

This brochure contains general information for educational purposes and is not intended to provide medical advice. Talk with your doctor or research team before acting on any information contained herein for advice specific to your situation.

Health Research

INCIDENTAL FINDINGS

Questions to ask before deciding to participate in research:

- > What kinds of findings will you share with me? If you are not sharing incidental findings with me, can you tell me why?
- > Do I have a choice about which findings you share with me? What if I don't want to know?
- > Will you ask me about my preferences throughout the study?
- > What happens if you find a serious medical condition or other information about my health?
- > Who will pay for my follow-up care and treatment?
- > What happens if you learn information that could affect my family planning decisions?
- > What happens if you learn something unexpected about my family history?
- > Will you be able to make sure any findings are correct?
- > Who can I talk to about these findings?



Participating in research is your choice.
Be informed. Ask questions. Get answers.



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During a research study, a researcher may notice something that he or she was not looking for. This is called an “incidental finding.” These unexpected findings are not directly related to the research. However, they may show important information about the health of a research volunteer.

Questions? Call us at

About health research

Research is not the same as personal medical care. When you visit your own doctor as part of your medical care, your health and well-being are your doctor's top priority. However, if you take part in a research study, your personal health is not the focus of the research. Medical research tries to answer a specific scientific question. Research tests and activities are not meant to provide you with medical care.

Participating in research is a choice

Protections are in place for the safety of all research volunteers (also called "research subjects") and to ensure volunteers are treated with respect. Being part of a research study is voluntary – it's your choice. Ask for help if you don't understand something. You should never feel rushed or pressured. You can change your mind at any time, for any reason.

What are incidental findings?

During a research study, a researcher may notice something that he or she was not looking for. This is called an "incidental finding." These unexpected findings are not directly related to the research. However, they may show important information about the health of a research volunteer.

What are some types of incidental findings?

There are many types of incidental findings. Some examples include:

- > Learning new information about you and your health
- > Finding a growth or spot on a CT, MRI, or PET scan or other test
- > Learning that you have a medical or psychiatric condition that you did not know about. (This condition may or may not be treatable.)
- > Discovering that you or your family members might have a risk of developing an illness in the future. (This could affect family planning decisions.)

Sometimes researchers may not know what a finding means, or how it might affect your life or your overall health.

Will researchers share their findings with me?

The decision to share research results and unexpected findings depends on the type of information and your preferences as a research volunteer. Researchers may share some or all of their findings with you. However, you may not learn about any findings for a very long time.

It is also possible that researchers will not share any results or incidental findings. However, you could still have a health problem or develop one in the future. Talk with your doctor or another healthcare provider if you have any questions about your health.

Ask the researchers what information they will share with you (if any). Ask what resources are available if you find out something unexpected about your health.

Learning of incidental findings

Benefits: You might benefit from learning about incidental findings. For example, these findings might tell you about your risk of developing a disease. In some cases, you might be able to take steps to reduce your risk. In other cases, this information might help you make decisions in your life. Some findings may also help your blood relatives, who might share your risk of developing a disease or condition. You should discuss any incidental findings with your doctor.

Risks: It can be very upsetting to learn unexpected information about your health. This is especially true if you learn that you have or will develop a condition that has no treatment or cure. There is a chance that incidental findings could affect your family or social relationships, change your family planning decisions, or affect you financially. You might need more tests and procedures to find out what the information really means. It's also possible that the information might be incorrect, so you would worry without cause.

The study team will go over an Informed Consent Form with you and explain the study goals and possible risks and benefits. Talk with the study team about incidental findings. Ask about the risks and benefits of learning about these sorts of findings. Consider how this kind of information might affect you and your family.