

Supplemental Table: Language describing plans related to returning research results from seven eMERGE projects.

Site Number	Return of Results Language
<p>Project 1</p>	<p>[site name] Personally-controlled health record (PCHR): You will receive access to a personally-controlled health record (PCHR). Through the PCHR, you/your child will be able to review your/your child's research data and, in the future, genetic test results. We have not yet created an organized way for you to view your/your child's genetic research data. In the future, you/your child will have the option of viewing your/your child's genetic test results through the PCHR after signing a separate consent form. If you/your child do not have a personal email account and/or access to the internet, we will help you set up an email account and locate places within [site name] and in the community where you can use a computer to log-in to your/your child's PCHR.</p> <p>Once you/your child turns 13 years of age you/your child can receive a separate login to access the PCHR. This means parents/guardians and participating children aged 13 years and older will have the ability to see and receive the same information as part of this study. You/your parent/legal guardian will have to sign a permission form allowing us to create a separate login for you/your child once you/your child turns 13 years of age.</p> <p>Once you/your child turns 18 years of age, you/your child will have the ability to decide to discontinue parental access to your/their PCHR record.</p> <p>[site name] Messaging System: If you sign up for a PCHR account, you/your child will receive messages about general research findings and findings related to your/your child's samples/data. Signing up for a PCHR is not a requirement for participation in this study but will offer participants the opportunity to receive information related to you/your child's health. If a researcher discovers a research result that may be important, the result will be reviewed by a board called the [local committee name]. The [local committee name] is a group of scientists, physicians, genetic counselors and other health professionals that is completely separate from the investigators of this research project. The [local committee name] will decide if it is important to inform participants such as you/your child of study findings and how to best inform participants of those results. When deciding this, the [local committee name] will look at the accuracy and health importance of the research finding in addition to other factors. This means that not all research results will be given to participants including yourself/your child.</p> <p>If the [local committee name] decides it is important to send out a message to you/your child, a message explaining the finding will be sent anonymously to your/your child's PCHR. You will have to log into your/your child's PCHR account to view the message. The message will include the name and contact information for a member of the study staff who will be available to answer questions regarding any messages that have been sent to you/your child.</p> <p>IMPORTANT NOTICE: There are certain conditions that do not develop until the adult years (>18 years of age). It is standard of care not to offer genetic testing to children for these adult onset disorders until they have reached 18 years of age and have decided they would like to know this information. Therefore, we will NOT send any messages about adult-onset disorders to you/your child and we will NOT allow access to the genetic data that corresponds to any adult-onset disorder until you/your child reaches the age of 18 years.</p> <p>The messages delivered by the [project name] system are meant to provide you with study information and results. They are not meant to replace the information and support that can be given in a clinical appointment with a genetic counselor, geneticist, and/or other clinicians. A member of the study staff may suggest a clinical appointment with a physician, genetic counselor or other health care provider so that you/your child may receive further assistance</p>

	<p>in understanding and using the study information.</p> <p><u>Will I be told individual results from the testing?</u></p> <p>In general, you will not be told individual results.</p> <p>However, it is possible that researchers may find a result that could be of importance to your/your child's health. If you say that you want to be told about these results, there is a process for providing them. A doctor at [site name] who understands the results would try to contact you to discuss the result. During this process, it is possible that your insurance company may also learn the result.</p> <p>And in signature section: By signing below I also request that [site name] notify me about any research findings that are important to my/my child's medical care. With this section, I understand that my insurance company may also learn about this finding.</p>
Project 3	
Project 4	<p>Results of tests and studies done solely for this research project are not part of your regular medical care and will not be included in your health record. However, there is a small chance that researchers could discover something that might be important to your health or medical care. If this happens, we will contact you to see if you want to learn more.</p>
Project 6	<p>This study involves testing the genes you inherited from your parents (also known as genetic testing). If a researcher finds that results obtained from the genetic testing performed on your samples may be useful for your health care, you will be contacted and given the choice to learn the test results. At this time, you will be given general information on the potential risks, benefits, and costs of choosing to learn the test results. The risks of learning genetic test results may include emotional upset, insurance or job discrimination, and/or family conflicts from learning unknown information about your parents or blood relatives. No test results will be put into your medical record unless you choose to learn the results of the testing. Sometimes results should be released only through a genetic counselor who can help explain the possible risks and benefits of learning this information.</p> <p><i>(Similar language is repeated in another section of the consent document)</i></p>
Project 7	<p>There may be the possibility that a researcher using your sample in the future finds a genetic result that has clinical implications for you or your family. If this happens, you may be contacted and asked if you would like to learn about this genetic research finding.</p>
Project 8	<p>You and your child will not be told about your child's individual research results.</p>
Project 9	<p><u>Consent Document</u></p> <p>The results are only for research purposes and will be stored in the [biobank name]. You and your child will not be told of the results of any research tests performed nor any personal information resulting from the analysis of your child's sample. No information about genes or inheritance will be reported to you or your doctor. Research results are often preliminary, inconclusive, and not necessarily valid for use by your physician in the management of your child's healthcare.</p> <p><u>Assent Document</u></p> <p>Since it takes a long time to do research and to understand what the results mean, we will not tell you, your parents, or your doctor about the studies that use your sample.</p>