<<CF-Main Approval Stamp - Approved>>

RESEARCH SUBJECT CONSENT FORM

TITLE:	MPN PROGRESSion Registry™ (PROGRESS-MPN): A U.S.-Based Observational Study Tracking Symptoms, Treatments, Clinical Outcomes, and Disease Progression in Myeloproliferative Neoplasms
PROTOCOL NO.:	MPN-PROG-2025-002 WCG IRB Protocol #20251868
SPONSOR:	MPN Research Foundation
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STUDY-RELATED PHONE NUMBER(S):	(773) 977-7216
EMAIL:	research@mpnrf.org
STUDY-RELATED CONTACT:	MPN Research Foundation Registry Program Manager

In this consent form, "you" and "your" refer to the participant, even when a Legally Authorized Representative (LAR) is providing consent.

Your participation in this study is voluntary. You may decide not to participate or you may leave the study at any time. Your decision will not result in any penalty or loss of benefits to which you are otherwise entitled.

If you have questions, concerns, or complaints, or think this research has hurt you, talk to the research team at the phone number(s) listed in this document.

RESEARCH CONSENT SUMMARY

You are being asked for your consent to take part in a research study. This document provides a concise summary of this research. It describes the key information that we believe most people need to decide whether to take part in this research. Later sections of this document will provide all relevant details.

Key Study Information

You are invited to participate in a research study called the MPN PROGRESSion Registry, sponsored by the MPN Research Foundation. This registry collects health and treatment

information from people diagnosed with myeloproliferative neoplasms (MPNs) to help researchers better understand disease progression, treatment outcomes, and ways to improve care.

Participation is completely voluntary. You may choose not to join or withdraw at any time. Your decision will not affect your medical care or any benefits you receive.

This consent form explains:

- Why the research is being done
- What participation involves
- What risks and benefits are involved
- How your information will be used and protected

Please read this form carefully and ask the research team any questions you have before deciding whether to take part.

Why is this research being done?

The purpose of this registry is to collect medical record data, patient-reported information, medical claims, and optional biospecimens from people diagnosed with MPNs. By creating a large, real-world dataset, the registry will help researchers better understand how MPNs progress over time, how patients respond to different treatments, and how care can be improved.

Specifically, this registry aims to:

- Identify risk factors for disease progression, symptoms, and treatment outcomes.
- Improve treatment strategies and patient care.
- Support drug development by providing data for research on new or improved therapies.
- Build a long-term research resource, allowing approved researchers from around the world to study valuable data collected from U.S.-based patients.
- Promote collaboration among patients, healthcare providers, and researchers to advance MPN research.

Who can take part in this research?

You must be 18 years or older to participate in this research. Currently, enrollment is limited to adults living in the United States.

How long will I be in this research?

Your participation in this research will continue indefinitely, as the registry is designed to follow long-term disease progression and treatment outcomes.

You may choose to leave the study at any time. You may stop responding to surveys at any time without letting us know, but if you want us to stop collecting information about you, you must notify the research team in writing (by email or letter) using the contact information provided. After you withdraw your permission to collect your information in writing, no new data will be collected about you, but any data already provided — including de-identified data — will remain

part of the study and cannot be removed. Withdrawing from the study will not affect your medical care or insurance coverage.

The research team may also remove you from the study if:

- You are no longer able to complete required surveys or activities.
- You withdraw permission for access to your medical records.
- You begin a treatment that makes you ineligible to continue.
- The sponsor, Institutional Review Board (IRB), or regulatory authorities decide to stop or change the study.
- You move outside the United States, as only U.S.-based patients can participate.

What happens to me if I agree to take part in this research?

If you agree to take part, the research team will collect health information from your medical records and ask you to complete online surveys about your symptoms, quality of life, mood, and fatigue.

You will complete these surveys about every six months. In addition, you will be asked to complete a short symptom check-in every three months. These surveys usually take about 5 to 30 minutes, depending on the length.

In the future, you may also be invited to provide an optional blood or tissue sample for additional research. If that happens, you will receive detailed information at that time and will be asked to give separate consent before providing any samples. You are not agreeing to provide samples by signing this consent form.

Survey completion window and reminders

You will have up to seven days to complete each survey after it is sent to you. If you do not complete the survey during this time, you may receive reminder messages to help you stay on track. Once you submit the survey or the seven-day window closes, the reminders will stop.

