# GUIDE TO myMPN PRIVACY SETTINGS

## Privacy Settings

### Customize Susie's preferred privacy settings

You are viewing default settings from myMPN. Use the dropdown menus to modify individual privacy settings. When satisfied, click "Accept and Continue."

![Select a guide](https://www.example.com/select-guide.png)

### Who can access your data and for what purpose...

- **Find/Analyze** except for name and contact details (click for details)
- **Export/Link** except for name and contact details (click for details)
- **Get Contact** find, view, use and export contact details (click for details)

<table>
<thead>
<tr>
<th>myMPN</th>
<th>myMPN Research Foundation</th>
<th>Researchers recommended by MPNRF</th>
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<th>Other Researchers</th>
<th>Researchers addressing your condition</th>
<th>All Researchers</th>
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### Choose who can see your data and for what purposes

![Select a guide](https://www.example.com/select-guide.png)

![Accept and Continue](https://www.example.com/accept-continue.png)
**DEFINITIONS**

Find/Analyze:

How to use this privacy preference setting...

The **discover and view my anonymous information** setting allows you to control to whom, and for what purpose, the selected participant’s anonymous health information may be included in results to search inquiries. Anonymous health information is de-identified.

- **Allow**: You are granting permission to the indicated researcher, support group or other entity to view the selected participant's anonymous health information in search results.
- **Deny**: You are expressly prohibiting the indicated researcher, support group or other entity from viewing the selected participant's anonymous health information in search results.

This service uses Private Access to let you control who can see your information, and for what purpose. Our default privacy policy is to not share any information without express consent.

Export/Link:

The "Export My Anonymous Information" settings allow you to control to whom your anonymous health information may be exported from the PEER database, into which this service saved your information. This affects your anonymous information only. Export of the data occurs when an authorized entity requests this, and will be reflected in your audit log records. Once data has been exported, this cannot be reversed. Proposed recipients may disclose an intended purpose or use for requesting this information, which is governed by their privacy policies and terms of use agreements. Careful review of these terms prior to authorizing export is thus recommended.

- **Allow**: You are authorizing the selected participant's anonymous health information to be exported to the indicated researcher, support group, or other entity.
- **Ask Me**: You are not deciding whether or not to permit export at this time. Instead, you are indicating a willingness to consider this based on a specific request from the indicated researcher, support group or other entity. If there is interest, Private Access will send you a notification, enabling you to decide at that time whether you wish to allow or deny the request for export. Your name and contact information will not be revealed to the interested party no matter what you decide.
- **Deny**: You are expressly prohibiting export of your anonymous health information to the indicated researcher, support group, or other entity.

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“Who can access your data and for what purpose?”

myMPN

MPN Research Foundation - Founded by patients for patients, the MPN Research Foundation is a catalyst for research funding in pursuit of new treatments – and eventually a cure – for myeloproliferative neoplasms (MPNs). Data from myMPN will be used to learn what works for some patients and does not for others. We'll share what we learn about symptoms and treatment, lifestyle and other factors through periodic reports and popups. In the longer term, we will be able to identify unmet needs in MPN research and to drive better standards of care for patients.

Researchers Recommended by MPNRF - The MPN Research Foundation has a dedicated group of researchers focused on improving treatments for patients with MPNs. Please visit our website to learn more about our funded research, advisors and recent successes.

OTHER RESEARCHERS

Researchers Addressing Your Condition - PEER (the Platform for Engaging Everyone Responsibly, the registry platform that’s used by this project) has a system that matches participants with researchers studying their condition. The “Researchers addressing your condition” setting lets you decide whether or not to include your information in this system, and share data with researchers studying your condition. All researchers invited to join the platform come with research projects or protocols reviewed by an oversight committee called an institutional review board (IRB). The IRB oversight protects participants by making sure studies follow proper ethics guidelines.
**All Researchers** - The “All researchers” setting lets you decide how your information should be shared with any researcher in PEER (the Platform for Engaging Everyone Responsibly, which is the registry platform that’s used by this project). All researchers invited to join the platform come with research projects or protocols reviewed by an oversight committee called an institutional review board (IRB). The IRB oversight protects participants by making sure studies follow proper ethics guidelines.

If you prefer, you can limit this setting and choose only certain researchers, groups, or individuals.

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**DATA ANALYSIS PLATFORMS**

**PCORNET** - The “PCORnet” setting lets you decide how your anonymous data, survey responses, and/or contact information should be shared with PCORnet, the Patient-Centered Outcomes Research Network (also called the National Clinical Research Network.) PCORnet conducts patient-centered research to help patients, clinicians, and caregivers make informed decisions on medical care. While there are no active studies using data shared here at this time, below are some examples of studies that were either conducted by PCORnet in the past, or that are currently in the planning stages. These may give you a feel for the types of research that PCORnet is doing, and will be updated to reflect current research activities as additional studies are launched and developed.

**ADAPTABLE Trial of Aspiring Dosing:** ADAPTABLE stands for “Aspirin Dosing: A Patient-centric Trial Assessing Benefits and Long-Term Effectiveness”. The study has been designed to compare the effectiveness of two daily doses of aspirin widely used to prevent heart attacks and strokes in individuals living with heart disease. Findings from this study will improve care and outcomes for patients with heart disease, and could save thousands of lives a year around the world.

**Obesity Demonstration Projects:** More than one-third of adults and one in six children in the U.S. are considered to be obese. In order to inform relevant questions on treatment and prevention, the Patient-Centered Outcomes Research Institute (PCORI) approved $9 million to fund two PCORnet research studies: one to examine the three main methods of bariatric, or weight loss, surgery; and the other to look at the effects of different types of antibiotics given to infants and young children on their weight in later childhood. These studies will provide patients and those who care for them with information on the comparative benefits and potential risks of each type of bariatric surgery procedure, and will also help parents and pediatricians to make better informed decisions about using antibiotics in early childhood.

**Mindfulness Demonstration Project (currently in the planning stages):** This study focuses on mindfulness as a means of coping with stress, anxiety, pain, and depression. While there have been many studies on the effect of different levels of mindfulness in decreasing the impact of these symptoms, there have been no direct comparisons of different amounts of mindfulness training. With this comparison, PCORnet stakeholders seek to shed light on the most effective level of mindfulness training for those seeking to alleviate stress, anxiety, pain or depression.

For more information about PCORnet, please visit their website at www.pcornet.org. For more information about PCORnet research, please visit the PCORnet research page at www.pcornet.org/research.

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**NEWLY RELEASED DATA ANALYSIS PLATFORMS**

Genetic Alliance occasionally works with academic, commercial, and publicly-funded groups on projects to transform ‘big data’ (lots of data) into meaningful answers. Choosing “Allow” means PEER (the registry platform that’s used by this project, the Platform for Engaging Everyone Responsibly) will automatically include the information you’ve shared in these projects. Choosing “Ask Me” means PEER will notify you about these opportunities when they arise and let you decide how you’d like to share your information then. Choosing “Deny” means PEER will not send you these notifications. Your data will not be included in these projects.

You can change this setting any time, and it will take effect immediately.
About Genetic Alliance: Genetic Alliance, a health advocacy nonprofit, manages and operates the Platform for Engaging Everyone Responsibly (PEER). Their mission, much broader than their historical genetics mission, specifically includes creating ways for individuals, families, and communities to transform health. PEER is one of the ways Genetic Alliance does this. Their work is overseen by a Council and an Ethics Team, and PEER is subject to annual IRB approval -- as is every project using the platform. For more information, please visit http://www.geneticalliance.org/.