An overview of results from the first extensive survey of MPN patients and healthcare professionals
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“MPNs are a complicated set of rare blood cancers. The LANDMARK SURVEY highlights the need to enhance awareness, education and communication so that we can improve patient care and help those living with MPNs know they are not alone.”

— Sara Goldberger, MPN LANDMARK SURVEY Steering Committee Member
An estimated 200,000 people in the U.S. are living with myeloproliferative neoplasms (MPNs), a group of rare blood cancers in which a person’s bone marrow does not function properly. The most prevalent Philadelphia chromosome-negative MPNs are myelofibrosis (MF), polycythemia vera (PV) and essential thrombocythemia (ET).

Over the past several years, there has been tremendous progress in understanding these diseases and their management. However, there is still a need to continue working together to advance scientific knowledge, as well as to further improve care and enhance quality of life for MPN patients.

The MPN LANDMARK SURVEY — the first large-scale, extensive analysis of MPN patients and physicians — identified gaps between patient perceptions of their disease management and physician self-reported practices, as well as the patient disease burden in the Philadelphia chromosome-negative MPN disease setting. This report highlights the commonalities and differences in five key areas — diagnosis, symptoms, disease impact, treatment and patient-physician relationships. More importantly, it illuminates in detail the patient experience with regard to the physical, psychological, emotional and financial challenges faced by individuals living with MPNs.

This report has two complementary purposes: First, it is intended to raise awareness of MPNs and their specific, multi-faceted disease burdens. Second, it is meant to inform and empower patients, physicians, caregivers and others in the MPN community about perceived gaps in care and communications.

The MPN physician and advocacy community is dedicated to easing the burden of MPNs for patients and their caregivers through education, support and collaboration.

This report will hopefully serve as another valuable resource that will advance understanding of these rare, progressive blood cancers and help improve the quality of care for people living with MPNs.
The MPN LANDMARK SURVEY was led by a steering committee comprised of the following MPN experts and thought leaders, which includes MPN specialists, allied health providers, patient advocates, epidemiologists and survey experts.

**Ruben Mesa, MD**  
MPN LANDMARK SURVEY Committee Chairman, Scottsdale, AZ

**John Boyle, PhD**  
ICF International, Fairfax, VA

**Salman Fazal, MD**  
Western Pennsylvania Cancer Institute, Pittsburgh, PA

**Christopher C. Gayer, PhD**  
Patient-Centered Outcomes Research Institute (PCORI), Washington, DC

**Sara Goldberger, BA, MS**  
Cancer Support Community, New York, NY

**Xiaomei Ma, PhD**  
Yale School of Public Health, New Haven, CT

**James Mangan, MD, PhD**  
University of Pennsylvania, Philadelphia, PA

**John O. Mascarenhas, MD, MS**  
Icahn School of Medicine at Mount Sinai, New York, NY

**Carole B. Miller, MD**  
St. Agnes Hospital, Baltimore, MD

**Maureen Thyne, PA**  
Weill Cornell Medical College, New York, NY

**Wendy Wilson, RN, MSN, OCN**  
Fred Hutchinson Cancer Research Center, Seattle, WA

The committee would like to acknowledge and thank the untold patients, doctors, caregivers and advocates who were the inspiration for this research and contribute so much to bringing understanding, compassion and strength to the MPN community.

“**LANDMARK provides new information and broad insight on the real impact of MPNs. More can and must be done to empower patients, raise awareness and ease the burden associated with these rare blood cancers.”**

— MPN LANDMARK SURVEY Steering Committee
Myeloproliferative neoplasms can have a significant, negative impact on patients and their loved ones. Our goal is to provide these individuals with the best care and available treatment options; however, we must also have a clear understanding of how MPNs affect physical and emotional health, as well as everyday life. There is always room to improve our knowledge and understanding in order to better meet patients’ needs.

The MPN LANDMARK SURVEY, funded by Incyte Corporation, is a milestone achievement in advancing our knowledge of the patient burden and identifying potential gaps in care. It is the first large-scale U.S. survey to look at the entire individual and document the widespread, persistent quality of life issues caused by MPNs.

The data from LANDMARK offer new insights on patient burdens, symptoms, disease diagnosis, management and treatment, communication challenges and related topics that affect the lives of people we care for.

