



For Research Participants

A Guide to Incidental Findings

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Primary findings are the results researchers are looking for when they conduct a test. Incidental findings are results that they discover, even though they were not looking for them. The Presidential Commission for the Study of Bioethical Issues (Bioethics Commission) released a report that helps researchers manage these incidental findings. This guide helps you understand what those findings might be, and what questions you might ask the research team to prepare for them.

What tests might have incidental findings?

Genetic testing:

Researchers might conduct a genetic test for their study. They might discover something in your DNA that they did not expect.

Tests on your blood or urine:

Researchers might do a test on your blood or urine. Usually researchers will order the test for a specific purpose. But the lab might conduct many tests in a bundle. As a result, researchers might discover something they were not looking for.

Imaging:

Researchers might order a medical imaging test, such as an X-ray, MRI, or ultrasound. Imaging sometimes shows things that researchers were not looking for.

What questions should I ask the research team?

What might you find?

Ask a member of the research team to explain the tests they will be conducting, and what results they might discover.

What will you tell me?

Some research studies do not return any results to participants. Ask the researchers if they will tell you about any of the results they discover, and if so, which ones. This will help you understand what you might learn from the tests they are doing.

What will happen next?

Ask the researchers how they will follow up on the results they find. For example, ask if they will help you find a doctor if they discover something that could be important for your health.

What if I don't want to know?

Make sure to tell the researchers if there are any results you don't want to know about. The research team will listen to your preferences, and determine how best to follow them.

PARTICIPANT EXPERIENCES

Isabelle signed up for a research study in which the researchers scanned her brain. The researchers saw something abnormal in her scan. They told Isabelle to see a doctor, and the doctor recommended surgery to take out a mass. She credits this finding with saving her life.



James took part in the same research study. The researchers scanned his brain. When the researchers reviewed his brain scans, they found nothing out of the ordinary. James was happy to be a part of an interesting research study.