

# ALL FREQUENTLY ASKED QUESTIONS

SHARING YOUR HEALTH EXPERIENCES AND CONCERNS MAKES A DIFFERENCE

## GENERAL INFO ABOUT THE STUDY

### WHAT IS THIS STUDY ABOUT?

The goal of the Person to Person Health Interview Study is to better understand how a person's social environment, culture, behaviors, genetic traits, and physical environments affect a person's health and risk for certain diseases. We also want to learn your opinions about mental health and addictions and how you, your family, and your community have been affected.

### WHO IS PAYING FOR THIS STUDY?

IU is funding the study as part of Indiana University's Grand Challenges Program. For more information about this program, please visit [grandchallenges.iu.edu](http://grandchallenges.iu.edu).

### IS THIS STUDY BEING DONE FOR IU HEALTH?

No. Indiana University and IU Health are separate organizations. While IU Health is a frequent partner of ours, it is not funding the study and will not have access to any confidential information about participants. We maintain this confidentiality even if a study participant uses IU Health as a primary care provider.

After results are analyzed and published, IU Health will make use of aggregate findings to reach out to Hoosiers statewide and implement new programs proposed.

### WHAT IS THE PRECISION HEALTH INITIATIVE?

The Precision Health Initiative (PHI) is an exciting new IU research program with a goal to help researchers **learn more about what affects people's health**. The goal is to have these research discoveries lead to more personalized care and treatments. This study is just one part of the PHI.

### WHAT IS PRECISION MEDICINE?

Precision medicine is health care that is based on you as an individual. It takes into account factors like where you live, what you do, your family health history, and even your genetic profile. Precision medicine's goal is to be able to tell people the best ways to stay healthy. If someone does get sick, precision medicine may help health care teams find personally tailored treatments that will work best.

### WHY IS HEALTH RESEARCH IMPORTANT?

We all want to live long and healthy lives. People who do health research are helping doctors and other health care providers learn better ways to keep us healthy and find new medicines and treatments for when we do get sick.



## **HOW LONG DOES THIS STUDY LAST?**

We expect to interview 2,750 Indiana residents through April 2021. Each person is randomly selected and will only participate for about 2.5 hours. If it is not possible for you to be available for a 2.5-hour period of time, we are happy to schedule a couple of visits to get the study completed.

## **WILL I GET THE RESULTS OF THE STUDY?**

Yes, you can get the results of the study, but it might take a while until we have enough cases to provide useful results and protect your individual data. After all participants in the study have completed the study requirements, the data will be analyzed and the results published in scientific journals. After the results are published, we can share the results with you if you request them. In the meantime, we will share progress occasionally. You can see how many households have participated to date—and a few statistics about the prevalence of health issues.

## **WHY YOU, WHY THE STUDY IS IMPORTANT, AND WHY RANDOM SELECTION**

### **HOW WAS I CHOSEN?**

The study is about Hoosiers' health, but no one is chosen because of a chronic medical condition or hospitalization. Your household's address was one of only a few thousand throughout the state of Indiana that were randomly selected to participate in this research—and a random adult will be chosen from your household to complete the interview. Your household will be representing many households in your local community.

### **WHY SHOULD I PARTICIPATE IN THIS STUDY?**

People participate in research for many different reasons. Three common reasons people take part in a study are to help others, to have their opinions heard, and to help advance science. Your participation will help us learn more about the health and well-being of Indiana residents. With your help, we can better understand the health challenges that are facing your local community so that we can work to address those and make our communities stronger, healthier, and safer. Your saliva samples, life conditions and experiences, and medical records will also help researchers unravel the causes of disease and new treatments. Participants have found the interview interesting and enjoyable.

### **I'M BUSY. WHY SHOULD I DO THIS?**

We understand that you are busy and thank you for considering being part of our study. We can conduct the interview with you whenever it is convenient—even several weeks from now. We can do part of it at another time, if that works better for you. Since you have been randomly selected, it is very important that you participate in order to ensure that your community is represented and that our findings accurately represent all Hoosiers.

### **I DON'T HAVE ANY HEALTH ISSUES OR CONCERNS. WHY SHOULD I DO THIS?**

Personal and public health impacts all of us, directly or indirectly. Part of our research measures the prevalence of common health issues in Indiana. Part of our research looks at how Hoosiers like you feel about health care delivery in your local community. These require that we give those in poor—and good—health an opportunity to share, be counted, and influence the future of healthcare.

## **JUST EMAIL ME. WHY ARE YOU SENDING GENERIC MAIL TO MY HOME OR STOPPING BY?**

For research studies like this one where participants are randomly selected, we only have your postal address. We do not know your name, phone number, email, or the number of adults living in your household unless you provide them to us. We send an advance letter by mail to alert you beforehand that a field interviewer will be stopping by in the coming weeks.

## **YOU EXPLAINED RANDOM SELECTION OF MY HOUSEHOLD. WHY DO YOU NEED TO RANDOMLY SELECT THE ADULT WHO PARTICIPATES IN MY HOUSEHOLD?**

When you talk to an interviewer or call in, we will check to see how many adults live with you. Our system will randomly choose the household member invited to participate in the study. Randomization ensures that different kinds of people and experiences will be represented—and that the results are an accurate reflection of your county. If we do not randomly choose adults, we may end up with an overabundance of one gender or age range.

