# MPN CONSENSUS REPORT

## Empowerment Through Understanding: Exploring the Challenges for People Living with Myeloproliferative Neoplasms (MPNs)

# TABLE OF CONTENTS

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CANCERcare®

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**David Alexander**
*MPN Patient and Advocate*

**Gabriela Hobbs, M.D.**
*Hematologist/Oncologist*

**Andrew Kuykendall, M.D.**
*Hematologist/Oncologist*

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# SETTING THE STAGE: KEY FACTS

**Myeloproliferative neoplasms, or MPNs,** are a group of rare, chronic blood cancers including polycythemia vera (PV), essential thrombocythemia (ET) and myelofibrosis (MF), characterized by the abnormal production of blood cells in the bone marrow.[1]

**In the United States, thousands of people live with MPNs, with a prevalence of approximately:**

**People living with PV[2]**
**100,000**

**People living with ET[2]**
**88,000**

**People living with MF[2]**
**18,500**

The complexity of MPNs and their impacts on people's lives make these cancers an important area of focus within both the oncology and rare disease communities.[3] However, despite considerable efforts to support people living with MPNs, **there remains a clear need for additional and enhanced resources and support.[4]**

Recognizing this gap, in 2024 Incyte convened a group of multidisciplinary community leaders, including patients, patient advocates and healthcare providers (HCPs) from across the U.S., at both in-person and virtual meetings. The aim of these assemblies was to thoroughly discuss and identify the most pressing issues facing Americans living with MPNs and develop an actionable roadmap to address these unique concerns and pave the way for improved patient support and outcomes.

**This report outlines research from across the field and proposes strategic recommendations to help better meet the needs of the MPN community, exploring three key themes outlined by the group's participants:**

1

## NAVIGATING THE EMOTIONAL AND SOCIAL IMPACT OF MPNs

People living with MPNs often experience significant emotional challenges, which can profoundly impact their lives and social interactions, including their ability to work.

2

## EMPOWERING PATIENTS, ENHANCING OUTCOMES: EFFECTIVE COMMUNICATION IN MPN CARE

Disconnects in communication between healthcare providers and patients, as well as academic and community health settings, impact people living with MPNs from receiving informed, comprehensive and effective care.

3

## INCLUSIVITY IN ACTION: TAILORING MATERIALS FOR *ALL* PEOPLE LIVING WITH MPNs

Given the broad range of people impacted by MPNs across ages, genders, ethnicities and other demographic considerations, there is a need for more inclusive, tailored educational materials across the landscape that address the diverse needs of the community.

## 1

# Navigating the Emotional and Social Impact of MPNs

People living with MPNs often experience significant emotional challenges, which can profoundly impact their lives and social interactions, including their ability to work.

# PEOPLE WITH MPNS OFTEN FACE SUBSTANTIAL EMOTIONAL AND SOCIAL CHALLENGES[3]

**MPN community leaders shared that people living with MPNs have difficulties adjusting to a "new normal" after being diagnosed and grapple with the emotional impacts of survivorship.** This can include fears of their condition progressing, but also fears about needing someone to care for them consistently for the rest of their life.[4]