LANDMARK validates many of our prior learnings and there are several takeaways that warrant continued discussion. For example, it’s very interesting to see the differences in patient-physician perceptions about treatment planning and goals. And, while the differences are important to note, at the end of the day both patients and physicians share similar goals in wanting to alleviate symptoms and avoid disease progression.

LANDMARK found that more than half of patients reported that their symptoms cause difficulty with activities of daily living, creating some physical, emotional or financial hardship. The degree of symptoms and spectrum of symptoms can vary; however, the impact is very real.

There is an opportunity to empower patients and develop a partnership with them to ensure they receive the information and support needed from their healthcare team. We want to confirm the symptoms they experience and create greater awareness of how MPN symptoms impact daily activities and employment.

The key findings outlined within this report are intended to support patients, physicians and the entire MPN community in ensuring that our perceptions and practices are aligned with what’s really happening in patients’ lives. As a group, we are proud to have contributed to this ground-breaking survey and hope that it proves useful in helping all of us better serve the diverse needs of MPN patients.

— The MPN LANDMARK SURVEY Steering Committee
Myeloproliferative neoplasms (MY-ah-lo-pro-LIF-er-uh NEE-o-plaz-uhms), or MPNs, are a group of blood disorders in which a person’s bone marrow does not function properly. Bone marrow is a spongy tissue where blood cells are primarily made. In people with MPNs there is an abnormal production of these blood cells. This can cause a host of symptoms and complications. MPNs afflict an estimated 200,000 people in the United States. They can be classified based on the presence or absence of a chromosomal abnormality called the Philadelphia chromosome. There are several types of Philadelphia chromosome-negative MPNs. The three main MPNs are myelofibrosis (MF), polycythemia vera (PV) and essential thrombocythemia (ET).

Although MPNs can strike anyone at any age, the diseases are more commonly diagnosed in individuals age 60 and older. MPNs are rare, chronic blood cancers. They are progressive diseases that develop slowly and may worsen over time. MF can be associated with shortened survival and PV can have complications that lead to shortened survival. However, in the majority of cases they can be successfully managed.

“LANDMARK highlights the impact of MPN symptoms on patients’ daily lives.”

— Salman Fazal, MD, Western Pennsylvania Cancer Institute, MPN LANDMARK SURVEY Steering Committee Member
PV BACKGROUND

PV is a rare blood cancer where the bone marrow produces too many red blood cells, white blood cells and/or platelets. Ninety-five percent of people with PV have a mutation—or change—in a certain gene in the body. Too many red blood cells can cause the blood to thicken, which prevents it from flowing normally through arteries and veins, and may increase risk of blood clots. Blood clots can cause a stroke, heart attack, or blockage of an artery in the lungs or in a vein deep within muscles in the arms or legs. PV affects approximately 100,000 people in the United States. Signs and symptoms may include:

- Symptoms of an enlarged spleen:
  - Pain or discomfort in the abdomen or under the left ribs
  - Feeling full even if little or no food has been eaten
- Decreased activity or inactivity
- Tiredness (fatigue)
- Itching (especially after a warm shower)
- Headache or dizziness
- Sweating (at night or during the day)
- Blurred vision or blind spots
- Painful burning of the hands or feet
- Bleeding from the gums and heavy bleeding from small cuts
- Bone pain

ET BACKGROUND

ET is a rare condition in which a person's bone marrow makes too many blood platelets (also known as thrombocytes). About half of people with ET have a mutation—or change—in a certain gene in the body. In people with ET, the overproduction of platelets can make it hard for the blood to flow, resulting in the formation of unnecessary clots and/or increased bleeding. ET affects approximately 71,000 to 88,000 people in the United States and its signs and symptoms may include:

- Symptoms of an enlarged spleen:
  - Pain or discomfort in the abdomen or under the left ribs
  - Feeling full even if little or no food has been eaten
- Decreased activity or inactivity
- Itching
- Night sweats
- Tiredness (fatigue) or weakness
- Burning or throbbing pain in the feet or hands
- Headaches
- Dizziness
- Blood clots (brain, hands, and feet)
The MPN LANDMARK SURVEY was designed in collaboration with an external steering committee of MPN experts and thought leaders, including MPN specialists, allied health providers, patient advocacy group members, epidemiologists and survey experts. The survey investigated patient and physician experiences for the three most common MPNs — myelofibrosis, polycythemia vera and essential thrombocythemia. The LANDMARK SURVEY was funded by Incyte Corporation.