## **WHAT IS INVOLVED IN PARTICIPATION**

### **WHAT DOES BEING IN THE STUDY INVOLVE?**

**If you agree to participate in all parts of the study, there will be only one 2.5-hour visit** that will take place in your home or another mutually agreed upon location at a time convenient to you. This visit will include:

- Answering a questionnaire (approximately 90 minutes) administered by a trained interviewer
- Having the option to respond to an extra 30-minute questionnaire that asks your opinions about drug abuse and addictions, and your social networks
- Allowing audio recordings of your opinions and experiences in your own words
- Allowing physical measurements to be taken, including blood pressure, oxygen level, pulse, height, weight, and waist/hip/neck circumference
- Providing a saliva sample by spitting into one plastic tube provided to you (approximately 30 minutes for the measurements and saliva sample combined)

### **WILL I BE PAID FOR MY TIME?**

**Yes!** You will receive up to \$125 for participating in all parts of the study. You will receive \$75 for completing the main questionnaire and measurements, \$25 for providing a saliva sample, and \$25 for answering the drug abuse and addictions questionnaire.

### **DOES THE INTERVIEW HAVE TO TAKE PLACE IN MY HOME?**

We prefer to conduct the study visit in your home to protect your privacy and confidentiality. Conducting the study in a public location puts you at risk for others hearing your responses to questions. However, if you prefer, we will identify a public location (like a local public library) where the interview can be conducted with minimal interruptions and as much privacy as possible.

## **WHAT SAFETY PRECAUTIONS ARE BEING TAKEN TO PROTECT ME FROM COVID-19?**

While no person-to-person activity is risk free, we have been working—and will continue to work—closely with public health experts to identify, minimize, and monitor risks for COVID-19 exposure. Here is what you can expect from us:

- Adherence to the latest safety guidelines from federal, state, and university agencies
- Suspension of research activities in any developing COVID-19 hotspots in Indiana
- Ongoing monitoring of the health status of every interviewer to ensure no one approaches your home who has knowingly been exposed to, or is showing symptoms of exposure to, COVID-19
- An advance call before your interview to see if anyone in your home has been or is ill (if this is the case, staff will reschedule your interview for a later date)
- Careful cleaning and sanitizing of all tablets and equipment immediately before and after your interview
- An interviewer who has limited direct contact with you and wears personal protective gear for the duration of your discussion (we can provide a disposable mask for you as well)

We are eager to keep our interviewers and you safe as we continue our important work to help improve Hoosiers' health and care. Please let us know if we can provide more details about safety precautions or can further accommodate you in any way.

## **WHY DO YOU WANT SALIVA SAMPLES?**

Researchers in the future will study things in samples like chemicals, biomarkers, and DNA. Chemicals include things like medications or drugs. Biomarkers are signals that something has happened in your body like a hormone change or infection. DNA is your unique genetic information.

## **WILL YOU NOTIFY ME IF COVID-19 SHOWS UP IN MY SALIVA SAMPLE?**

We have no current plans to test saliva samples for COVID-19.

## **CAN I MEASURE MYSELF SO THE INTERVIEWER DOESN'T NEED TO TOUCH ME?**

No, the interviewer must do all body measurements. It is not possible for anyone to accurately take their own measurements. Our interviewers will be wearing face masks, protective eyewear, and gloves while in direct contact with you. We carefully disinfect all equipment before and after each use.

## **DO I HAVE TO WEAR A MASK DURING MY INTERVIEW?**

We recommend it—especially if you are 60 years or older, have any underlying medical conditions, or the interview occurs in a space where we cannot sit about six feet apart from you. We can provide a disposable mask for you.

## **CAN I READ THE CONSENT FORM?**

You can read the Consent Form on the study website.

## **WHO CAN I CALL TO SCHEDULE AN INTERVIEW?**

If your household has been randomly selected to participate, you can schedule an interview by calling our Indiana University study line at **1-844-875-0057** (toll free). You may also have received a door hanger with the phone number of the professional field interviewer who will be interviewing you. If so, please call your interviewer to arrange an interview time. If no one answers, please leave your name, complete address, and a phone number, and we will return your call promptly.

## **CONFIDENTIALITY, DATA SECURITY, AND WITHDRAWAL**

### **ARE MY ANSWERS CONFIDENTIAL?**

**Yes!** We understand privacy may be a concern and are dedicated to keeping your answers confidential. All research projects must be approved by an Institutional Review Board. Their job is to protect participant safety, welfare, and confidentiality. IU's Institutional Review Board has approved this study.

### **HOW WILL YOU PROTECT MY INFORMATION?**

As researchers at Indiana University, we have the utmost concern for protecting our participants' data. While no one can guarantee complete confidentiality, we have taken many steps to ensure that we protect your personal information, including:

- Information we have about you will be stored on protected computers. We will limit and keep track of who sees the information.
- We will remove your name and other direct identifiers (like your date of birth) from your information and replace them with a code. There will be a master list linking the codes to names, but we will keep it separate and secure.
- In order to access your health information, researchers must promise not to try to find out who you are.
- We will tell you if someone accesses your data who does not have permission to do so.
- Your identity will not be included in reports published about the study or databases in which results may be stored.