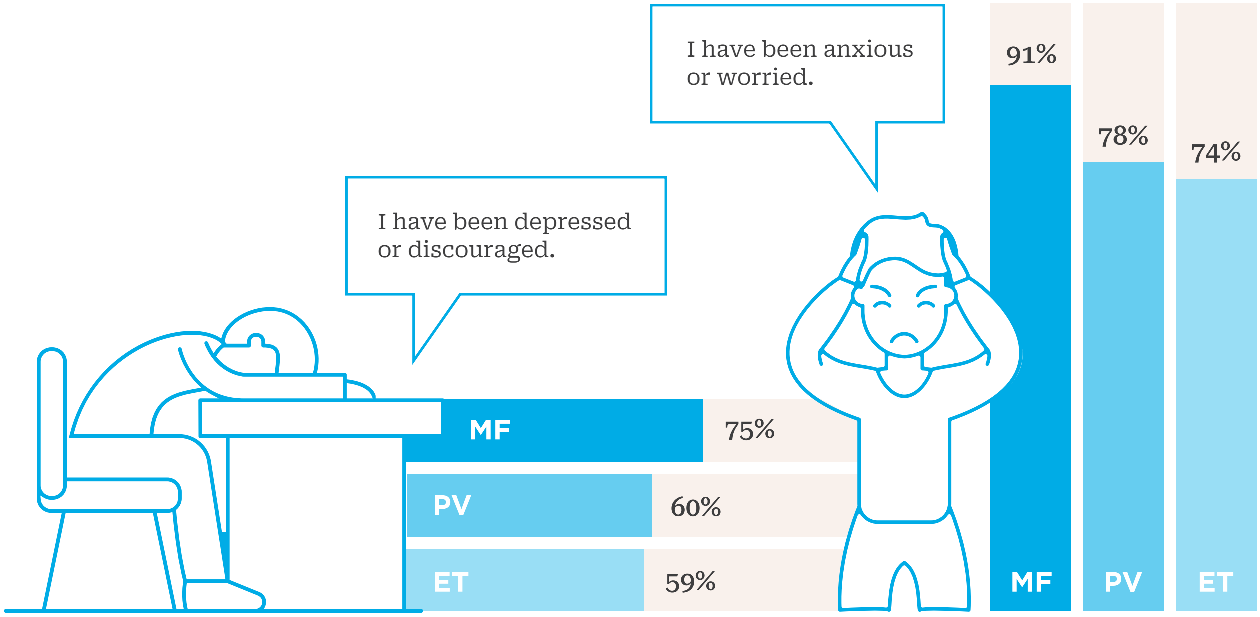
Additionally, they explained that despite suffering from a serious condition, those with MPNs often do not *appear* visibly ill, which can lead to misunderstandings about their health status, as others may not recognize them as being sick.[4]

Leaders note how this can cause feelings of isolation, as friends and family at times treat them overly cautiously or, conversely, expect them to function "normally" despite their limited capacity to do so. Socially, the situation can become a "vicious cycle of isolation." MPN community leaders reported that because people living with MPNs often decline social invitations due to their health, they receive fewer invitations over time, further diminishing their support system.[4]

This feeling of isolation is compounded by the fact that many people living with MPNs do not have personal connections to friends or family with the condition and may face these circumstances alone.

> **"We often see a vicious cycle of isolation where patients don't tell their families, they don't tell their friends, they don't tell their employer [that they are sick]. And because they don't look sick, many people with MPNs don't have the necessary support systems which can make a big difference in their quality of life."**
>
> **KAPILA VIGES**
> Chief Executive Officer, MPN Research Foundation

According to a survey of 699 people between the ages of 18–90 in the U.S. living with MPNs, **more than half reported that their condition has caused at least some emotional or social impact on them.**[4]



**MPN community leaders reported other factors contributing to a complex mix of emotions and social dynamics that can significantly impact patients' lives:**

- Fear of disease progression
- Concerns about becoming dependent on others for care
- Guilt driven by inability to perform daily tasks or sustain responsibilities
- Pressure to serve as caregivers to others living with health issues[4]

# LIVING WITH AN MPN DEEPLY AFFECTS INTERACTIONS IN THE WORKPLACE

**According to community leaders, living with MPNs can often influence people's sense of capability and confidence at work.** Managers and coworkers often struggle to understand how the unseen symptoms of MPNs can challenge an individual's capacity to perform consistently. For those living with MPNs, this lack of understanding can lead to shifts in self-perception and feelings of self-doubt, undermining their confidence and ability to advocate for themselves in the workplace.[4]

> **"When I was first diagnosed with PV, my boss showed little understanding of my MPN and its impact on my life. Even while I was undergoing treatments for my cancer, I faced constant phone calls and emails demanding immediate attention to work assignments. Trying to manage those pressures during the challenging first year of my diagnosis was incredibly difficult. Ultimately, I had to rebuild my life and career, which led me to where I am today as an MPN advocate."**
>
> **DAVID WALLACE**
> Founder, Chief Executive Officer and Executive Director,
> MPN Cancer Connection

Despite these challenges, many people strive to maintain a sense of normalcy and continuity in their careers. They endeavor to "keep going," which requires not only managing their health, but also navigating the complexities of workplace dynamics. This involves educating employers and colleagues about their condition, a task that requires a delicate balance of transparency and self-protection. Successfully advocating for necessary accommodations—such as flexible working hours or the ability to work from home—becomes a crucial aspect of their work life, enabling them to continue contributing their talents while managing their health.[4]