PATIENT SURVEY

Patients diagnosed with MF, PV or ET were recruited from multiple sources to participate in a survey through online and newspaper campaigns and by invitations from MPN specialists. Patient data were collected from May through July of 2014 using a web-based survey tool. The survey was conducted in English only and on average took about 22 minutes to complete. Patients did not receive any compensation for their participation. The national sample of patients yielded three independent subsamples, one for each of the MPN diseases. A total of 813 patients completed the survey: 207 with MF, 380 with PV and 226 with ET.

PHYSICIAN SURVEY

This was designed as a national probability sample of specialists treating patients with MPNs using a double-blind selection process. A series of random samples were drawn from the American Medical Association/American Osteopathic Association listings of physicians in direct patient care with a primary medical specialty of hematology, oncology or hematology/oncology. Medical residents and interns were excluded. The initial respondents were sent letters in advance explaining the survey’s purpose and length, participation requirements and the fair market value U.S. $185 remuneration for completing the survey. Physicians were eligible to participate if they had at least 2 patients with MF, 5 patients with PV or 5 patients with ET in the past year. Subsequent samples were sent e-mail and fax invitations. The physician data were collected online May through July of 2014 using a web-based survey instrument (English only) designed to complement the patient questionnaire. The national sample of physicians yielded three independent subsamples, one for each of the MPN diseases. A total of 457 physician surveys were completed: 156 for physicians treating MF patients, 250 for physicians treating PV patients and 51 for physicians treating ET patients.

Limitations and Disclosures: Limitations of the study were primarily a result of the descriptive design, self-reported nature of the survey, variations in respondent demographics, and challenges related to the relatively low prevalence of MPNs. The study was designed to be analyzed descriptively, which precluded statistical comparisons of the data. Because all results were self-reported by patient respondents, including treatments and risk factors used in the calculation of prognostic risk scores, data concerning symptom severity, outcomes, and comorbidities were not confirmed with clinical measures or respondents’ treating physicians. In addition, the sampling procedures may have introduced self-selection biases that could have affected the demographics of the respondents who participated. For example, relatively few low-risk respondents with MF or PV completed the survey; it remains unclear if this accurately represents the MPN population in the United States or if more severely affected patients with MF and PV were more motivated to participate. Respondents were predominantly college educated, with a mean annual household income > $75,000, compared with the median US household income in 2013, which was $52,250. In addition, although some symptom- and quality of life-related questions were adapted from the validated MPN-SAP and European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire—Core 30 instruments, the MPN LANDMARK SURVEY itself did not include use of validated quality of life instruments. As a result, the MPN LANDMARK SURVEY may underrepresent the symptom burden experienced by the general MPN patient population. Because patients with MPNs are somewhat rare, the sample needed to be recruited by nonprobability sampling methods, which restricted the use of probability statistics to generate sample estimates. Notwithstanding these limitations, this was the only feasible methodology for assessing these rare conditions in a nationally distributed general population sample.
“Although MPN symptoms may not be as severe as some other cancers, the impact on our daily lives is very real. As a patient, I want to feel empowered to advocate for myself, work with my healthcare team to manage my symptoms, and live life to the fullest.”

— ROBIN, PV Patient
OVERVIEW

MPNs can have life-altering effects on the patients who suffer from them, as well as their loved ones. The MPN LANDMARK SURVEY has helped to gather a broad set of information that wasn’t previously available about the day-to-day hardships and challenges for people living with MPNs. Even more importantly, it provides new insights that can help the community find better ways to provide care.

Perhaps the most noteworthy finding from the survey was the significant impact of MPNs in patients’ daily lives. More than half of patients reported that their diseases had caused them at least some physical, emotional and financial hardship in the past month. Not surprisingly, a high percentage of MF (81%), PV (66%) and ET (56%) patients agreed that their symptoms diminished their quality of life.

This data, however, doesn’t adequately convey the true impact of these burdens which, for more than half of all patients surveyed, interfered with family or social life; caused pain and discomfort that limited activities; and made them feel anxious, worried, depressed and/or discouraged.

