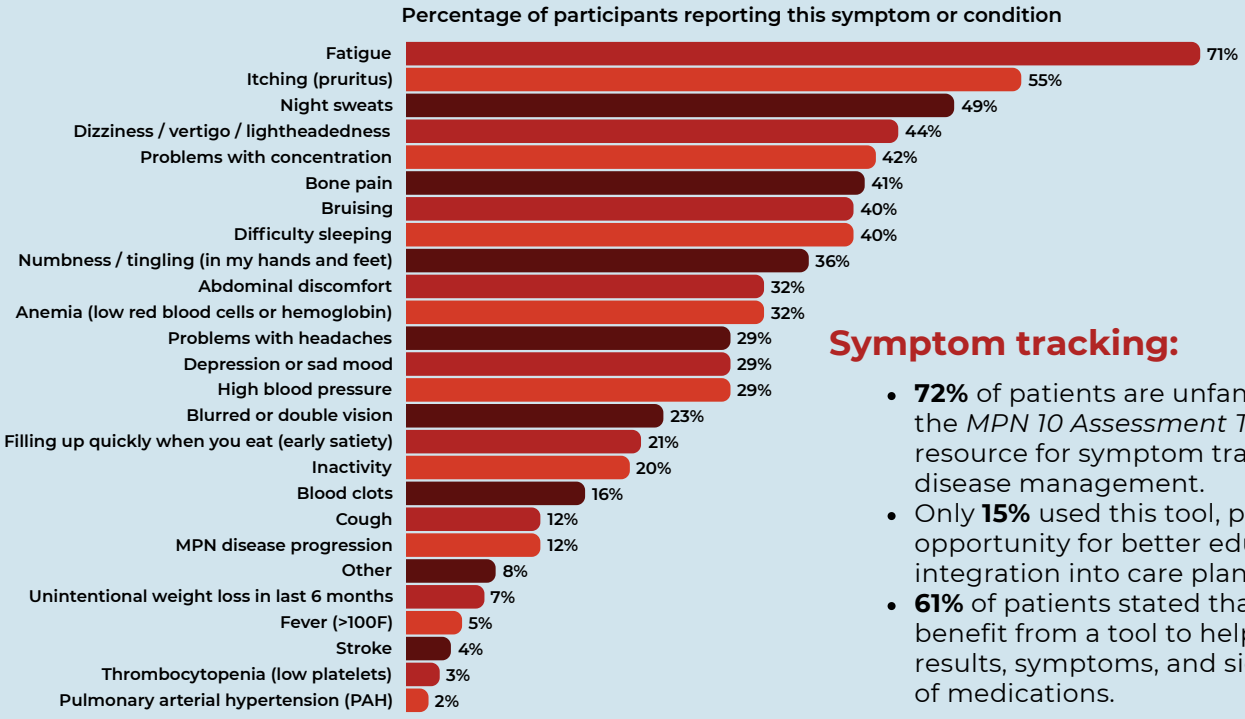
- **47%** an academic medical center
- **26%** a local or community hospital unaffiliated with a medical school
- **10%** both
- **16%** other/unsure

Patient awareness and specialist access:

- **85%** of patient participants were aware of their genetic mutations.
- **70%** of patients had access to an MPN specialist, but this leaves **30%** without specialized care.

MPN Patient & Caregiver Unmet Needs Assessment preview

Patient symptoms and conditions experienced



Symptom tracking:

- **72%** of patients are unfamiliar with the *MPN 10 Assessment Tool*, a critical resource for symptom tracking and disease management.
- Only **15%** used this tool, presenting an opportunity for better education and integration into care plans.
- **61%** of patients stated that they would benefit from a tool to help track test results, symptoms, and side effects of medications.

Treatment goals:

- **46%** of patients felt that they had adequate education on disease progression.
- Patients prioritized the following:
  - Slowing disease progression: **80%**
  - Normalizing blood cell counts: **54%**
  - Improving quality of life: **52%**
  - Having more energy: **48%**
- Yet, only **54%** of patients felt their individual goals for treatment are considered by their providers.
- Only **44%** believed they had the information they need on complementary therapies such as nutrition, exercise, and mindfulness.

Clinical trial participation:

- **71%** of patients reported their providers had *not* discussed clinical trial options with them.
- Only **10%** of patients participated in a clinical trial.

Supportive resources:

- **48%** of patients felt they had adequate emotional resources to help them cope with their MPN diagnosis.
- Only **47%** of patients could connect with other MPN patients and caregivers.
- Only **19%** of patients had financial resource information.

A significant portion of respondents — **72%** across all MPNs — agree that their quality of life is affected.

As we continue to better understand participant responses, we'll refine our analysis to gain more accurate insights.

Join our network of patients, caregivers, researchers, clinicians, and industry today!

mpnresearchfoundation.org

Thank you to the sponsors whose support made this initiative possible — Sobi, Morphosys, Incyte, Karyopharm, PharmaEssentia, Bristol Myers Squibb, and Sumitomo Pharma.

patientengagement@mpnrf.org