

## **Electronic Medical Records in Genomic Research (eMERGE) study FAQ**

### **What is the eMERGE Research study about?**

The eMERGE Network includes the University of Washington and 9 other institutions working together in healthcare research. We want to learn if a new tool developed in this research improves healthcare for Adults who have high risk for developing certain common diseases. This tool is called the **Genetic Informed Risk Assessment** or GIRA for short. The GIRA will consider people's genetic (DNA) makeup as well as personal and family histories and environmental factors to determine their risk of developing common conditions such as diabetes, heart disease, and cancer. The research will look at how the GIRA report is used to guide healthcare for both the patient and the medical care provider.

### **What kind of genetic disease risk results will I get?**

Participants will get genetic risks reports from clinical genetic testing labs and the research GIRA report. The reports will indicate whether participants' risks are higher than or similar to that of the general population for conditions such as diabetes, heart disease, and cancer. If you are at increased risk, your doctor can help you understand what you can do to reduce your risk.

### **Why was I asked to participate in this research?**

Patients who receive their primary care at UWMC have been contacted to join this study. We hope to include people of different aged, races, ethnicities, and sex/gender minority categories in order to conduct comprehensive and inclusive research, that we think will ultimately providing improved healthcare for all people.

### **If I participate in the study, what will I be asked to do?**

All research activities can be on 'online" or by phone, You will be asked to sign a consent form and complete a set of surveys about you and your family's health. If we already have a DNA sample for you from previous research, once you provide consent, we will use the DNA for genetic testing in this study. If no DNA sample exists, we will send you a saliva collection ("Spit Kit") in the mail with a return envelope. We can collect DNA from saliva. Over time we may contact you to ask that you provide feedback on your experience in the study.

### **How long will I be in the study?**

Your active participation will last about 12-18 months. We may access your UWMC medical records for approximately 4 years after your enrollment to understand how the GIRA report is used in guiding healthcare decisions.

### **When will I get my genetic risk results?**

Our goal is to have genetic risk results for all participants within 6 months of enrollment. Once your report is available, you will receive communications either by mail or by phone. If you have questions about your results, you may contact us by phone to discuss them in detail. The results will then be put into your medical record. People who can already view your health record will be able to see your report. This may include health professionals such as doctors, nurses, pharmacists, and genetic counselors. You are encouraged to contact the study if you have questions.

### **Will this study cost me anything?**

No. There are no costs for you for enrolling in this study. The genetic testing and genetic counseling– if needed– is free.

### **Will I receive payment if I'm part of this study?**

You will receive a \$25.00 gift card after completing each of the 3 health surveys ( totaling \$75.00).

### **Are there any risks to participating in this study?**

We are very careful to keep your genetic and medical information secure. However, if a data breach did occur, there is a risk of a loss of confidentiality. We consider this risk to be low.

If your report shows you have an increased risk for a condition, you may feel worried or anxious. You can talk with a genetic counselor on our study team, or your doctor, to discuss your concerns.

### **How do you keep my information secure?**

In this study, both genetic and health information will be shared with other eMERGE Network researchers. However, it will be de-identified, meaning identifying information like your name, address, phone numbers, or email address **will be** removed before it is shared. The goal of sharing information within the eMERGE Network is to have many people collaborating on healthcare discoveries. We will not sell any of your information, including your genetic information.

Every effort will be made to protect your privacy and confidentiality. Study information will only be used for research and is legally protected from other uses by a federal certificate of confidentiality. This means that the information cannot be used by law enforcement or others who might want to gain access to your identifiable genetic or other information.

**I am not sure about whether I should take part or not. What should I do?**

You can contact our study coordinator, Brenda Mutai, with a voice message 206-616-4525, or email [emerge4@uw.edu](mailto:emerge4@uw.edu) with any questions. You may also find it helpful to discuss with your friends and family and with your doctor.

**What if I no longer want to participate?**

You can withdraw from this study at any time by contacting our study coordinator, Brenda Mutai, with a voice message 206-616-4525, or email [emerge4@uw.edu](mailto:emerge4@uw.edu). This will not affect your future medical care.

**What will be done with my information after this study?**

The eMERGE study is scheduled to actively end in 2025. However, researchers may continue to examine de-identified information about you after the study is over.

**What legal protections are there for my genetic test results?**

Employers and health insurance companies are prevented by law from discriminating against you based on genetic test results. The federal law that prevents this discrimination is called the Genetic Information Non-discrimination Act (GINA). GINA does not protect active duty military, but the military has other privacy protection policies. Some states have additional protections. You should talk with our study team if you have further questions in this regard.

**Will my genetic risk report affect types of insurance, like life insurance, long-term care insurance, or disability insurance?**

GINA does not protect against discrimination for life, long-term care, or disability insurance. It may become harder to get these types of insurance if you learn that you have an increased risk for a condition through this study. You should talk with our study team if you have further questions in this regard.

## Who is sponsoring this research study?

The National Institutes of Health (NIH) is funding the eMERGE Network. The University of Washington is one of 10 sites in the eMERGE Network working together to conduct this research