Fatigue may contribute to many of these disruptions to everyday activities. It is the symptom all MPN patients reported experiencing most often and wanting to resolve. Patients rank fatigue, problems with sexual desire and inactivity as their most severe symptoms. Despite their symptomatic burden, most patients surveyed live independently, and only some rely on a caregiver.

This report provides a summary of the key findings from the LANDMARK SURVEY focused on five specific areas: diagnosis, symptoms, disease impact, treatment and patient-physician relationships.

“My MPN symptoms reduce my quality of life.”

MF 81%

PV 66%

ET 56%

= Remaining percentage of MPN patients who responded “neither agree nor disagree,” “disagree” or “strongly disagree.”
Current State of Health
MPN patients surveyed were asked to rate their current state of health from very poor to excellent. The majority of patients surveyed reported their health as fair to very good.

MPN Patient Reliance on a Caregiver
(usually a spouse/partner)

41% 22% 15%
The onset of MPNs typically occurs between the ages of 50 and 60, although nearly 30% of ET patients surveyed were diagnosed before they turned 45. In contrast, about 54% of MF patients surveyed were not diagnosed until they were 60 years or older. The average age of patients at the time of diagnosis was 59 for MF, 55 for PV and 52 for ET. Forty to 45% of all MPN patients in the survey experienced some of their symptoms for more than two years before receiving a formal diagnosis. Broader and more impactful awareness and educational programs around MPN symptoms could help lead to earlier diagnoses and potentially ease the symptomatic burdens for more MPN patients sooner.

Symptoms at Time of Diagnosis
Most MPN patients reported that they experienced fatigue at the time of diagnosis, along with other symptoms listed below.

<table>
<thead>
<tr>
<th>MF (58%)</th>
<th>PV (44%)</th>
<th>ET (38%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Night sweats: 28%</td>
<td>Itching: 29%</td>
<td>Headaches: 23%</td>
</tr>
<tr>
<td>Abdominal discomfort: 26%</td>
<td>Facial flushing: 24%</td>
<td>Feeling dizzy/ lightheaded: 20%</td>
</tr>
<tr>
<td>Difficulty sleeping: 25%</td>
<td>Hypertension: 24%</td>
<td>Numbness in hands/ feet: 19%</td>
</tr>
<tr>
<td>Weight loss: 25%</td>
<td>Difficulty sleeping: 23%</td>
<td>Hypertension: 17%</td>
</tr>
<tr>
<td>Early satiety: 21%</td>
<td>Headaches: 22%</td>
<td>No symptoms: 16%</td>
</tr>
<tr>
<td>No symptoms: 19%</td>
<td>No symptoms: 11%</td>
<td>No symptoms: 11%</td>
</tr>
</tbody>
</table>
History of Bleeding Prior to Diagnosis

MPNs may be associated with a risk of bleeding or clotting events. Patients were asked if they had a history of bleeding prior to their MPN diagnosis. Most patients surveyed had a history of bleeding and about a third experienced a more serious bleeding event, such as a heart attack, blood clot or stroke, prior to diagnosis.

Patients with a history of bleeding

- MF 73%
- PV 64%
- ET 65%

Patients with a more serious bleeding event

- MF 36%
- PV 26%
- ET 28%
Though symptoms can vary depending on disease type, fatigue stands out as the most common, severe and debilitating across MPNs. Inactivity and problems with sexual desire were two other symptoms MPN patients reported as severe; however, not surprisingly, by a wide margin fatigue is the symptom all MPN patients would most like to resolve.
Most Severe Symptoms Reported by MPN Patients

<table>
<thead>
<tr>
<th>Symptom</th>
<th>MF</th>
<th>PV</th>
<th>ET</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Problems with sexual desire</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Inactivity</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Problems concentrating</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Difficulty sleeping</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Weakness</td>
<td></td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Muscle aches</td>
<td></td>
<td></td>
<td>✓</td>
</tr>
</tbody>
</table>

Patient-Physician Agreement on Symptom Severity

While patients reported fatigue, problems with sexual desire and inactivity as the most severe symptoms across diseases, physicians surveyed had a different perspective on the top symptoms that most negatively affect patient quality of life.
### MPN Symptoms Patients Most Want to Resolve

