

## NIH genomics researchers to share data and clarify informed consent

Scientists who work on genomics and are funded by the U.S. National Institutes of Health (NIH) must post their data online so that others can build on the information, the agency has said in an [update](#) to its guidelines.

The change, which expands the remit of an earlier data-sharing policy, is not expected to drastically alter research practices — many genomics researchers are accustomed to sharing their data. But the latest policy, released on August 27, gives clearer instructions for gaining the informed consent of study participants. The NIH will now require researchers to tell study participants that their data may be broadly shared for future research.

Informed consent will be required not just for genomic data, but also for cell lines or clinical specimens such as tissue samples, even when they are stripped of information that directly identify the source. That extension, which the NIH has not previously required, is a “big step”, says Ellen Wright Clayton, a bioethicist and lawyer at Vanderbilt University in Nashville, Tennessee.

The agency has been working on the changes for several years, as new technologies have rapidly made it easier and cheaper for researchers to gather, analyse and share genomic data. Even anonymized, or ‘de-identified’, data can sometimes be traced to the individuals who provided them.

**Read the full, original story: [US agency updates rules on sharing genomic data](#)**