Could being in this research hurt me?

This study is low risk, but there are some potential risks and discomforts you should know about:

- **Loss of privacy:** Even though the study uses strong security protections, there is a small risk that your personal information could be seen by unauthorized individuals.
- **Emotional discomfort:** Some survey questions may feel sensitive or upsetting. You can skip any questions you do not want to answer.
- **Genetic risks:** There is a small risk of misuse or unintentional sharing of genetic information. However, U.S. law (the Genetic Information Nondiscrimination Act, or GINA) provides some protections against genetic discrimination.

If you are injured or experience harm as part of this research please contact the research team using the information provided.

Mental health survey risks

This study includes questions about your mood and mental health, including feelings of depression. Some of these questions may feel sensitive or upsetting, and you can skip any you do not want to answer.

If your survey responses suggest possible mental health concerns, you will receive an automated pop-up message with information about national mental health and crisis support resources. Please note that the research team will **not** provide medical care, counseling, or follow-up, and your healthcare provider will **not** be contacted by the study team.

If you have concerns about your mental health or safety, we strongly encourage you to contact your healthcare provider or one of the national support resources provided.

Will being in this research benefit me?

You will not receive direct personal benefit from participating in this research. However, the information collected may help researchers better understand MPNs, improve future treatments, and advance care for others with these conditions.

You may also receive general updates on the progress of the registry or be invited to take part in additional research studies, but participation in those is optional and would require separate consent.

What other options do I have besides this registry, and can I still join other studies?

Participation in this research is completely voluntary. If you choose not to join, or if you decide to withdraw later, you can continue to receive your usual medical care and participate in other research studies or registries if you wish.

Additional Information About the Study: Safety Monitoring

This study is observational, meaning it does not involve experimental treatments or clinical interventions. The research team will monitor the information you provide and your medical records for significant health-related findings. With your permission, important findings may be shared with your healthcare provider.

Will I be informed of study findings?

You will not receive individual medical advice or personal health results from this research other than the significant health findings reported to your physician if you agree. However, you may receive general updates about the progress of the registry and overall research findings from the study population.

In the future, you may also be offered access to an optional online dashboard. This dashboard may allow you to view your own reported information alongside general, de-identified study summaries. Use of this tool will be entirely optional and is not intended to replace medical care or advice from your healthcare provider.

What are my responsibilities if I take part in this research?

If you choose to participate in this research, you are responsible for:

- Providing accurate and complete information about your health and medical history.
- Completing surveys about your symptoms, treatments, and quality of life at the requested times.
- Allowing access to your medical records so the research team can collect necessary data.

You should also notify the research team if you experience major changes in your health or treatments during the study.

Will it cost me money to take part in this research?

You will not be charged for participating in this research. There is no cost to you for completing surveys, allowing access to your medical records, or taking part in other study activities.

What happens to the information collected for this research?

Your participation in this research involves the collection and storage of health-related data to support scientific studies on myeloproliferative neoplasms (MPNs). Below is a detailed explanation of how your data will be handled, stored, and shared.

How Will Your Information Be Used?

The information collected from your medical records, and self-reported surveys will be used to:

- Understand disease progression and identify patterns in MPN development.
- Support scientific research aimed at improving MPN treatment options and patient care.
- Monitor real-world outcomes for individuals with MPNs to better understand their experiences and responses to various treatments.
- Advance drug discovery efforts by providing de-identified data to researchers studying new treatment approaches.

Who Will Have Access to Your Information?

Your personal and medical information will only be shared with authorized individuals and organizations involved in this research, as described in this consent form. This may include the MPN Research Foundation, select service providers (such as data management or technical support teams), regulatory agencies, and the study's institutional review board (IRB).

Only de-identified data — meaning data with your name and other identifying details removed — will be shared with approved researchers. These may include researchers from universities, nonprofit organizations, and companies, to support scientific and medical research.

Your information will not be used for sales, marketing, or advertising purposes, and you will **not** receive commercial outreach based on your participation.

How Will Your Privacy Be Protected?

Your privacy is very important, and several safeguards are in place to protect your information:

- De-identification: Before any research analysis or sharing, your name and other direct identifiers will be removed so the data cannot reasonably identify you.