**MF**
1. Fatigue 47%
2. Abdominal discomfort
3. Bone pain

**PV**
1. Fatigue 33%
2. Itching
3. Difficulty sleeping

**ET**
1. Fatigue 33%
2. Hypertension
3. Hand/feet numbness

### MPN Symptom Management

**Exercise**
- MF 60%
- PV 63%
- ET 69%

**Nonprescription supplements**
- MF 48%
- PV 35%
- ET 46%

### Patient-Physician Agreement on Symptom Reporting

Patients in the survey were asked to report all the symptoms they had ever experienced. Physicians were asked for the five symptoms they heard the most from their patients. Findings showed that there is agreement between patients and physicians on the top symptoms; however, there were some gaps:

- More than half of MF and PV patients reported **difficulty sleeping**; however, less than 10% of physicians reported this as a top symptom.
- Half of ET patients experienced **numbness or tingling** in their hands or feet, whereas only 14% of physicians reported as a top-five symptom.

Additionally, while many patients felt their doctors ask how they are feeling overall and don't ask about specific symptoms, most physicians reported that they proactively ask patients about specific symptoms.
Symptom Recognition
Patients in the survey often did not recognize the connection between certain symptoms they were experiencing and their MPN. For example, patients with MPNs often have difficulty sleeping; however, some patients who reported this symptom did not realize it was related to their MPN. In contrast, many physicians surveyed reported that “all” or “almost all” of their patients recognized their symptoms as MPN-related.

MPN patients who did not recognize that their MPN may cause difficulty sleeping

<table>
<thead>
<tr>
<th></th>
<th>MF</th>
<th>PV</th>
<th>ET</th>
</tr>
</thead>
<tbody>
<tr>
<td>MF</td>
<td>49%</td>
<td>64%</td>
<td>76%</td>
</tr>
</tbody>
</table>

Physicians who felt all or most patients recognize MPN-related symptoms

<table>
<thead>
<tr>
<th></th>
<th>MF</th>
<th>PV</th>
<th>ET</th>
</tr>
</thead>
<tbody>
<tr>
<td>MF</td>
<td>52%</td>
<td>34%</td>
<td>26%</td>
</tr>
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</table>

The Broader Impact of Symptoms
MPN patients surveyed reported that in the past month they have experienced:

A change in sleeping habits

<table>
<thead>
<tr>
<th></th>
<th>MF</th>
<th>PV</th>
<th>ET</th>
</tr>
</thead>
<tbody>
<tr>
<td>MF</td>
<td>57%</td>
<td>53%</td>
<td>47%</td>
</tr>
</tbody>
</table>

Trouble focusing

<table>
<thead>
<tr>
<th></th>
<th>MF</th>
<th>PV</th>
<th>ET</th>
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</thead>
<tbody>
<tr>
<td>MF</td>
<td>53%</td>
<td>55%</td>
<td>48%</td>
</tr>
</tbody>
</table>

A change in appearance

<table>
<thead>
<tr>
<th></th>
<th>MF</th>
<th>PV</th>
<th>ET</th>
</tr>
</thead>
<tbody>
<tr>
<td>MF</td>
<td>52%</td>
<td>38%</td>
<td>32%</td>
</tr>
</tbody>
</table>

A change in appetite

<table>
<thead>
<tr>
<th></th>
<th>MF</th>
<th>PV</th>
<th>ET</th>
</tr>
</thead>
<tbody>
<tr>
<td>MF</td>
<td>47%</td>
<td>38%</td>
<td>35%</td>
</tr>
</tbody>
</table>
The Emotional Impact of MPNs

Although patients and physicians surveyed agreed that patients with MPNs often feel very anxious, worried, depressed or discouraged about their condition, in some areas, physicians estimated the emotional impact of MPNs to be even greater than what was reported by patients.

For example, most physicians reported that their patients experience a great deal of anger, irritability, stress or feelings that their disease is controlling their life. Patients, on the other hand, reported that these feelings had less of an emotional impact than what the doctors perceived.

