



MyVHL: Frequently Asked Questions

What is a patient registry?

A patient registry is a collection of information about individuals, usually focused around a specific diagnosis or condition, that is provided by the patients themselves. Registries can help lay the foundation for future research and promote better understanding of a disease.

The difference between a patient registry and one that is clinician/researcher driven is that in a patient registry, all data is voluntarily provided and submitted by the patient. This allows us the opportunity to encourage collaboration between researchers and institutions.

Why are patient registries needed?

Patient registries can provide health care professionals and researchers with first-hand information about people with certain conditions, both individually and as a group, and over time, to increase our understanding of that condition.

What types of data are collected in MyVHL?

All types of data can be collected, including data related to the following:

- Natural history data that captures longitudinal information about the disease
- Diagnosis and treatment
- Management of care
- Quality of life
- Clinical testing samples
- Clinician reporting
- Healthcare providers
- Lifestyle

It sounds like these registries collect personal health information. Is there a risk that such information could be disclosed?

Government agencies have strict privacy requirements set by law such as the Federal Information Security Management Act (FISMA), and the Health Insurance Portability and Accountability Act (HIPAA). The likelihood of identifiable personal information being shared is very small. **VHLA promises to never share your data with anybody without your consent.**

What benefits will someone receive from participating in MyVHL?

Participation in MyVHL is likely to increase what we know about VHL, help health care professionals improve treatment, and allow researchers to design better studies, including development and testing of new treatments. Individuals (and their families) who choose to participate should understand that participation will not guarantee a treatment or cure for VHL.

Additionally, in order to show our appreciation for your help in participating in MyVHL toward finding a cure, VHLA will provide a \$50 Amazon gift card to all US-based participants with VHL who complete all of their applicable surveys, as well as submit scans and/or a signed Records Release Form.

How do I receive my \$50 Amazon gift card?

To receive your Amazon gift card, all you have to do is click Participate, register/login to MyVHL, complete and submit all of the applicable surveys and upload scans and/or a signed Records Release Form. Once you have completed all of the steps, you will be contacted by a VHLA staff member to thank you for participating and to send you your gift. Please note that you must have VHL and be based in the United States in order to receive the gift card.

How is the data collected?

The data are collected online by patients that register and grant consent to enter their own personal data or the data on behalf of another participant, if he or she is legally authorized to do so.

Can data be collected worldwide?

Yes, MyVHL can be accessed from anywhere in the world, and international participation by the patient community and research collaborations are supported and encouraged.

Who has access to the information in a registry?

The data in MyVHL is accessible only to qualified and trained VHLA staff. Any outside requests for de-identified data must first go through a review process and be approved by the MyVHL Research Committee. No identifiable data will ever be shared with anyone.

Who owns the data from a registry? Who makes decisions about how these data will be used?

The data collected in a disease registry is stripped of personal information. It belongs to the VHL Alliance. Personal identifying information is kept private. The MyVHL Research Committee makes decisions about how the de-identified data can be used or shared.

Will anyone else know my name?

Your personal information such as your name, address, or other information that identifies you or your family will be labeled with a code number, encrypted, stored in a secure place and protected with a password. Only qualified and trained VHLA staff will have access to the code and be able to identify you, if needed. Your identifiable information will not be shared with anyone outside of VHLA. Approved scientists, researchers, and clinicians, will be given only the de-identified information and may search the de-identified data for patients for their studies. We call this information “de-identified” because all personal identifiers have been removed.

All other information (such as hard copies of records) will be stored in locked files and destroyed in accordance to the standards established by the HIPAA Privacy Act. To review the entire HIPAA Privacy Act, and for information about how it applies to patients, see the Office for Civil Rights website.

Can insurance companies access my medical information and/or my participation in this study?

No, insurance companies are not and will not be granted access to research records. Participants do not have to tell their health insurance companies that they have participated in a research project. Research is different from clinical care. Research records are not a part of a person’s medical record.

The Genetic Information Nondiscrimination Act (GINA) of 2008 is intended to prohibit the improper use of genetic information. GINA provides comprehensive protection to individuals so that they may avail themselves of genetic diagnostic tests for the advancement of their individualized medical care without the threat of discrimination from

insurance companies based on their personal genetic makeup. To review the entire Genetic Information Nondiscrimination Act of 2008 and other helpful information regarding GINA, go to <http://www.genome.gov/11510239>.

Can a participant withdraw from MyVHL?

Yes. MyVHL is free and voluntary; there is no penalty for choosing to withdraw at any point.

How is MyVHL different from a clinical trial?

MyVHL collects information voluntarily from people with VHL, BHD, SDH and HLRCC.

A clinical trial is the study of new ways to prevent, detect or treat diseases or conditions. Participating in MyVHL does not mean a person has signed up for a clinical trial.