For U.S. Healthcare Professionals

A closer look at polycythemia vera (PV) symptoms

Despite lasting perceptions of minimal disease burden, **88% of people with PV are experiencing symptoms** at the time of their diagnosis.[1,2] These symptoms can impact their quality of life.

Patients may not realize that **symptoms like fatigue, brain fog, or itching are connected to their PV**, so they may normalize them or attribute them to aging or stress.[2,3]

Providing patients with a symptom tracker can help them to better recognize their PV symptoms and inform discussions with their doctors during appointments.[4,5]

Asking appropriate questions during patient visits can help them decode unspoken symptoms. Use the QR code at the end of this fact sheet to download a PV discussion guide.[1,6]

Symptoms of iron deficiency[6-8]

- Fatigue
- Problems with concentration (brain fog)
- Physical inactivity
- Weakness and dizziness

Symptoms due to splenomegaly, caused by processing excess red blood cells[1,9]

- Early satiety
- Abdominal pain or discomfort
- Cough

Constitutional symptoms[9]

- Night sweats
- Pruritus
- Bone pain
- Fever
- Unintentional weight loss (more than 10 pounds, within the last 6 months)

Emotional strain may start at diagnosis[1,10]

Effective management of PV should offer rapid, consistent, and durable hematocrit (HCT) control, iron balance, and vigilant attention to the daily impact of patient symptoms.[4]

Symptoms take a toll on quality of life[1]

62% of people with PV report reduced quality of life

Even with low-risk PV or less severe symptoms, over half of people with PV report that their symptoms reduced their quality of life, making them feel vulnerable and alone.[1,10]

PV and its symptoms can impact[1,9]:

- Overall quality of life
- Mood
- Physical functioning
- Work performance
- Family and social life

Use symptom tracking and symptom-focused questions to enhance communication with your patients

Make symptom assessment a regular part of PV management. Using validated tools, such as the **MPN-SAF questionnaire or PROMIS Fatigue Short Form,** can help identify unspoken concerns and quantify disease burden more accurately.[9,11–12]

Assessing mental and emotional well-being as a routine practice helps physicians understand each patient's comprehensive experience with PV.[4]

Download a discussion guide with the QR code below to help you and your care team better understand your patients' experience with PV and guide shared decision making.

Downloadable symptom assessment tools

Use these tools to help assess PV symptoms:

MPN-SAF Questionnaire →

PROMIS Fatigue Short Form →

Downloadable symptom tracker for patients

Help patients track their PV symptoms over time:

Patient PV Symptom Tracker →

Scan the QR code to visit our website at RethinkPVpro.com and get resources for your patients and office staff.

References: 1. Mesa RA, Miller CB, Thyne M, et al. Myeloproliferative neoplasms (MPNs) have a significant impact on patients' overall health and productivity: the MPN Landmark survey. *BMC Cancer.* 2016;16:167. doi:10.1186/s12885-016-2208-2. **2.** Mesa RA, Miller CB, Thyne M, et al. Differences in treatment goals and perception of symptom burden between patients with myeloproliferative neoplasms (MPNs) and hematologists/oncologists in the United States: findings from the MPN Landmark survey. *Cancer.* 2017;123(3):449-458. doi:10.1002/cncr.30325. **3.** Bradford A, Young K, Whitechurch A. Disabled, invisible and dismissed-The lived experience of fatigue in people with myeloproliferative neoplasms. *Cancer Rep (Hoboken).* 2023;6(1):e1655. doi:10.1002/cnr2.1655. **4.** Kuykendall AT, Fine JT, Kremyanskaya M. Contemporary challenges in polycythemia vera management from the perspective of patients and physicians. *Clin Lymphoma Myeloma Leuk.* 2024;24(8):512-522. doi:10.1016/j.clml.2024.04.003. **5.** Manz K, Heidel FH, Koschmieder S, et al. Comparison of recognition of symptom burden in MPN between patient- and physician-reported assessment - an intraindividual analysis by the German Study Group for MPN (GSG-MPN). *Leukemia.* 2025;39(4):864-875. doi:10.1038/s41375-025-02524-7. **6.** Verstovsek S, Harrison C, Kiladjian J, et al. Markers of iron deficiency in patients with polycythemia vera receiving ruxolitinib or best available therapy. *Leuk Res.* 2017;56:52-59. doi:10.1016/j.leukres.2017.01.032. **7.** Cleveland Clinic. *Iron-Deficiency Anemia.* December 11, 2024. Accessed July, 2025. Available at: https://my.clevelandclinic.org/health/diseases/22824-iron-deficiency-anemia. **8.** Ginzburg YZ, Feola M, Zimran E, Varkonyi J, Ganz T, Hoffman R. Dysregulated iron metabolism in polycythemia vera: etiology and consequences. *Leukemia.* 2018;32(10):2105-2116. doi:10.1038/s41375-018-0207-9. **9.** Mesa RA, Schwager S, Radia D. The Myelofibrosis Symptom Assessment Form (MFSAF): an evidence-based brief inventory to measure quality of life and symptomatic response to treatment in myelofibrosis. *Leuk Res.* 2009;33(9):1199-1203. doi:10.1016/j.leukres.2009.01.035. **10.** National Cancer Institute (NCI). *Emotions and cancer.* April 9, 2025. Accessed July, 2025. Available at: https://www.cancer.gov/about-cancer/coping/feelings. **11.** PROMIS. *PROMIS Fatigue: Scoring Manual.* HealthMeasures; 2023. Accessed July, 2025. Available at: https://www.healthmeasures.net/. **12.** Emanuel, R. M., Dueck, A. C., Geyer, et al. Myeloproliferative neoplasm (MPN) symptom assessment form total symptom score: Prospective international assessment of an abbreviated symptom burden scoring system among patients with MPNs. *J Clin Oncol.* 2012;30(33), 4098–4103. https://doi.org/10.1200/JCO.2012.42.3863