

# The big ethical issues clinical genomics needs to solve

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For all its potential to detect rare and inherited conditions and guide effective treatments, clinical genomics is still a relatively young domain with unresolved ethical issues. A recent webinar explored the most pressing of these for physicians, including the ones having to do with standard of care.

The webinar, “Medical and Ethical Challenges in Clinical Genomics,” produced by the AMA Academic Physicians Section, featured a presentation by AMA member Wayne W. Grody, MD, PhD. He directs the Molecular Diagnostic Laboratories and Clinical Genomics Center at Ronald Reagan University of California, Los Angeles Medical Center.

Dr. Grody explained why clinical genomics is fraught with unanswered questions about how it ought to be applied.

## Focus first on individuals

Whereas genome-level DNA sequencing is effective at detecting individual gene mutations—such as BRCA1 and BRCA2, which are associated with breast cancer and ovarian cancer—genomic testing looks at all of a person’s genes.

But there are stubborn questions surrounding it. Among them: When is it appropriate to order genomic testing? And are physicians compelled to share all the results with patients?

Imagine, for example, getting genomics test results on a 3-year-old girl with epilepsy and seeing a risk of breast and ovarian cancer.

“There is no risk at age 3—there’s no risk for at least another 20, 30, 40 years,” Dr. Grody said, noting that parents might not be focused on a hypothetical risk of breast cancer 40 years from now. “They’re worried that their child is seizing nonstop and getting a developmental delay. So do you report it or not?”

"Obviously, you're not going to remove the breasts and ovaries of a 3-year-old girl. You'd go to jail if you did that. So all this is going to do is stigmatize the girl, and maybe cause insurance problems and so on."

But if her epilepsy is treated and she then grows up and, say, dies at age 25 of metastatic breast cancer, her physician could face litigation for knowing this risk and never disclosing it.

"I've been through many ethical issues in my 30-plus-year career in genetics," Dr. Grody said. "This is the thorniest of all, and I don't even claim to know the answer."

Explore the latest in genetics and genomics, including cancer genetics, neurogenetics, and pharmacogenetics with the JAMA Network™. Also, learn more about genome editing and the AMA *Code of Medical Ethics*.

Also find more guidance from the AMA *Code of Medical Ethics* on genetic testing of children.

## Don't forget about communities

At the population level, clinical genomics is—like many domains within public health—struggling with issues of equity.

"For one thing, the population databases we use are very skewed toward Europeans," Dr. Grody said. The reasons for this do point to systemic racism.

They include:

- Existing cohorts are largely white.
- The reference human genome—the one mapped by the Human Genome Project—is white.
- Historically marginalized racial and ethnic groups have less access to inclusion in studies.
- Some historically marginalized racial and ethnic groups have legitimate reasons to distrust medical research.
- Most genomic researchers are white, and researchers tend to do research in their own communities.

Find out more about the AMA's strategic plan to embed racial justice and advance health equity and read how the AMA fights for greater health equity by identifying and eliminating inequities through advocacy, community leadership and education.

And stay informed about techniques and innovations in genomics and precision medicine such as genetic testing, its applications for cancer care, as well as their effects on improving patient care.



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