**IN A SURVEY OF**

**904**

**people between the ages of 18–70 in the U.S. living with MPNs,**

**50.5%**

**reported at least one change in employment status status due to their diagnosis, most commonly:[5]**

**30.2%**

Left a job

**24.8%**

Went on medical disability leave

**21.8%**

Had reductions in work hours for at least three months

The emotional toll of MPNs, coupled with the need to maintain professional engagements, can be daunting. However, **MPN community leaders who have successfully navigated these challenges reported finding a renewed sense of purpose and self-assurance, balancing their health and their professional lives.** Engaging with work not only provides a useful daily and financial structure but also offers a psychological boost, reinforcing their identity and value beyond their illness.[4]

# RECOMMENDATIONS

**Creating a resource-rich environment for people living with MPNs was central to the recommendations provided by community leaders.**

The theme of accessibility was repeated throughout discussions to ensure that a wide array of tools is not only available, but also tailored to the unique needs of people across the community. Recommendations underscore the value of community and connection, aiming to provide education and strengthen social networks, fostering a sense of belonging and shared experiences.

## 1 ADULT “SURVIVORSHIP” TOOLKIT

Develop a resource, available in multiple formats, that can serve as a centralized hub for people to access a wide range of MPN-specific programs and resources. These elements can include educational materials, financial assistance tools, support groups and other relevant information to help patients manage their condition and overall care.

### THOUGHT-STARTER: THE TERMINOLOGY OF “SURVIVORSHIP”

MPN community leaders had differing views around the use of the term “survivorship” in the context of how people living with MPNs prefer to identify themselves. Some felt the term was appropriate and hopeful, while others expressed reservations that people who are actively managing a chronic cancer like an MPN often feel that they are not “survivors,” but rather are “dealing with” or “living with” their condition long-term. Given the nuances around this terminology, the group acknowledged that further discussions would help to ensure appropriate language is identified and used across materials.

## 2 PATIENT EDUCATION/SUPPORT GROUPS AUDIT + ENHANCEMENT

Compile comprehensive list of existing support groups, both local and national, as a resource for people living with MPNs and acknowledgment of the rich content already available from the advocacy community. As part of this, conduct a comprehensive audit of current offerings across the MPN community to identify gaps and opportunities for improvement to provide greater educational content and support for group leaders.

## 3 PEER-TO-PEER MATCHING SYSTEM

Consider an online matching system to connect patients with one another, pairing individuals based on factors like diagnosis, stage of treatment or specific needs. Connecting people based on their unique journeys can strengthen and sustain vital support networks, which may ultimately improve experiences and support for people living with MPNs.

> **“We find that support groups are effective when the meetings are built around discrete topics with guest speakers, facilitated by a peer who themselves have received some coaching on meeting facilitation.”**
>
> **NATALIE GIOCONDO**
> President, MPN Advocacy
> & Education International

## 2

# Empowering Patients, Enhancing Outcomes: Effective Communication in MPN Care

Disconnects in communication between healthcare providers and patients, as well as academic and community health settings, prevent people living with MPNs from receiving informed, comprehensive and effective care.

# ENHANCING HEALTHCARE PROVIDER-PATIENT DIALOGUE IS ESSENTIAL FOR THOSE LIVING WITH MPNs

Effective communication between healthcare providers and those living with MPNs ensures that patients understand their condition and management options.[3] This is especially important when building a comprehensive care team. MPN community leaders noted that the management of MPNs often requires a multidisciplinary approach, involving not just oncology, but specialties such as cardiology and nephrology, to manage potential long-term survivorship issues. Given this, patients need to work with their care teams to help facilitate strong, ongoing dialogue.[4]

Additionally, **patients frequently report wanting to play a bigger part in their treatment decisions.** This is especially important given that HCPs may have differing views and expectations on how well treatments are working compared to patients.[3] These discrepancies between HCPs and patient perceptions can be seen in recent research related to symptom recognition[4]:

- More than half of patients with PV or MF reported difficulty sleeping; however, less than 10% of physicians reported this as a top symptom they hear from people living with MPNs
- Half of patients with ET reported experiencing numbness or tingling in their hands or feet, but just 14% of physicians reported this as a top five symptom

With this in mind, community leaders emphasized that it is critical for patients to be prepared ahead of their appointments. They should feel empowered to ask questions, speak about symptoms they may be experiencing, request access to their health records and get second opinions when they feel it is needed.

