



Readings

Description

Part of unit 7 of the extensive [Course on Genomics, Ethics and Society](#), this section provides readings on genomics and privacy.

Body

Week 1

Everyone should read both readings this week!

The first reading this week is the Executive Summary of *Privacy and Progress*, the report discussed in the Background Material for this unit.

1. Presidential Commission for the Study of Bioethical Issues (2012). Executive summary. In *Privacy and progress in whole genome sequencing* (pp. 1-11). Washington, D.C.: Government Printing Office.

This report raises some of the different ways in which genetic information may be distributed, and how such distribution might compromise privacy - from taking DNA samples involuntarily left on a coffee cup, to the secure storage of data that has been voluntarily obtained, but which may contain information relevant to other family members who may not know or have consented. It then makes a number of recommendations about policies, privacy and consent which have been influential in subsequent debates about policy on genetic privacy.

The second reading this week, Gutmann & Wagner's "Found your DNA on the web" picks up from where *Privacy and Progress* left off. Gutmann - the chair of the committee that produced the report - co-authored this Hastings Center Report which focuses on how identifiable individuals are if their genetic data is stored in large datasets in the cloud. The report argues that identifiability is no longer a "bright line" - either you are identifiable or you're not - because you can be *more or less* identifiable based your online genetic data; and that what matters is not that the data is distributed, but that it is not *misused*.

2. Gutmann, A., & Wagner, J. W. (2013). Found your DNA on the web: Reconciling privacy and progress. *Hastings Center Report*, 43, 15-18.

Question for Reflection: These papers together make a number of recommendations about obtaining, storing and distributing genetic data. Do you think these recommendations are sufficient to protect - or perhaps overprotective of - genetic data? Are there further recommendations that you think should be made? Do you think that non-experts would be able understand the information they would need to understand, in order to give fully informed consent?

Week 2

Welcome to the last week's readings for this course!

There are three readings this week. The first reading is required **for graduates only**, and it's a paper from the *Annual Reviews* series. This review focuses on privacy protection and data sharing, in particular how "data sharing tests current ethical principles and oversight mechanisms for medical research." As an *Annual Reviews* article, this paper reliably summarizes the state of these debates as of 2012 when it was published.

1. Kaye, Jane. 2012. "The Tension between Data Sharing and the Protection of Privacy in Genomics Research." *Annual Review of Genetics and Human Genetics* 13: 415-431

Our second reading, for both undergraduates and graduates, explores a wide range of ethical issues created by the changing technology and economy of genomic data. It provides a useful overview of how issues concerning data management have

changed over time, and how existing data management protocols have come to seem inadequate. In particular, the paper raises concerns about the idea of "broad consent" - and whether individuals should expect any privacy with respect to their genetic data. A number of different models of consent, transparency, and participant involvement are discussed, as well as the management of incidental findings.

2. McEwen, J. E., Boyer, J. T., & Sun, K. Y. (2013). Evolving approaches to the ethical management of genomic data. *Trends in Genetics*, 29, 375-382.

The final paper here (again, for everyone) is a one-page editorial from *Nature* on privacy and genomic data, prompted by a National Institutes for Health working group on HeLa cellgenomic data (the subject of the case study for this unit). The editorial raises concerns that measures taken in this case may neither ensure the Lacks' family privacy nor enable sufficient access to the data for research. More generally, the editorial is concerned about the possibility that, despite GINA, disclosure of genetic information could be used for discriminatory practices.

3. "Privacy and protection in the genomic era." Editorial. *Nature*, 19, 1073.

Questions for Reflection: Suppose your genome had been sequenced, and your genetic data was available in an online database. What kinds of use for your data would you consent to? How open would your consent be? What kinds of concerns would you have about your genetic data being openly available, even if de-identified?

Recommended Readings

- Bailey, R. (2013, October). Does the royal baby deserve genetic privacy? *Reason*.
- Ball, M. P., et al. (2014). Harvard Personal Genome Project: lessons from participatory public research. *Genome Medicine*, 6.
- Caulfield, T., et al. (2008). Research ethics recommendations for whole-genome research: Consensus statement. *PLoS Biology*, 6, 0430-0435.
- Centre for Genetics Education (2013, January 15). Some ethical issues in human genetics and genomics.
- Greely, H. T. (2007). The uneasy ethical and legal underpinnings of large-scale genomic biobanks. *Annual Review of Genomics and Human Genetics*, 8, 343-364.

- Hansson, M. G. (2009). Ethics and biobanks. *British Journal of Cancer*, 100, 8-12.
- Oliver, J. M., et al. (2012). Balancing the risks and benefits of genomic data sharing: Genome research participants' perspectives. *Public Health Genomics*, 15, 106-114.
- Ploug, T., & Holm, S. (2013). Informed consent and routinization. *Journal of Medical Ethics*, 39, 214-218.

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