For U.S. Healthcare Professionals

Staying on top of polycythemia vera (PV)

A guide to enhanced patient discussions

Fostering open dialogue with patients and their caregivers is key to effective treatment planning and managing expectations.[1–3] Use this guide to help you and your care team better understand each patient's comprehensive experience with PV and enhance their care plan.

PRE-VISIT CHECKLIST

- ✓ Review any history of thromboembolic events (TEs) or changes in the patient's test results, medications, or supplements

DURING EACH PATIENT VISIT, THE FOLLOWING QUESTIONS CAN ASSIST YOU IN:

- ✓ Detecting emerging risks
- ✓ Helping monitor current care plans
- ✓ Addressing real-world challenges (e.g. symptoms affecting quality of life)
- ✓ Helping patients gain clarity on their diagnosis and actively engage in their treatment plan

HOW ARE YOU FEELING?

- **How is PV impacting your life, both physically and emotionally?**
- **Have you had to make any life changes to accommodate your PV?**

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.[4,5]

ARE YOU EXPERIENCING ANY NEW OR WORSENING PV SYMPTOMS?

- **Which symptom is the most burdensome?**
- **How are your symptoms affecting daily activities, work, sleep, or mood? Are you able to do what you need/want to do, day to day?**

In an observational study, worsening symptoms affected 47% (n=133/285) of PV patients, of which the majority were actively treated.*[6†‡]

Symptom burden in PV is more than discomfort—it's associated with significantly reduced overall survival (P=0.002).[6†‡]

**227 (79%) and 217 (76%) patients were actively receiving cytoreductive and antiplatelet therapy, respectively.*[6]

†A multicenter, observational study comprising patients from 13 academic and community centers. Eligibility criteria were patients >18 years old, enrolled with a diagnosis of PV, essential thrombocythemia (ET), or myelofibrosis (MF; primary or post-PV/ET) according to World Health Organization and/or International Consensus criteria, and having completed at least one MPN-SAF TSS questionnaire between April 2013 and August 2022.

‡Myeloproliferative Neoplasm Symptom Assessment Form Total Symptom Score (MPN-SAF TSS) score >35

If your patients are unable to give clear answers on their symptoms or are not monitoring them at all, suggest they use a symptom tracker to better inform future discussions. Scan the QR code on the following page to download a symptom tracker to share with your patients.

DO YOU UNDERSTAND YOUR LATEST BLOOD TEST RESULTS?

- **Do you understand the values we are monitoring and why?**

If you are monitoring your patients' iron levels, emerging evidence shows a significant association between iron deficiency in PV and a higher risk of TEs.[7,8]

HOW ARE YOU DOING ON CURRENT TREATMENT?

- **Are you experiencing any symptoms which are not getting better or being addressed?**[4]
- **Are you experiencing any worsening symptoms like fatigue, brain fog, or itching?**[4–6]
- **Are there any other burdens you are experiencing with your PV management?**[4]

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.[3]

HOW CAN WE BETTER UNDERSTAND AND SUPPORT YOU?

- **Help connect your patient to organizations providing knowledge, support, and resources to help people living with PV. Examples can be found by following the QR code below**

Creating a partnership and sharing in the decision-making process can help patients with PV feel less alone and more empowered as they navigate their symptoms.[4,9]

POST-VISIT CHECKLIST

- ✓ Remind the patient of their upcoming blood tests (schedule tests if needed) and why keeping HCT under the 45% threshold is important[10]
- ✓ Encourage the patient to visit RethinkPV.com for information and resources to help them better understand their PV
- ✓ Encourage the patient to use/continue using their symptom tracker
  - Use the QR code below to download a symptom tracker

Assessing mental and emotional well-being as a routine practice helps physicians understand each patient's holistic experience with PV.[3]

Learn more about the hidden burden of PV →

Scan the QR code to visit our website at RethinkPVpro.com and download additional resources for your practice and your patients.

Click Here →

References: 1. 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. **2.** 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. **3.** 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. **4.** 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. **5.** 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. **6.** Poullet A, Busque L, Sirhan S, et al. Symptom burden in myeloproliferative neoplasms: clinical correlates, dynamics, and survival impact-a study of 784 patients from the Quebec MPN research group. *Blood Cancer J.* 2025;15(1):51. doi:10.1038/s41408-025-01234-8. **7.** Hung SH, Lin HC, Chung SD. Association between venous thromboembolism and iron-deficiency anemia: a population-based study. *Blood Coagul Fibrinolysis.* 2015;26(4):368-372. doi:10.1097/MBC.0000000000000249. **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. doi:10.1016/j.clml.2024.04.003. **9.** National Cancer Institute. *Emotions and Cancer.* National Cancer Institute. https://www.cancer.gov/about-cancer/coping/feelings. Updated April 9, 2025. Accessed August, 2025. **10.** Marchioli R, Finazzi G, Specchia G, et al. Cardiovascular events and intensity of treatment in polycythemia vera. *N Engl J Med.* 2013;368(1):22-33. doi:10.1056/NEJMoa1208500.