- Limited Access: Only authorized personnel — such as designated staff at the MPN Research Foundation, approved service providers, regulatory agencies, or the IRB — will have access to identifiable information, and only as needed to manage or oversee the study.
- Confidentiality Protections: All data will be stored in secure systems, and anyone handling study information must follow strict confidentiality agreements and security procedures.

These measures help ensure that your personal information is protected and used only as described in this consent form.

Website Use Before Joining the Study:
Before you decide whether to join the MPN PROGRESSion Registry, you may visit and explore the registry's online portal. Please note that general website use — including browsing pages or viewing content before providing consent — involves routine data collection such as cookies, site traffic logs, IP addresses, browser type, and device information.

This general website data is collected to maintain, secure, and improve the website and is not used for research purposes. No health, survey, or medical data will be collected or used for research unless and until you provide informed consent by signing this form.

General website data may be shared with authorized service providers (such as IT vendors or technical partners) for technical support, website analytics, and maintenance. This data is stored securely and retained only as long as necessary to operate and improve the website.

You may adjust your browser settings to limit or block cookies if you choose. If you have any questions about how general website data is handled, you may contact the registry team at research@mpnrf.org.

Medical Record Access and Chart Abstraction
As part of this study, you are authorizing your healthcare provider(s) to share your medical records with the research team and other authorized parties described in this consent form. This may include relevant information such as your diagnoses, treatments, lab results, imaging reports, and pathology findings. This process — sometimes called chart abstraction — helps ensure that the information collected for the registry is accurate and complete.

All collected information will be protected as described in this consent form and used only for the approved research purposes.

You have the right to revoke (cancel) your authorization at any time by contacting the study team in writing (or by E-mail) at the address in this form. If you do so, no new records will be collected or shared, but information already collected will remain part of the study.

Please note:

- Your healthcare provider will not condition your medical treatment, insurance coverage, or benefits on whether you agree to this authorization.

- Once your medical records are disclosed to the study, they may no longer be protected under federal privacy laws, though the research team will continue to protect your confidentiality as described in this consent form.

Tokenization and Data Linkage
To better understand disease progression and improve the quality of research, your study information (such as medical records, survey responses, and optional biospecimen data) may be linked with other health-related data sources. These may include health insurance claims databases, electronic health records from other institutions, or national disease registries.

We will use a special privacy technique called tokenization to protect your identity. This means your name, date of birth, and other personal details are replaced with a secure random code (token), so your data can be safely matched across sources without revealing who you are. A trusted third-party expert will handle this process and will not use your personal information for any other purpose.

Only de-identified, coded data will be used for research purposes.

Will My Information Be Used for Future Research?
Yes. The data or biospecimens collected in this study will be de-identified and may be used for future research related to myeloproliferative neoplasms (MPNs). De-identified data may also be shared with approved researchers or organizations conducting scientific studies focused on MPN disease progression, treatment outcomes, or related topics.

You will not be asked to provide additional consent for these future uses because your identifying details will be removed, and your privacy will be protected. Although your identifying details will be removed from your information, if we share information about your whole genome sequence (all of your genes), we cannot guarantee complete privacy because your genome is unique to you.

Will My Information Be Published?
The results of this research may be published in medical journals, presented at scientific conferences, or shared with the research community. However, your name and other identifying information will not be included in any publications, presentations, or public reports.

Legal and Regulatory Disclosures
We take every reasonable measure to protect your privacy and keep your information confidential. However, complete confidentiality cannot be guaranteed. If required by law, your information may be shared with regulatory authorities for oversight, compliance, or safety purposes.

In addition, a description of this clinical trial will be available on http://www.ClinicalTrials.gov, as required by U.S. Law. This Web Site will not include information that can identify you. At most, the Web site will include a summary of the results. You can search this Web site at any time.

If you have questions or concerns about how your data will be used, stored, or shared, please contact the research team before deciding whether to join the study.

Who can answer my questions about this research?

If you have questions, concerns, or complaints, or if you believe you have been harmed as part of this research, please contact the research team using the phone number or email listed in this consent form.

This study is overseen by WCG Institutional Review Board (IRB), an independent group that reviews research for participant safety and rights. You may contact the WCG IRB at 855-818-2289 or clientcare@wcgclinical.com if:

- You have questions, concerns, or complaints that the research team has not addressed.
- You are not getting answers from the research team.
- You cannot reach the research team.
- You want to speak with someone independent about the research.
- You have questions about your rights as a research participant.

