

Guidelines on sharing individual genomic research findings with family

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A blue-ribbon project group funded by the National Institutes of Health has published the first consensus guidelines on how researchers should share genomic findings in research on adults and children with other family members. The recommendations, published in the *Journal of Law, Medicine & Ethics*, offer direction on sharing information before and after the death of an individual research participant.

"These recommendations will have an impact on future human subject protection policies when genetic [research](#) is performed," says Gloria Petersen, Ph.D. of Mayo Clinic, who co-authored the guidelines with Susan Wolf, J.D., of the University of Minnesota, and Barbara Koenig, Ph.D. of the University of California, San Francisco.

The authors say the explosive growth of genomic research has led to tough questions about what to do with the resulting information. Should researchers share an individual's private results with family members who may share that genetic risk? The question often pits individual privacy against family need.

Until now, the authors say, researchers have had no guidance on how to balance the two. For example in cancer genomics, a research participant may die, leaving researchers with no idea whether they can reach out to offer [family members](#) the deceased individual's results. These policy gaps can leave siblings, [children](#) and other relatives without crucial information about their potential health conditions. "What makes these issues so challenging is current bioethics, [law](#), and research rules focus

on protecting individuals, but genetics is about families," Dr. Wolf says.

The guidelines were developed after a multiyear consensus process involving experts in medical genetics and genomics, genetic counseling, genomic researchers, biobanks and repositories, human research protection, bioethics, and law.

The [recommendations](#) include:

- Researchers should anticipate requests from relatives for participant results and seek participant preferences on sharing and who should serve as the participant's representative after death.
- Researchers should strive to protect the choices of research participants as to what information is shared and the privacy of participant results.
- Relatives, rather than researchers, generally should be the ones to raise the question of sharing individual results, as researchers generally are obligated to respect the privacy of participant data.
- In unusual cases in which sharing is likely to avert imminent harm, researchers may be ethically justified in reaching out to a participant's relatives to offer serious and actionable genomic information.

More information: [onlinelibrary.wiley.com/journal/1111/\(ISSN\)1748-720X](https://onlinelibrary.wiley.com/journal/1111/(ISSN)1748-720X)

Provided by Mayo Clinic

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