

# Data Sharing and Genomic Privacy: Research Participants' Perspectives

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# Data Sharing and Genomic Privacy

- Genomic research = culture of broad data sharing
- Decisions about data sharing involve privacy-utility trade-off
- The right to privacy has been recognized by the U.S. Supreme Court as a fundamental liberty deserving protection
- However, it is not an absolute right and individuals waive their right to privacy every day

### GENETICS

## Genomic Research and Human Subject Privacy

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Interest in understanding how genetic variations influence heritable diseases and the response to medical treatments is intense. The academic community relies on the availability of public databases for the distribution of the DNA sequences and their variations. However, like other types of medical information, human genomic data are private, intimate, and sensitive. Genomic data have raised special concerns about discrimination, stigmatization, or loss of insurance or employment for individuals and their relatives (1, 2). Public dissemination of these data poses nonintuitive privacy challenges.

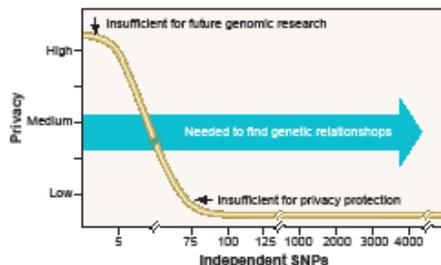
Unrelated people of the 3.2 billion (3). Now, the forensic identification of 15 locations or repeats (4, 5). Single nucleotide polymorphisms (SNPs) can be used to identify someone has a data and performance data, a small set of successful matches for an individual. In a genotypic, phenotypic, or linked to records would be

The world is Specifying DNA statistically independent uniquely define more, if some of that are relative to be tested is about kinship confirm it. Thus, the identifiable is ve

Tension between the desire to protect privacy and the need to ensure access to sci-

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Trade-offs between SNPs and privacy.

Genomic data has led to a search for new technologies. However, the hurdles may be

information. No genetic data will be provided unless a user can demonstrate that he or she is associated with a bona fide academic, industrial, or governmental research unit and agrees to our usage of data access (10). prevent data abuse monitor usage.

Social are intricate about better trustworthy government United States Portability of 1996 (Federal Privacy) eventually fort data with However, address us for human genetic data. Recent debates in Iceland, Estonia, Britain, and elsewhere (12-15), reveal a range of views on the threats posed by genetic information. The United States may be at one end of this spectrum as its cit-

2004: "Specifying DNA sequence at only 30 to 80 statistically independent SNP positions will uniquely identify a single person."

OPEN ACCESS Freely available online

PLOS GENETICS

## Resolving Individuals Contributing Trace Amounts of DNA to Highly Complex Mixtures Using High-Density SNP Genotyping Microarrays

Nils Homer<sup>1,2</sup>, Szabolcs Szelinger<sup>1</sup>, Margot Redman<sup>1</sup>, David Duggan<sup>1</sup>, Waibhav Tembe<sup>1</sup>, Jill Muehling<sup>1</sup>, John V. Pearson<sup>1</sup>, Dietrich A. Stephan<sup>1</sup>, Stanley F. Nelson<sup>2</sup>, David W. Craig<sup>1\*</sup>

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2008: Can uniquely identify an individual from pooled or aggregate DNA data.



**GINA**  
GENETIC INFORMATION  
NONDISCRIMINATION ACT

# My Conclusions

- Important to accurately describe risks and benefits for informed decision making
- Perceived risks and benefits more important than actual risks and benefits
- Protection is important, but respect is also (and maybe more) important

# To share or not to share: A randomized trial of consent for data sharing in genome research

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## Balancing the Risks and Benefits of Genomic Data Sharing: Genome Research Participants' Perspectives

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Participants from 6  
Genomic Studies at  
BCM Randomized  
(N=323 making 335  
decisions)

Traditional  
Consent

Binary  
Consent

Tiered  
Consent

Subjects debriefed, shown all three consents, and given the  
opportunity to change their consent form or data sharing option.