What if I am injured because of taking part in this research?

This study does not involve medical treatments, drug administration, or experimental procedures, so the risk of injury or harm is very low.

If you believe you have experienced a health issue related to this research you should:

- Contact the research team using the information provided in this consent form.
- Seek emergency medical care if needed. Call 911 or go to the nearest emergency room if you have a medical emergency and inform the medical staff that you are a research participant.

If you experience an unexpected injury or illness related to this study, your health insurance may be billed for any necessary medical treatment. You are responsible for checking with your insurance provider about coverage.

Will I be paid for taking part in this research?

You will not receive direct payment for each study activity you complete. However, to thank you for your time and encourage ongoing participation, the registry will hold periodic drawings for gift cards.

Winners are randomly selected, and gift cards are mailed to the address you provide. You do not need to take any additional steps to enter the drawings.

Participation in the registry is completely voluntary. If you have questions about the drawings or wish to opt out, please contact the registry team.

Future Contact for Research Opportunities

We may contact you in the future to let you know about other research studies related to MPNs, such as clinical trials, surveys, or observational studies. Taking part in any future research is

completely up to you and would require a separate consent form. You will be able to let us know if you agree to be contacted when you enroll in the research study. You will be able to change this preference at any time using the online platform for the research study.

Medical Records Authorization and Release

This section explains how we will access your medical records and how your privacy will be protected.

What Information Will Be Shared

By signing this consent form, I give permission for my doctors, clinics, hospitals, labs, pharmacies, and other healthcare providers to share my health information with the MPN Research Foundation and the research team.

This includes:

- My medical history, diagnoses, and doctor's notes
- Lab and pathology reports
- Imaging test results (like X-rays or scans)
- Treatment and medication records
- Hospital and surgery reports
- Insurance and billing information related to my MPN care

Why We Need This Information

We will use this information to:

- Study how MPNs progress and how patients respond to treatments
- Support scientific research to improve care and develop new treatments
- Help prepare scientific papers, reports, or presentations
- Safely combine (link) your data with other health sources using secure methods like tokenization (which replaces your name with a random code to protect your identity)

How Long This Authorization Lasts

This permission will last until the end of the registry or until I cancel it.

I understand:

- I can cancel this permission at any time by contacting the research team or my healthcare provider in writing.
- Canceling it will stop new information from being shared, but information already collected will stay in the study.
- My doctors will still treat me, and my insurance will still cover me even if I choose not to sign this form.
- I cannot take part in this study if I do not sign to agree to share my health information.

How We Protect Your Privacy

I understand:

- Once my information is shared with the research team, it may no longer be protected under federal privacy laws like HIPAA, but the team will still follow strict rules to keep it private, as explained in this consent form.
- My name and personal details will be removed (de-identified) when sharing results or doing research.
- All data will be stored securely, and only authorized people will be allowed to access it.

Your Rights

- I can ask to see or get a copy of my medical records from my healthcare provider.
- I can ask for a copy of this signed consent form.
- I know that joining this study is my choice, and I can say no without it affecting my medical care.

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Statement of Consent:

By signing below, I confirm that:

- I have read and understand this consent form, including the section about the use and release of my medical records.
- I have had the opportunity to ask questions, and all my questions have been answered.
- I voluntarily agree to participate in this research study and authorize the release of my medical records as described in this consent form.
- I understand that I will receive a copy of this signed consent form for my records.

For Participants Providing Consent

Signature of Participant (electronic): _____

Printed Name of Participant: _____

Date: _____

For Participants Unable to Consent (Legally Authorized Representative required)

My signature below confirms my permission for the participant to take part in this registry. I have explained the study to the participant to the extent they are able to understand, and the participant has indicated their willingness to participate, if capable.

☐ **By checking this box, I confirm that I have discussed the study with the participant (to the extent possible) and obtained their verbal or nonverbal agreement ("assent") to participate.**

Signature of Legally Authorized Representative (electronic):
_____
Printed Name of LAR: _____
Relationship to Participant: _____
Date: _____

Note to Participant/LAR: In cases where the participant is unable to provide a physical or electronic signature, assent will be documented solely through the Legally Authorized Representative's confirmation above.