### I have been irritable/angry

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>A great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>MF Patients</strong></td>
<td>58%</td>
<td>22%</td>
</tr>
<tr>
<td><strong>MF Physicians</strong></td>
<td>22%</td>
<td>37%</td>
</tr>
<tr>
<td><strong>PV Patients</strong></td>
<td>62%</td>
<td>19%</td>
</tr>
<tr>
<td><strong>PV Physicians</strong></td>
<td>11%</td>
<td>28%</td>
</tr>
<tr>
<td><strong>ET Patients</strong></td>
<td>62%</td>
<td>20%</td>
</tr>
<tr>
<td><strong>ET Physicians</strong></td>
<td>10%</td>
<td>22%</td>
</tr>
</tbody>
</table>

### I have had trouble coping with the stress

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>A great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>MF Patients</strong></td>
<td>50%</td>
<td>25%</td>
</tr>
<tr>
<td><strong>MF Physicians</strong></td>
<td>13%</td>
<td>31%</td>
</tr>
<tr>
<td><strong>PV Patients</strong></td>
<td>54%</td>
<td>23%</td>
</tr>
<tr>
<td><strong>PV Physicians</strong></td>
<td>24%</td>
<td>40%</td>
</tr>
<tr>
<td><strong>ET Patients</strong></td>
<td>57%</td>
<td>23%</td>
</tr>
<tr>
<td><strong>ET Physicians</strong></td>
<td>18%</td>
<td>45%</td>
</tr>
</tbody>
</table>

Note: Labels for data under 10% are not displayed.
Over half of patients report that their condition has caused at least some emotional or social impact on them in the past month.

### Social Impact

<table>
<thead>
<tr>
<th></th>
<th>MF Patients</th>
<th>MF Physicians</th>
<th>PV Patients</th>
<th>PV Physicians</th>
<th>ET Patients</th>
<th>ET Physicians</th>
</tr>
</thead>
<tbody>
<tr>
<td>“I have been anxious or worried.”</td>
<td>91%</td>
<td>78%</td>
<td>74%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>“I have been depressed or discouraged.”</td>
<td>75%</td>
<td>60%</td>
<td>59%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>“I have avoided social interactions.”</td>
<td>12%</td>
<td>26%</td>
<td>39%</td>
<td>21%</td>
<td>10%</td>
<td>18%</td>
</tr>
<tr>
<td>Not at all</td>
<td>75%</td>
<td>39%</td>
<td>84%</td>
<td>29%</td>
<td>86%</td>
<td>35%</td>
</tr>
</tbody>
</table>

Note: Labels for data under 10% are not displayed.
Impact on Daily Activities

For the first time, the LANDMARK SURVEY has provided data that show the extent of the life-changing repercussions of MPNs. Most MPN patients reported that their condition caused at least some interference in their daily activities, as well as with their:

- **Sex life**
  - MF 64%
  - PV 49%
  - ET 42%

- **Family or social life**
  - MF 79%
  - PV 63%
  - ET 55%

Many patients also reported that **pain and discomfort** limited their activities to some degree:

- MF 61%
- PV 52%
- ET 45%
**Impact on Employment**

Maintaining a productive work life is another major challenge for patients with MPNs, especially MF. The LANDMARK SURVEY is the first time the impact of MPNs on employment and productivity has been reported.

Many MF patients who were working after their diagnosis said the disease caused them to reduce their hours at work, voluntarily terminate their job, take early retirement or go on disability. For PV and ET, about a third of patients also had to reduce their hours as a result of their disease. For patients who continued to work, 15 to 30 percent reported staying home from work at least one day in the past month and the overall average time for work absences was three days per month.

MPN patients in the workforce reported that their disease caused them to:

---

### Reduce hours at work

- **MF**: 59%
- **PV**: 37%
- **ET**: 30%

### Voluntarily leave their job

- **MF**: 31%
- **PV**: 21%
- **ET**: 11%
Impact on Productivity
Patients surveyed were asked if they had experienced lost productivity at work and at home over the last 30 days.

Patients who reported canceling at least one planned activity over the past month

- MF: 41%
- PV: 29%
- ET: 28%

Patients who spent at least one day in bed (all or most of the day) over the past month

- MF: 32%
- PV: 23%
- ET: 25%

Patients that stayed home from work at least one day over the past month

- MF: 29%
- PV: 19%
- ET: 23%
In general, most MPN patients are very satisfied with their communication and relationship with their healthcare providers regarding treatment. The survey found some disagreement about treatment plans, compliance, establishing goals for therapy and communications. The most common treatment to manage all three diseases was aspirin. Nine of 10 PV patients have had a phlebotomy and 40% of MF patients have had a transfusion. In addition to an array of drugs, about 60% of patients manage their symptoms with exercise and 35–50% take non-prescription supplements.