# INTEGRATING ACADEMIC INSIGHTS INTO COMMUNITY MPN CARE IS IMPERATIVE

MPN community leaders also agree that connectivity between academic and community health settings must be enhanced. **They find that most people living with MPNs receive treatment at community health centers;** however, these settings often face a range of challenges that can impact the quality of patient care.[4]

> **“As rare diseases, MPNs can be isolating, and we often see patients going through the impacts of survivorship on their own. It can be hard for people with MPNs to know what questions to ask and even more challenging in the community health setting.”**
>
> **RACHEL SAKS**
> Senior Director of Education and Programs,
> Cancer Support Community

MPN community leaders noted that delays in diagnosis are a common issue in community settings, which can lead to delayed treatment, potentially worsening people’s prognosis. Leaders also highlighted that some patients treated in these settings reported not being fully aware of all the options available to them, including participation in clinical trials that can offer access to the latest therapies. Others shared that some community providers lack awareness of existing resources and clinical guidelines, causing further gaps.[4]

> “We now have treatment guidelines for MPNs, and they are a wonderful place for community oncologists to start in developing a treatment plan. The key is ensuring that treating oncologists are aware of these guidelines. Beyond that, there’s a real opportunity to create bridges between community oncology and academic centers so patients can be aware of all the knowledge and resources that are available, and so they can access the right care for themselves.”
>
> **DAVID ALEXANDER**
> MPN patient and advocate

Strengthening the links between academic research institutions and community health settings can facilitate a better knowledge exchange around advanced treatment strategies.

This connectivity ensures that new research is quickly translated into practices in community settings, elevating overall standards of care and improving patient outcomes.[4]

**30%**

**of MPN patients have a**

**DELAY IN DIAGNOSIS**

**OR MISDIAGNOSIS**

**due to their care team’s lack of knowledge about MPNs[6]**

# RECOMMENDATIONS

**Empowering patients to take an active role in their healthcare journey and enhancing the quality of their interactions with healthcare providers was central to the recommendations provided by MPN community leaders.**

A significant part of this dialogue was devoted to ideas that would help prepare patients with the necessary tools and knowledge to engage confidently and productively during medical appointments. The group acknowledged that it is the role of both patients and healthcare providers to collaborate and engage in productive, supportive dialogues.

## 1 APPOINTMENT PREPARATION

Develop materials to help patients prepare for their appointments with healthcare providers, including important information to share, questions to ask, ways to advocate for themselves during the visit and key existing guidelines. This can ensure patients are well-equipped to make the most of their interactions, rather than feeling frustrated or unsure of how to engage.

> **“MPN specialists play a very specific role in the care of patients. In order for people with MPNs to get the most out of their appointments, it’s important for them to come prepared with questions and historical information about their own health.”**
>
> **GABRIELA HOBBS, M.D.**
> Hematologist/Oncologist

## 2 SPECIALIST ROADMAP

Develop an interactive, online tool that patients can use to keep track of the various specialists involved in MPN care, such as oncologists, cardiologists and nephrologists, among other practitioners. The tool can be formatted as a decision tree to help patients “choose their own path” while also providing education on the different roles and responsibilities of various specialists, who to go to with needs and questions, important information to share and questions to ask and best channels to communicate with their providers so they can more effectively manage their care team.

> **“A program or platform that helps people with MPNs understand the role of MPN specialists who may be in their area, and which specialists accept new patients outside of state lines, would help improve the process for getting treatment and overall care for patients and their loved ones.”**
>
> **ANDREW KUYKENDALL, M.D.**
> Hematologist/Oncologist

## 3

# Inclusivity in Action: Tailoring Materials for *All* People Living with MPNs

Given the broad range of people impacted by MPNs across ages, genders, ethnicities and other demographic considerations, there is a need for more inclusive, tailored educational materials across the landscape that address the diverse needs of the community.

