

FREQUENTLY ASKED QUESTIONS for HARVARD PILGRIM HEALTH CARE MEMBERS
REGARDING RESEARCH AT
HARVARD PILGRIM HEALTH CARE INSTITUTE

What are the reasons a Harvard Pilgrim Health Care (HPHC) member might participate in a research study conducted at HPHC Institute?

HPHC members may choose to participate in research conducted at HPHC Institute because they:

- want to help others and contribute to better scientific understanding;
- want to help researchers develop new drugs, treatments, or services; and/or
- have not been helped by available treatments for their health problems.

What type of research is conducted at HPHC Institute?

Studies at HPHC Institute include projects with face-to-face interaction and those where existing data on groups of people is used to answer important policy, safety or disease management questions.

These studies often involve:

- de-identified data about patient care or treatment patterns;
- surveys or interviews to gather data from members or providers; and
- testing system-based interventions to improve health care.

To learn more about specific research projects at HPHC Institute, please see:

<https://www.populationmedicine.org/research>

Will my data be used for a research study?

Your information might be used for research purposes when an Institutional Review Board (IRB) or Privacy Board has reviewed and approved a study that includes methods to protect your privacy, or for the planning of future research.

How will you protect my privacy?

We follow state and federal privacy laws that require us to maintain the privacy and security of all forms of information used in research, including electronic, written and verbal information. HPHC computers are protected through passwords and ongoing monitoring of security threats. All staff must complete annual privacy and security training, and access to information is limited to employees who require it to do their job. The full details of HPHC, Inc. Notice of Privacy Practices can be found here:

<https://www.harvardpilgrim.org/public/docs/notice-of-privacy-practices>

What if I prefer that my data NOT be used for research?

HPHC members may request that their data not be used for research purposes by contacting the HPHC Customer Service Department at (888) 333-4742 or checking www.HarvardPilgrim.org/Members for more information. HPHC considers all such requests consistent with federal and state legal requirements.

What if I decide that I don't want to continue to participate in a research study?

Participation in any study is completely voluntary, so you do not have to participate in any study if you don't want to and you may withdraw from a study at any time. If you choose not to participate it will have no effect on your health insurance coverage. If you decide to withdraw, you must tell your researcher in writing.

What will happen to any information collected on me if I withdraw from a research study? The informed consent form document that you sign when you volunteer to participate in the research study will tell you what will happen to your information if you withdraw. You may withdraw from a research study at any time.

I gave consent for my child to be part of a research study, does the informed consent process change if my child turns 18 while participating in a study?

When your child reaches age 18, he/she will be an adult under the law and will be able to provide informed consent to participate in a study for him/herself.

What is the difference between a research subject and a research participant?

There is no difference between these terms, and we use them interchangeably.

If I have questions about a research study, whom should I contact?

- If you have questions about a research study, you should contact your research study team directly.
- If you have a question about your rights as a research participant, a complaint about the study or a concern about research activities, please contact the IRB at 1-800-807-6812.
- For additional information about participating in human subjects research, see:
 - the Research Subject Advocacy page at Harvard Catalyst:
<https://catalyst.harvard.edu/services/rsa/> or the Office for Human Research Protections page at: www.hhs.gov/About-Research-Participation.