Physicians surveyed only recommended drug treatment in about half of patients with moderate symptoms (MF 53%; PV 47%; ET 53%) and the majority of patients with severe symptoms (MF 84%; PV 75%; ET 74%).

Physician-Patient Perspectives on Treatment

“Even though I believe mild to moderate MPN symptoms can significantly impact patient quality of life, I rarely recommend drug treatment for patients with mild symptoms.”

“Most of us are very satisfied with our physician relationships, communications and treatment of our conditions.”

Physicians surveyed only recommended drug treatment in about half of MPN patients with moderate symptoms. Most felt they kept patients informed of new treatment options.

Across diseases, more than a third of MPN patients felt that their physician did not keep them informed about new treatment options.

Physician-Patient Perspectives on Treatment Plans

Nearly all physicians reported they had created a treatment plan of established goals for their patients; however, about a third of patients did not believe their doctor had created a treatment plan for them.
**Top Therapy Goals**

Patients and physicians were asked, aside from a cure for the condition, what was their most important goal for therapy. The most common goals selected were:

**Patients**

- **MF**
  - 42% Slow/delay disease progression
  - 21% Better quality of life
  - 11% Healthy blood counts
  - 7% Symptom improvement

- **PV**
  - 25% Slow/delay disease progression
  - 24% Prevent vascular/thrombotic events
  - 18% Healthy blood counts
  - 12% Better quality of life

- **ET**
  - 34% Prevent vascular/thrombotic events
  - 21% Slow/delay disease progression
  - 17% Healthy blood counts
  - 14% Better quality of life

**Physicians**

- **MF**
  - 53% Symptom improvement
  - 26% Better quality of life
  - 12% Slow/delay disease progression
  - 4% Reduce blood transfusions

- **PV**
  - 43% Prevent thrombotic events
  - 20% Symptom improvement
  - 14% Hematocrit levels <45%
  - 11% Better quality of life

- **ET**
  - 57% Prevent vascular/thrombotic events
  - 18% Better quality of life
  - 14% Symptom improvement
  - 4% Slow/delay disease progression
Treatment Compliance

Treatments non-compliance is an area of concern that is important to note. The LANDMARK SURVEY found that the majority of physicians reported that their patients sometimes or often do not wish to comply with their treatment recommendations. This warrants further research to uncover the reasons for this finding and determine if certain treatments and disease-management recommendations are associated with higher rates of non-compliance.

Physicians who reported patients sometimes or often do not wish to comply with treatment recommendations.

Recommending Drug Treatment

Physicians reported they most frequently recommended drug treatment in patients with the following symptoms:

<table>
<thead>
<tr>
<th>Symptom</th>
<th>MF</th>
<th>PV</th>
<th>ET</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symptomatic splenomegaly</td>
<td>76%</td>
<td>82%</td>
<td>74%</td>
</tr>
<tr>
<td>Drenching night sweats</td>
<td>66%</td>
<td>64%</td>
<td>62%</td>
</tr>
<tr>
<td>Unintentional weight loss</td>
<td>59%</td>
<td>57%</td>
<td>57%</td>
</tr>
<tr>
<td>Fever</td>
<td>59%</td>
<td>55%</td>
<td>56%</td>
</tr>
</tbody>
</table>
Additional Treatment Challenges for PV Patients

- **63%** Most PV patients surveyed reported feeling stress or anxiety around managing their hematocrit levels.
- **46%** Physicians surveyed estimated that almost half of PV patients required treatment in addition to phlebotomy to control their condition.
- **56%** Physicians also estimated that an average of 12% of PV patients refused or could not tolerate phlebotomy treatments.
- **12%** More than half of PV patients who discontinued treatment with hydroxyurea did so because they could not tolerate or were resistant to the medication.