# WORDS MATTER IN THE MPN COMMUNITY

**The language used to communicate with people living with MPNs holds significant weight in fostering an inclusive and supportive environment.** MPN community leaders recommended avoiding terms like “minority” and “underserved,” which can inadvertently marginalize groups. Instead, adopting terms like “under-represented” or “under-resourced” more accurately reflects disparities in healthcare access and representation occurring within the broader medical system.[4]

Addressing the diverse age groups within the MPN community also requires tailored communication. The term “youth” encompasses a broad spectrum, from young children and teenagers to young adults. MPN community leaders shared that each subgroup is not only at a distinct developmental stage but also faces unique challenges related to their condition. Young children may need simpler explanations and reassurances to cope with their illness, while teenagers often seek more detailed information that resonates with their growing desire for autonomy. Young adults navigating pivotal life decisions about careers and relationships require information that addresses how MPNs can impact these significant milestones.[4]

**Carefully considering language that addresses the needs and concerns of various populations within the broader MPN community can help ensure that no one feels overlooked or misunderstood.[4]**

> **“Having digestible, credible and informative resources available for people at every stage of the disease—from initial diagnosis to learning about treatment options and beyond—is so important. Materials need to reflect the communities they serve—not just language, but imagery and design that speaks to them. That’s how we build trust and ensure information resonates.**

**AICHA DIALLO**

Vice President of Programs, Patient Empowerment Network

# REPRESENTATION IS IMPORTANT

Educational materials must be thoughtfully crafted to ensure they resonate with the diverse populations affected by MPNs. The MPN community leaders shared that this process should not only include utilization of language that is accessible and free from medical jargon, but also feature imagery that reflects the demographic and cultural diversity of the community.[4]

The importance of people seeing themselves reflected in these materials cannot be understated. For instance, using images that depict a variety of ethnic backgrounds and age groups, along with stories that address specific cultural and community contexts, can help bridge the gap between generic medical advice and personalized patient support. Studies also show that when bilingual discharge instructions are provided to patients with limited English proficiency, they are less likely to be readmitted or visit the emergency room.[7,8]

**When people identify with educational resources, it fosters a greater sense of**

**INCLUSION & RELEVANCE,**

**enhancing engagement and the likelihood of the information being utilized effectively.**[9]

> **We often have patients come to us frustrated because educational materials are not in their native language, making it hard for them to access the resources they need to help manage their disease. Recently, we had a patient come to us for help understanding the background of a clinical trial she was considering participating in. The materials were only provided in English, and the patient didn't speak the language, so she had to run the 40-page document through a translation app. We envision a world where it's much easier for patients like her to get the information they need."**

