

Do patients have an ethical obligation to share their data for research?

# Overview



- ▶ Ethical obligation to participate in research
- ▶ Data research = obligation is sufficient to override consent
- ▶ Upshot: concept of public interest/benefit doing more work...but very vague

# Data philanthropy



## Patientslikeme

“I feel very excited that the information being used from my situation will contribute to research to help other people. Without that data, the research will not continue to grow.”

Letitia, member with epilepsy, joined in 2010

*“Given my status, what is the best outcome I can hope to achieve, and how do I get there?”*

<https://www.patientslikeme.com/research/dataforgood>

<https://www.patientslikeme.com/research/digitalme>

# Data traders

- ▶ “Whenever a patient is seen by a doctor, or enters their information into a medical app or platform, they’re providing the health community an invaluable resource: their data. But they’re not getting compensated for it.” Savvy Platform designers.

## This co-op lets patients monetize their own health data

A new, collectively owned platform called Savvy connects healthcare companies and practitioners with patients who can directly inform their work—and get compensated for doing so.



# Implications

Coming soon: everyone's genetic anonymity undermined by distant relatives – and there's nothing you can do about it

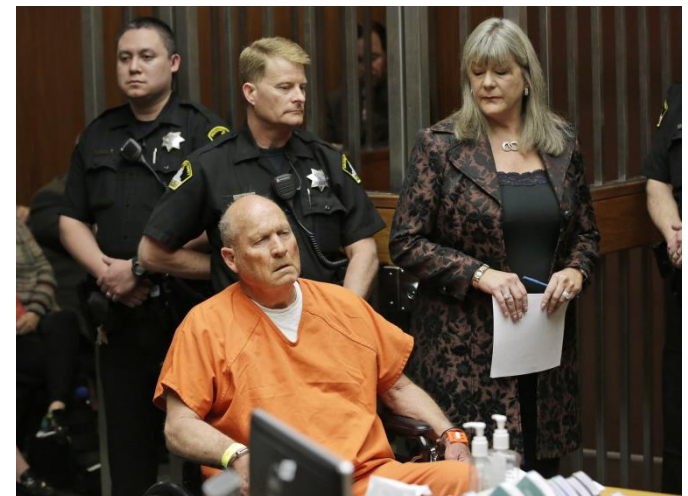
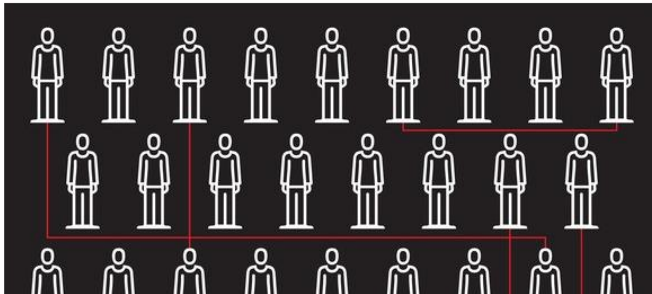
Posted on Oct 20, 2018 by Glyn Moody

## With genetic-identity registries, it's the end of anonymity as we know it

50 pm | Updated October 13, 2018 at 7:44 pm

MEGAN MOLTEN, SCIENCE 10.11.18 02:04 PM

### GENOME HACKERS SHOW NO ONE'S DNA IS ANONYMOUS ANYMORE



# Research ethics



- ▶ Dominant position: research supererogatory
- ▶ An obligation to participate in research
- ▶ 3 potential grounds to support the obligation to participate:
  - beneficence (rule of rescue) (Harris, Rhodes)
  - fairness (Harris)
  - to support public goods (Schaefer, Emanuel, Wertheimer)
- ▶ The existence of a moral obligation to participate does not, on its own, license compulsory research

# Data research obligation



- ▶ An obligation to participate in secondary *data* research
- ▶ 3 objections to the existence of a general obligation
  1. Lack of access to the benefits
  2. Subject protection and autonomy
  3. Public trust and the social licence

Not compelling in relation to data research

# Data research obligation



- ▶ So an obligation to participate in data research is more compelling than a general obligation
- ▶ This obligation could be enforceable = justification of co-opting data for the public good



# Research ethics review



- ▶ Some secondary data use goes through research ethics/IRB review

# Waivers for secondary research



- ▶ gaining **consent** would be impractical, or would impede the scientific validity of the study
- ▶ **public good** or **social value**
- ▶ poses **minimal harm** to participants

# Summary



- ▶ An obligation for citizens to contribute data for research that offers public benefit
- ▶ This obligation is sufficient to override the requirement to get patient consent for *data* research
- ▶ But we need a more robust account of public good/ interest