Finding genetic disorders in patients during studies presents prickly ethical questions

Back in 2020, Cristen Willer, a professor of cardiovascular medicine at the University of Michigan in Ann Arbor, was leading her laboratory on a search for the genetic underpinnings of an often deadly heart condition called aortic dissection.

As the results came in, she was troubled by some of the answers she was getting. They were quite clear — but they had the potential both to help and hurt some patients who had volunteered for the study and their families.

Willer and her team needed to devise an effective and ethical way to notify the research participants about their genetic variants while preserving their “right to not know” about the harmful aberrations.

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Willer’s work set a precedent for handling similar issues of disclosure stemming from genetic discoveries made in samples from biobanks, which could become increasingly common as genomic medical research continues to take off.

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“We sent the information by letter, but we decided not to reveal the specific genetic change in the letter. We just said, ‘We found some information that we think will be important to your medical care. Please contact this genetic counselor to make an appointment, and she will explain it all to you,’” [Willer said].

This is an excerpt. Read the original post here.