**VILMARIE RODRIGUEZ**
Vice President of Patient Assistance and Community Engagement, CancerCare

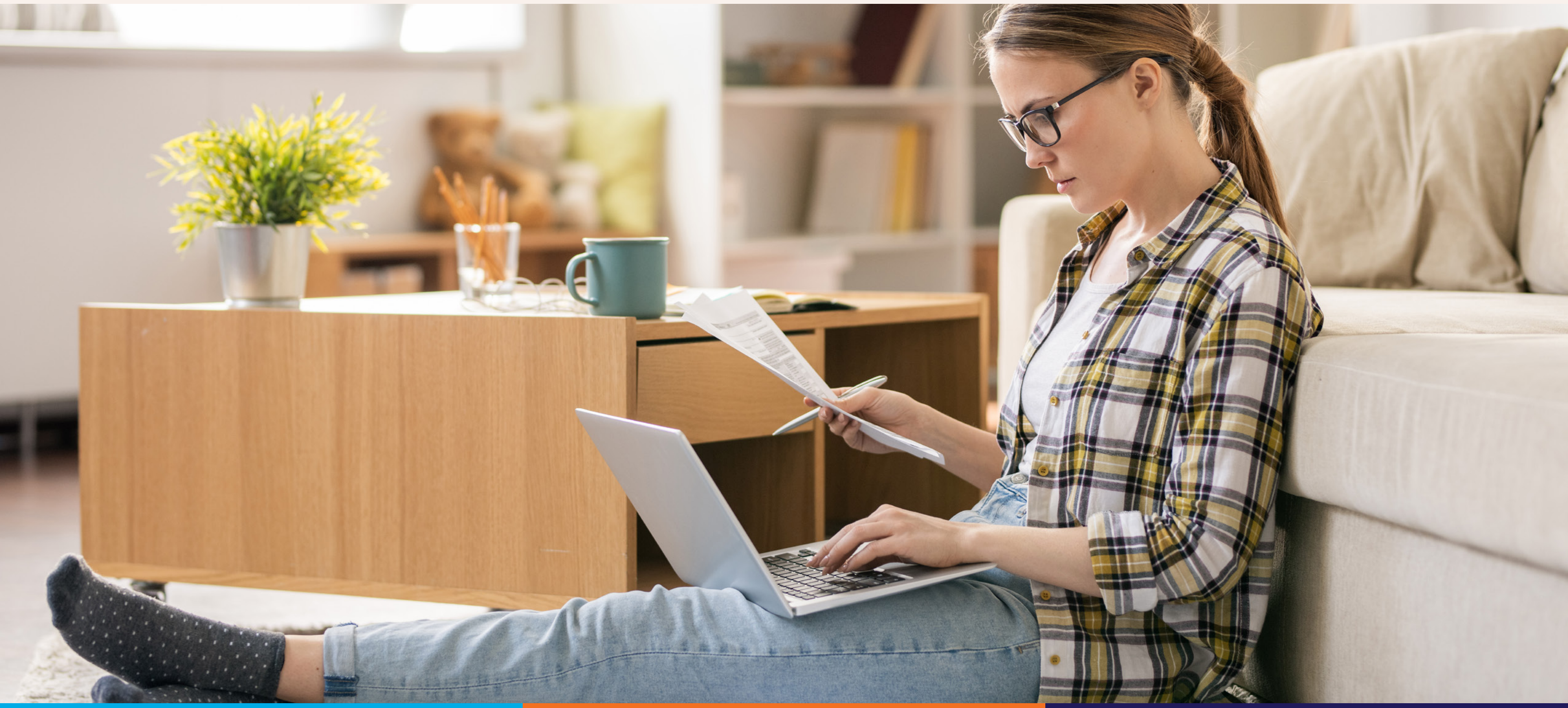
# RECOMMENDATIONS

## Discussions placed a clear emphasis on developing relevant materials for those living with MPNs across ages, genders, ethnicities and other demographics

This includes young adults as they transition from pediatric to adult oncology care—a significant milestone for some in the MPN journey. To address the unique challenges that occur during this critical time, community leaders proposed resources that would provide young adults with the necessary tools and support systems to navigate this period, foster independence and build confidence in managing their health.

### 1 "LIFE SKILLS" CHECKLIST

Develop a life skills checklist detailing the transition from pediatric to adult oncology care to help provide comprehensive guidance on a range of life skills necessary for young adults to effectively manage their MPN care, including information on insurance coverage, financial planning, medication management, appointment scheduling and other practical aspects of self-care.



## 2 BUDDY SYSTEMS

Create a peer-to-peer support network pairing young adult patients with more experienced mentors living with MPNs to provide younger patients with insights and strategies to navigate the adult healthcare system. Parents should also be involved in this system to similarly gain knowledge and build confidence to support their children in this new phase of life.

## 3 REPRESENTATIVE RESOURCES

As noted above, develop resources that depict the diversity and range of people living with MPNs and accurately represent their lived experiences.

> **“There are innumerable ways to make resources resonate as strongly as possible, particularly if they address the non-medical aspects of living with MPNs. Topics that address everyday experiences like pursuing a successful career with MPNs, planning for a family and leading an active life, can be very helpful.”**
>
> **AMY LANE**
> Senior Information Specialist,
> The Leukemia & Lymphoma Society

# KEY CONSIDERATIONS FOR OUTPUTS

**To ensure that the recommendations provided throughout this report serve the specific needs of the MPN community, participating leaders suggest the below considerations for the development of new supporting tools and materials:**

## FORMAT

Materials should be available in multiple formats—including digital as well as printable/downloadable hard copies. Recognizing that people learn and engage in different ways, materials should extend beyond written content (e.g., audio/video content, interactive tools).

## ACCESSIBILITY

Content should be widely accessible, not owned and distributed by a single organization but rather with the goal of distribution to all relevant organizations across the MPN community.

## LANGUAGE

Considering the nuances of language is especially important considering the emotional challenges associated with living with MPNs. For materials to be effective, they must be published in a variety of languages and reviewed and edited by native speakers.

## CULTURAL REPRESENTATION

Materials should be tailored to the specific needs and preferences of various populations within the broader MPN community, including imagery and ideas that reflect its cultural diversity, representing various ethnic backgrounds and age groups.

# CONCLUSION

By anchoring efforts in the lived experiences of people with MPNs, enhanced support can be accessible to all. The path forward involves exploring the recommendations outlined in this report and engagement across the MPN community and supportive organizations and institutions to evolve these approaches over time.

## Thank You

**Incyte thanks the participating MPN leaders for their insights and contributions as well as their continued to commitment to making a positive difference for people living with MPNs.**

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