Follow-up Interview  
(N=229, out of 285 eligible)

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**Table 1.** Consent Form Data Release Options

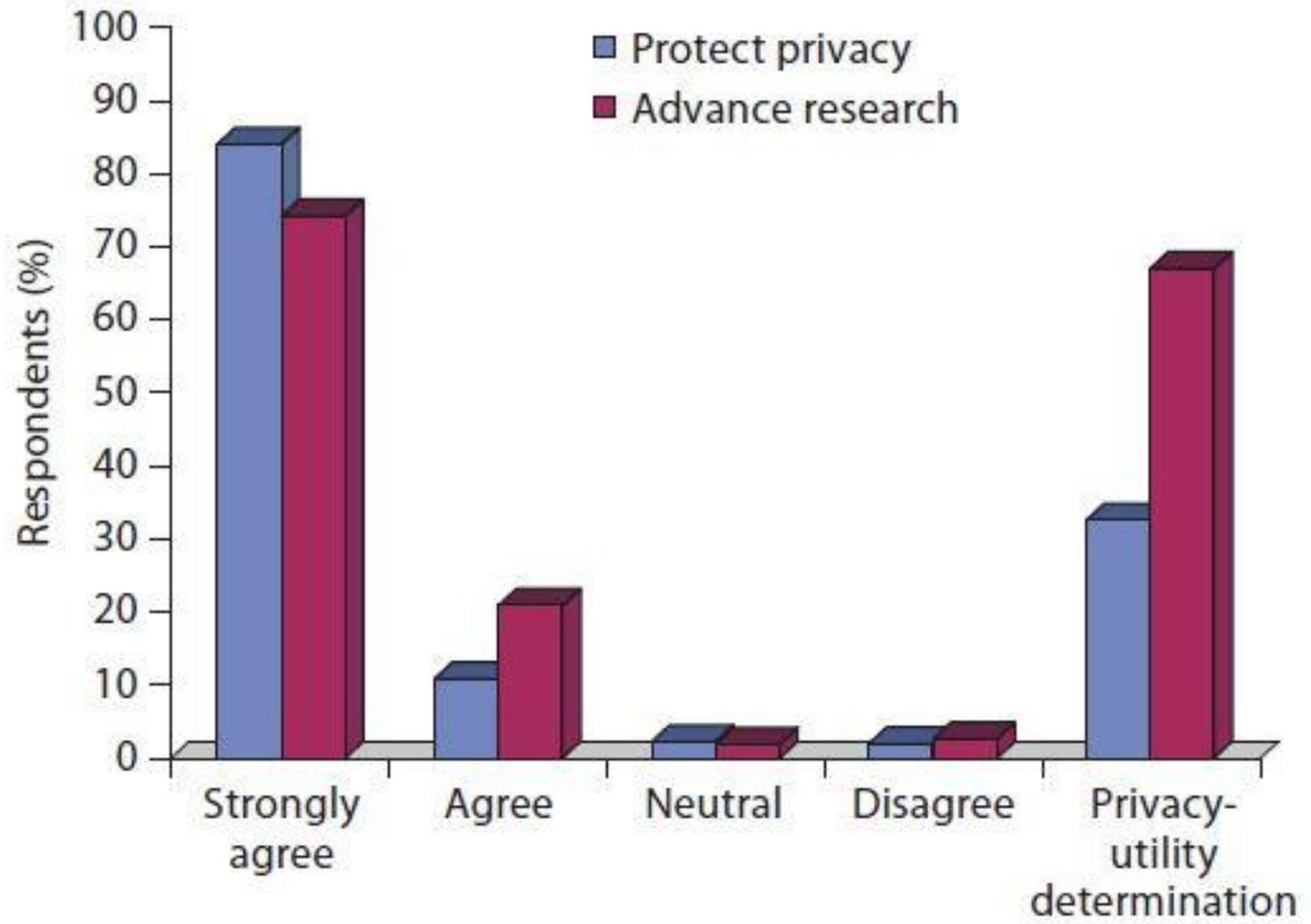
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<b>Type of Consent</b>	<b>Option to participate in study but refuse data sharing</b>	<b>Data Sharing Options</b>
<i>Traditional</i>	No	○ No options; agree to data sharing or do not consent to participate in study
<i>Binary</i>	Yes	○ I consent to the release of my genetic and clinical information into scientific databases, both publicly accessible and restricted. ○ I do not consent to the release of my genetic and clinical information into any scientific databases, other than those maintained for the purposes of this study.
<i>Tiered</i>	Yes	○ I consent to the release of my genetic and clinical information into scientific databases, both publicly accessible and restricted. ○ I consent to the release of my genetic and clinical information into restricted databases only. ○ I do not consent to the release of my genetic and clinical information into any scientific databases, other than those maintained for the purposes of this study.

