

Do biobanks that accept anonymous DNA have a responsibility to inform donors when they discover a treatable genetic defect?

What should happen when researchers, while sequencing a participant's DNA as part of a large study, discover gene variants that increase the risk for conditions that might be prevented with medical treatment or surveillance?

Some researchers believe they have an obligation to find the participants — often years after they provided a DNA sample — contact them, and tell them what they have found. But, some research subjects, like Ms. [Marin] Konstadt, feel they have a right not to know.

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Is it ethical for doctors to let them insist they can opt out of learning more without first knowing the particular risk they are facing?

For Dr. Robert Green, an investigator for the biobank with Ms. Konstadt's DNA, the Mass General Brigham Biobank, and author of [a recent paper](#) about its policies, the answers are clear.

The consent form for the biobank tells participants that if the researchers find a worrisome variant, and if there is an intervention that can reduce risk, the participants will be contacted. There will be seven attempts to reach participants — calls and letters — before the team gives up.

"We are offering the information, not forcing participants to accept it," said Dr. Green.

[**This is an excerpt. Read the original post here.**](#)