Utilization of Prognostic Risk Tools in Treating MF

- **83%** The majority of physicians surveyed who treat patients with MF report utilizing a prognostic risk score assessment to classify their patients.
- **54%** In contrast, only about half of MF patients reported that their physician provided a risk classification for their condition.
- **63%** Physicians who reported that they did not use a prognostic risk score assessment tool for the management of their patients either:
  1) did not find these tools useful
  2) were not familiar with any available prognostic risk assessment tools or
  3) thought they were useful but did not have enough time to incorporate them into their practice.
Another notable finding that warrants further attention from the MPN community is the fact that more than one in three patients changed physicians because they were unhappy with the care they received. Additional research could investigate why they were dissatisfied. Did they have problems with communications or personality conflicts? Were their expectations unrealistic? Keep in mind, however, that the vast majority of patients are now quite happy with their current MPN physicians. In fact, about nine in 10 are satisfied with their physicians’ overall treatment and management of their disease.

**Nearly Half of All Patients Have Changed Physicians**

Across MPNs, the most common reason for changing physicians was unhappiness with the care received from the physician.

*“Although most of us have switched physicians, we are highly satisfied with our current physicians.”*
**Patient Satisfaction**

The majority of patients and physicians surveyed were *satisfied with their current communication* about the condition and its treatment.

- **MF 91%**
- **PV 87%**
- **ET 84%**

"The majority of us are satisfied with our current communication about MPNs."

Almost all MPN patients surveyed agreed that their *physician was genuinely concerned about helping them*.

- **MF 96%**
- **PV 93%**
- **ET 95%**

"Most of us agree that our MPN patients felt we were genuinely concerned about them."

Most MPN patients reported that they felt their *physician understood how much their condition had an impact on their life*.

- **MF 84%**
- **PV 73%**
- **ET 74%**

"We understand how much our MPN patients’ conditions impact their quality of life."
Sources of Disease Information

Another finding that should be examined further is the fact that MPN patients often do not rely on their healthcare providers as a primary source of disease information. Although more than 20% of patients report getting information from their physicians’ offices, roughly 90% are turning to the internet to learn more about their disease. Additional research may be warranted to uncover the reasons for this finding.

<table>
<thead>
<tr>
<th>Source</th>
<th>MF</th>
<th>PV</th>
<th>ET</th>
</tr>
</thead>
<tbody>
<tr>
<td>Internet</td>
<td>90%</td>
<td>87%</td>
<td>88%</td>
</tr>
<tr>
<td>Online Discussion Groups</td>
<td>47%</td>
<td>45%</td>
<td>54%</td>
</tr>
<tr>
<td>Physicians’ Offices</td>
<td>27%</td>
<td>22%</td>
<td>20%</td>
</tr>
</tbody>
</table>

Physician Support to Learn about Diagnosis

The majority of patients across diseases felt their doctor did not provide information to help them learn about their diagnosis.
THE PATH TO BETTER CARE

The MPN community wants to enable the best care for people affected by MPNs. The LANDMARK SURVEY moves the community closer to that shared goal by quantifying the symptomatic burdens experienced by patients and also raising important questions such as:

- How to address the treatment goal disconnect between patients and healthcare professionals?
- How can healthcare professionals help alleviate patient concerns around disease progression?
- What can be done to educate primary care physicians and the general public to improve the speed of diagnosis following initial symptoms?
- Why are more than one-third of patients who change healthcare professionals unhappy with the care they received from their former physicians?
- How can healthcare professionals more closely align their practices with patients’ treatment goals and quality of life needs?
- Why are so many patients not complying with treatment recommendations?
- How can healthcare professionals become patients’ first choice for information about MPN diseases?
- What partnerships or alliances need to be formed to accelerate progress on effective drugs or therapies?
- What else should be done to alleviate patients’ physical, financial, social, work and emotional hardships and improve their quality of life?

This survey provides the signposts on the path to better lives for people affected by MPNs. Now it is up to the MPN community to work together, find answers and implement solutions large and small that will pave the road to success.

SHARE THE KNOWLEDGE

The LANDMARK SURVEY is an abundant information resource to be mined by the entire MPN community. The data from LANDMARK offer new insights on patient burdens, symptoms, disease diagnosis, management and treatment, communication challenges and related topics that affect the lives of people we love and care for. Healthcare professionals especially can use this information to better align their practices and communications with patients’ real-world needs. The steering committee hopes that patients, physicians and everyone in the MPN community will gain value from this report and share their knowledge and ideas to better the lives of MPN patients worldwide.