

GENETIC TESTING REGISTRY

With an increasing number of genetic tests available through laboratories, the National Institutes of Health (NIH) recognizes the importance of making information about these tests easily accessible to researchers, patients, consumers, health care providers, payers, and others. Therefore, NIH is initiating the development of the Genetic Testing Registry (GTR), a registry that will provide a centralized location for test developers and manufacturers to voluntarily submit test information such as indications for use, validity data, and evidence of the test's usefulness.

The overarching goal of the GTR is to advance the public health and research into the genetic basis of health and disease. As such, the Registry will have several key functions:

- Encourage providers of genetic tests to enhance transparency by publicly sharing information about the availability and utility of their tests.
- Provide an information resource for the public, including researchers, health care providers and patients, to locate laboratories that offer particular tests, and
- Facilitate genetic and genomic data-sharing for research and new scientific discoveries.

Interacting with stakeholders—such as laboratory test developers, manufacturers, health care providers, patient and consumer groups, and researchers—will be a critical part of developing the GTR.

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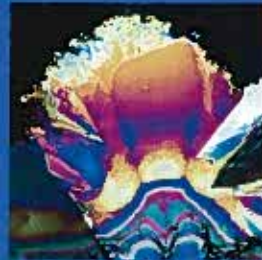
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Seeking Input on....

- Types of genetic tests that should/should not be included in the registry
- Potential uses of the Registry for researchers, patients, health care providers, payers, and genetic testing entities
- Data elements to include in the Registry and information to collect for each element (e.g. lab certifications, test methodologies, intended use, analytical validity, etc.)
- Benefits and risks of sharing information about the availability, accessibility, scientific basis, validity, and utility of genetic tests
- Referencing other resources (e.g. published studies, government recommendations, etc.)
- Processes to make data submission as easy as possible
- Methods to ensure continued stakeholder input into the maintenance of the Registry



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