

Living with MPNs Survey

Participant Information Sheet

INTRODUCTION:

Please read this information sheet carefully before you make your decision about participating in the study. If you have any questions or do not understand something in this letter, please call the HRA study coordinator toll free at (855) 563-6341.

Your participation in this study is entirely voluntary. If you choose not to participate, or if you stop answering the study questionnaire at any point, this decision will not impact your medical or health care in any way.

PURPOSE:

The purpose of this study is to learn more about the impact of Myeloproliferative Neoplasms (MPNs) on work/productivity and the related financial impact to patients and their families.

- This survey includes questions on disease diagnosis, symptoms, impact on everyday life and work/productivity, treatment, and demographic information.
- In order to estimate the financial impact of the disease, a few questions will be asked about your income and the responses will be kept confidential.

PROCEDURES:

To participate in this study, you will need to have access to a computer and the Internet. **This web-based survey will take approximately 30 minutes to complete.** Please take the entire survey at a single time. When taking the survey, try to identify a location that will allow you to concentrate on your responses. The survey is best accessed via a desktop, laptop, or tablet. While discouraged, if you are taking the survey on a handheld mobile device, you may need to hold the device horizontally for a better view.

RISKS AND DISCOMFORTS:

This study should not involve any physical risk to you. There is no study medication involved, and you will not receive any medical benefits from participating in this study. Nothing will change about your regular medical care whether or not you participate in this study.

It is possible that some of the questions you will be asked could make you feel uncomfortable. You may be asked to answer questions about private matters that relate to your present state of health, which could cause you to feel a loss of privacy.

Your participation is voluntary. You may decline to answer any of the questions presented in the questionnaire, and you may choose to stop answering the questionnaire at any time by closing your browser.

Your privacy is protected. HRA will not share your personally identifiable information with anyone without your permission. Your responses to this survey are also confidential. Publications resulting from this research will not individually identify you. While all of these study procedures are designed to protect the information you provide and keep your participation confidential, there could be a risk of unintentional loss of confidentiality of your information because it is being provided over the Internet.

CONTACTS:

You can ask questions about the study at any time. You can call the study coordinator at any time if you have any questions or concerns about the study.

Quorum Review reviewed this study. Quorum Review is a group of people who review research studies to protect the rights and welfare of research participants. Review by Quorum Review does not mean that the study is without risks.

If you have questions about your rights as a research participant, if you are not able to resolve your concerns with the study, if you have a complaint, or if you have general questions about what it means to be in a research study, you can call Quorum Review or visit the Quorum Review website at www.quorumreview.com.

Quorum Review is located in Seattle, Washington.

Office hours are 8:00 AM to 5:00 PM Pacific Time, Monday through Friday.

Ask to speak with a Research Participant Liaison at 888-776-9115 (toll free).

ALTERNATIVES:

This study does not involve any treatment for your health condition. Due to the nature of this study, which is limited to answering a questionnaire once via the Internet, your alternative is to not participate.

BENEFITS:

You will not receive any medical benefits from participating in this study. However, your responses may help researchers better understand, and develop ways to improve, the experience of future patients with MPNs.

FINANCIAL ASPECTS:

Compensation

If you are eligible and complete the entire survey you may choose to receive a \$25 gift card. The first few questions will determine if you are eligible to complete the full survey. If you do not meet eligibility, you will be exited from the survey.

Once you have completed the survey, you will be given the opportunity to provide your mailing address to receive the gift card. Your contact information will **ONLY** be used for this study and for the purposes of sending your gift card. If you leave the survey early, or prefer not to provide your mailing address, you will be ineligible for compensation. Only one questionnaire response (and one gift card) per person will be allowed.

SPONSOR:

The study is sponsored by Incyte Corporation and conducted by a third party survey company, Health Research Associates, Inc. (HRA), a research organization with experience in health care research.

AGREEMENT TO PARTICIPATE:

After you have read and understood this information about the study and have called the research coordinator to ask any questions you might have had, please decide if you would like to participate. To take part in this study, log on to the questionnaire site [ADD URL], confirm your willingness to participate, and answer the screening questions.

Once you do that, you will see the questionnaire on the screen. When you get to the end of the questionnaire, you have the opportunity to provide a mailing address to receive study compensation.

Thank you for your time and consideration!