You may also choose not to answer any questions or provide any information that you do not want to. The researchers for this study are also happy to talk with you about how your personal information will be protected.

### **WILL MY HEALTH INFORMATION BE SHARED WITH ANY INSURANCE COMPANIES (HEALTH, LIFE, DISABILITY, ETC.)?**

This is not a study for insurance companies. This is medical and social research. We will not share your health information with any insurance company or health care provider—including IU Health. But, if you are injured while taking part in the study and you have insurance, your insurance may be billed.

## **WILL MY INSURANCE KNOW IF I TAKE PART IN THE STUDY?**

We will not let your insurance know if you participate in the study unless you are injured. We do not expect you to be injured. Answering surveys and giving samples are very safe activities. They are unlikely to cause injury. But if you are injured because of your participation and you have insurance, your insurance may be billed to cover any medical care you receive.

## **WILL YOU SELL MY EMAIL ADDRESS OR PHONE NUMBER?**

No, we will never sell your address, phone number, or **any** personal information.

## **WILL YOU TEST MY SAMPLES FOR DRUGS?**

While the Person to Person Health Interview Study researchers do not plan to test your samples for drugs, it is possible that other researchers in the future may want to do so. At that time, we would contact you again to ask for your consent to test your samples for medications and drugs. This information would only be used for health research. It would not be used for any other purpose.

## **WHERE AND FOR HOW LONG WILL MY SAMPLES BE STORED?**

IU has a biobank where your sample will be stored. This is a permanent facility that already holds thousands of samples. There is no time limit for how long your samples will be stored.

## **HOW LONG WILL YOU KEEP MY INFORMATION?**

Unless you withdraw (quit) from the study, there is no limit on how long your health data will be stored and used for research. Your data may be useful in improving health for generations to come.

## **HOW DO I WITHDRAW FROM THE PERSON TO PERSON HEALTH INTERVIEW STUDY?**

You can decide to withdraw at any time by calling the research director, Dr. Hank Green, at **812-855-6005**. If researchers have already used your information in their studies, we cannot get it back. But we will remove your information and destroy your samples so that they cannot be used for new studies.

## **HEALTH RESOURCES AND OPPORTUNITIES**

### **I AM HAVING HEALTH PROBLEMS. HOW CAN I GET HELP?**

Our interviewers are not medically trained and can't offer you any medical advice. We urge you to talk with your health care providers for answers to your personal health questions.

### **I DON'T HAVE A DOCTOR. HOW CAN I FIND ONE?**

There are many helpful websites that may help you find a health care provider. A few sites that may be helpful are:

[www.medlineplus.gov/directories.html](http://www.medlineplus.gov/directories.html)

[www.hhs.gov/programs/providers-and-facilities](http://www.hhs.gov/programs/providers-and-facilities)

## WHAT IF I GET SICK SOON AFTER COMPLETING MY INTERVIEW?

If you become ill or are diagnosed with COVID-19 within 14 days of your home visit or contact with our staff, please call the toll-free study line or your interviewer to report your illness. We can route you to helpful resources.

## HOW CAN I GET TESTED FOR COVID-19?

If you think you need a COVID-19 test, call your primary health care provider or local health department. Tell them about your symptoms and how you think you may have been exposed to the virus. They can let you know where testing is available near you.

## HOW CAN I PARTICIPATE IN MORE RESEARCH STUDIES?

You are never required to participate in research—and can decline or withdraw at any time. When you complete the person-to-person interview, we will ask for your consent to be contacted to participate in other related IU research studies. If you consent, you may be invited to participate in studies about COVID-19, exposures to environmental contaminants like chemicals and dust, and more.

If you are interested in health-related opportunities led by researchers at a variety of Indiana's universities, you may also consider joining the registry of volunteers at:

**[allinforhealth.info](http://allinforhealth.info)**

# STUDY BENEFITS & CONTACTS

## PARTICIPANTS GET ...

- **Your voice heard** on your community's health needs, including the availability and delivery of care for you and those around you
- **Highlights of what was learned** at the study's end
- **A token of appreciation** (\$75-\$125 gift card on the spot)

## CONTACT US ANY TIME ...

**IU Person to Person Health Interview Study**  
**1-844-875-0057** (toll free) or **[P2Psurv@indiana.edu](mailto:P2Psurv@indiana.edu)**

**IU Center for Survey Research** (study administration)  
**[CSRsolv@indiana.edu](mailto:CSRsolv@indiana.edu)**

### Researchers

- Dr. Hank Green, Research Director  
**812-855-6005** or **[hdgreen@indiana.edu](mailto:hdgreen@indiana.edu)**
- Dr. Bernice Pescosolido, Principal Investigator  
**812-855-6256** or **[pescosol@indiana.edu](mailto:pescosol@indiana.edu)**