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	Before Debriefing			After Debriefing		
	<i>Public Release</i>	<i>Restricted Release</i>	<i>No Release</i>	<i>Public Release</i>	<i>Restricted Release</i>	<i>No Release</i>
<b>All Participants</b>	83.9	6.6	9.6	<b>53.1</b>	<b>33.1</b>	<b>13.7</b>
<b>Consent Type</b>						
Traditional	100.0	0.0	0.0	62.1	31.9	6.0
Binary	84.9	0.0	15.1	50.9	30.2	18.9
Tiered	66.4	19.5	14.1	46.0	37.2	16.8

*\*Groups that were more restrictive in their decisions: Hispanic, Unmarried, Educated (at least some college), Parents deciding on behalf of their child*



# Individual Variation Re: Privacy-Utility Trade-Off

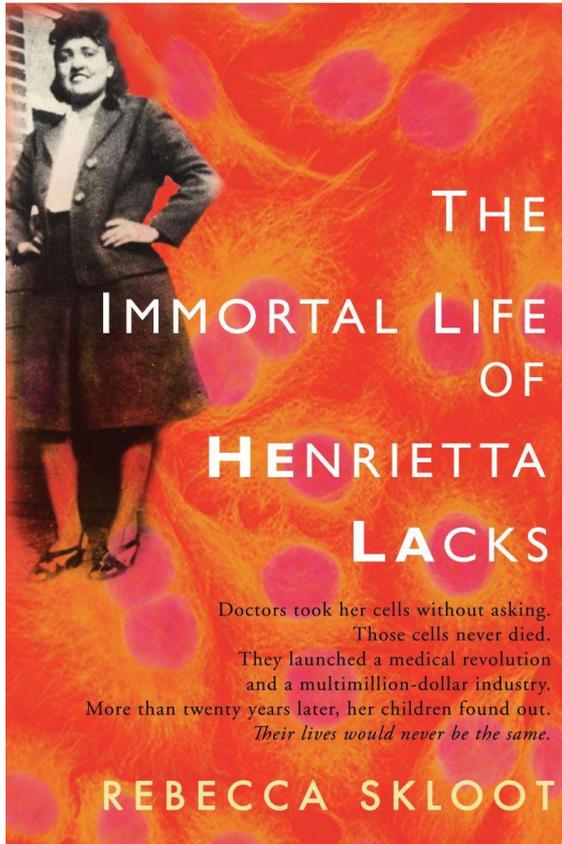


# Desire for Involvement and Respect

- The majority (93.2%) of participants reported it is somewhat to extremely important for them to be involved in the decision about whether to share their genetic information.
  - How: ask me
  - Why: RESPECT

- *You can borrow your sister's bike....If you do it without asking, well, she's going to get mad. But if you just ask her, then she probably would've just said yes and it would've been no big deal. It's obviously a simplistic analogy, but at the same time, you have to show respect to the individuals that you're asking to be subjects. (548)*

# Respect, Transparency, and Public Trust



Carletta Tilousi, Havasupi

**State to destroy 4 million newborn blood samples  
Published 06:30 a.m., Tuesday, December 22, 2009**