

Conversation
Series



For Consumers

A Guide to Incidental Findings

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Primary findings are the results you and your direct-to-consumer (DTC) provider are looking for when you sign up for a test. Incidental findings are results that your provider discovers, even though you were not looking for them. The Presidential Commission for the Study of Bioethical Issues (Bioethics Commission) released a report that helps DTC providers manage these incidental findings. This guide helps you understand what those findings might be, and how you might prepare for them.

What tests might have incidental findings?

Genetic testing:

If you sign up for a DTC genetic test, there might be some results in your report that you do not expect.

Tests on your blood or urine:

The DTC company might perform tests on a sample of your blood or urine. You might choose the test for a specific purpose, but the company might conduct many tests together in a set. So you or the company might discover something you were not looking for.

Imaging:

Medical imaging includes X-rays, MRIs, and ultrasounds. Since the image covers a large area, the picture might show something you or the provider were not looking for.

What questions should I ask the DTC provider? (Try asking a customer service representative. If there is no one available to ask, the materials that the company provides might have the answers to these questions.)

What might you find?

Find out from the DTC provider what tests they will conduct, and what results they might find.

What will you tell me?

Ask your DTC provider if they will tell you about all the results they discover. This will help you understand what you might learn from the tests.

What will happen next?

Find out from the DTC provider how they will follow up on the results they find. Make sure you understand how you will be notified, and whether a doctor will be involved.

What if I don't want to know?

Make sure you understand what kinds of results might be discovered before you sign up for the test. This way, if information will be provided that you don't want to know, you can decide not to sign up.

CONSUMER EXPERIENCES

Maria and her brother David bought a genetic testing kit from a company to learn about their DNA. The company found out that Maria and David were only *half* siblings. They were warned that the company might find an incidental finding, but they were still shocked to discover the news.



From: CDC/Amanda Mills

Mark also bought a kit from the same company. He was curious about his risk for some diseases that ran in his family. He learned some information about his risk for heart disease and was connected with his distant relatives, but did not find out anything that surprised him.