



Online Ethics Center  
FOR ENGINEERING AND SCIENCE

## Additional Resources

### Description

Part of unit 7 of the [Course on Genomics, Ethics and Society](#), this is a bibliography of recent news articles, academic articles, websites, videos, and other resources on ethics, genomics, and privacy.

### Body

## News Stories on Genetic Privacy

### [Privacy and screening of newborns](#)

<[http://www.worldmag.com/2014/12/expanded\\_newborn\\_screening\\_raises\\_privacy\\_concerns](http://www.worldmag.com/2014/12/expanded_newborn_screening_raises_privacy_concerns)  
News story from December 2014 about concerns for privacy from the genetic screening of newborns, as the Newborn Screening Saves Lives Reauthorization Act was passed.

### [Insurance plans and genetic testing](#)

<<http://www.benefitscanada.com/benefits/health-benefits/genetic-testing-the-next-employee-benefit-60662>>  
News story from December 2014 about the possibility of genetic testing for inherited disease being included in companies' health insurance packages - and the possible risks to privacy this may pose.

### ["Poking holes in genetic privacy"](#)

<[http://www.nytimes.com/2013/06/18/science/poking-holes-in-the-privacy-of-dna.html?pagewanted=all&\\_r=0](http://www.nytimes.com/2013/06/18/science/poking-holes-in-the-privacy-of-dna.html?pagewanted=all&_r=0)>

New York Times article on how easily individuals can be identified from their genetic data, and how difficult the data is to anonymize

[The Future of Genetic Privacy](http://www.huffingtonpost.com/dov-fox/the-future-of-genetic-privacy_b_3747047.html) <[http://www.huffingtonpost.com/dov-fox/the-future-of-genetic-privacy\\_b\\_3747047.html](http://www.huffingtonpost.com/dov-fox/the-future-of-genetic-privacy_b_3747047.html)>

Huffington Post article on - well - the future of genetic privacy, primarily in the context of crime (an area we haven't yet considered).

## **Websites of Relevant Individuals and Institutions**

[Council for Responsible Genetics](http://www.councilforresponsiblegenetics.org/Projects/PastProject.aspx?projectId=1)

<<http://www.councilforresponsiblegenetics.org/Projects/PastProject.aspx?projectId=1>>  
Website of the Council for Responsible Genetics, section on Genetic Testing, Privacy and Discrimination.

[National Human Genome Research Institute - on genetic discrimination](http://www.genome.gov/10002077)

<<http://www.genome.gov/10002077>>

This is the part of the NGHRI that concerns genetic discrimination; if you look at the link on the left of this page, you'll see a link on informed consent, also be relevant for thinking about privacy issues.

[National Institute of Health on Genetic Discrimination & Privacy](http://ghr.nlm.nih.gov/spotlight=thegeneticinformationnondiscriminationactgina)

<<http://ghr.nlm.nih.gov/spotlight=thegeneticinformationnondiscriminationactgina>>

[Electronic Privacy Information Center: Genetic Privacy](https://epic.org/privacy/genetic/)

<<https://epic.org/privacy/genetic/>>

## **Links to Commentaries and Papers on Genetic Privacy**

[Ethics, genomics and cloud computing](http://www.ncbi.nlm.nih.gov/pubmed/25248396)

<<http://www.ncbi.nlm.nih.gov/pubmed/25248396>>

New article. Abstract: The biggest challenge in twenty-first century data-intensive

genomic science, is developing vast computer infrastructure and advanced software tools to perform comprehensive analyses of genomic data sets for biomedical research and clinical practice. Researchers are increasingly turning to cloud computing both as a solution to integrate data from genomics, systems biology and biomedical data mining and as an approach to analyze data to solve biomedical problems. Although cloud computing provides several benefits such as lower costs and greater efficiency, it also raises legal and ethical issues. In this article, we discuss three key 'points to consider' (data control; data security, confidentiality and transfer; and accountability) based on a preliminary review of several publicly available cloud service providers' Terms of Service. These 'points to consider' should be borne in mind by genomic research organizations when negotiating legal arrangements to store genomic data on a large commercial cloud service provider's servers. Diligent genomic cloud computing means leveraging security standards and evaluation processes as a means to protect data and entails many of the same good practices that researchers should always consider in securing their local infrastructure. *European Journal of Human Genetics* advance online publication, 24 September 2014; doi: 10.1038/ejhg.2014.196.

**Leila Jamal, Julie C Sapp, Katie Lewis, Tatiane Yanes, Flavia M Facio, Leslie G Biesecker and Barbara B Biesecker. [Research participants' attitudes towards the confidentiality of genomic sequence information](http://www.nature.com/ejhg/journal/v22/n8/full/ejhg2013276a.html). *European Journal of Human Genetics* 2014**

<<http://www.nature.com/ejhg/journal/v22/n8/full/ejhg2013276a.html>>

Respecting the confidentiality of personal data contributed to genomic studies is an important issue for researchers using genomic sequencing in humans. Although most studies adhere to rules of confidentiality, there are different conceptions of confidentiality and why it is important. The resulting ambiguity obscures what is at stake when making tradeoffs between data protection and other goals in research, such as transparency, reciprocity, and public benefit. Few studies have examined why participants in genomic research care about how their information is used. To explore this topic, we conducted semi-structured phone interviews with 30 participants in two National Institutes of Health research protocols using genomic sequencing. Our results show that research participants value confidentiality as a form of control over information about themselves. To the individuals we interviewed, control was valued as a safeguard against discrimination in a climate of uncertainty about future uses of individual genome data. Attitudes towards data sharing were related to the goals of research and details of participants' personal

lives. Expectations of confidentiality, trust in researchers, and a desire to advance science were common reasons for willingness to share identifiable data with investigators. Nearly, all participants were comfortable sharing personal data that had been de-identified. These findings suggest that views about confidentiality and data sharing are highly nuanced and are related to the perceived benefits of joining a research study.

**[Empirical research on the ethics of genomic research](http://onlinelibrary.wiley.com/doi/10.1002/ajmg.a.36067/full)**

<<http://onlinelibrary.wiley.com/doi/10.1002/ajmg.a.36067/full>>

Article on incidental findings in the American Journal of Medical Genetics.

**[American Journal of Bioethics: focus issue on genetic privacy](http://www.tandfonline.com/toc/uajb20/10/9#.VJhclUA4iA)**

<<http://www.tandfonline.com/toc/uajb20/10/9#.VJhclUA4iA>>

## **Links to Useful Videos on Genetic Privacy**

**[Talk by bioethicist Arthur Caplan from NYU "Ethical and Legal Dilemmas in Genetic Testing"](https://www.youtube.com/watch?v=C-CbT5XyKU4)** <<https://www.youtube.com/watch?v=C-CbT5XyKU4>>

**[Talk by lawyer Jeffrey Rosen on privacy rights \(including, but not exclusively on, genetic privacy\)](https://www.youtube.com/watch?v=t3A9tjkSybw)**

<<https://www.youtube.com/watch?v=t3A9tjkSybw>>

**[Australian TV panel program on "Your Genetic Profile: Ethics and Legal Issues"](https://www.youtube.com/watch?v=w45ElshP1mk)** <<https://www.youtube.com/watch?v=w45ElshP1mk>>

[Continue to Recommended Readings](#)

### **Rights**

Use of Materials on the OEC

### **Resource Type**

Instructor Materials

### **Topics**

Privacy and Surveillance

Human Subjects Research

Confidentiality

Emerging Technologies

**Discipline(s)**

Genetics and Genomics

Life and Environmental Sciences