

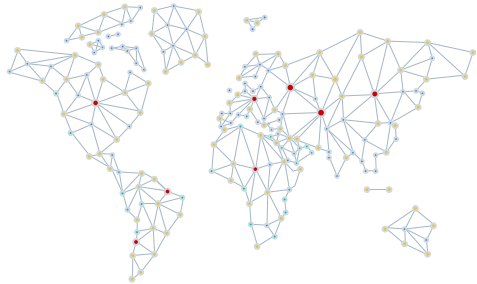
ETHICAL DATA USE IN BIOMEDICAL RESEARCH

A Shifting Landscape

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ALL VIEWS EXPRESSED ARE PERSONAL OPINIONS.

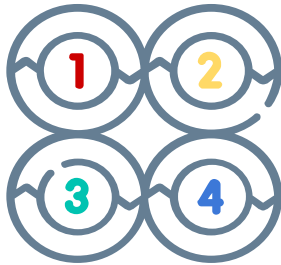
They do not reflect official positions of the U.S. National
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QUANTITY

We are producing more data than ever

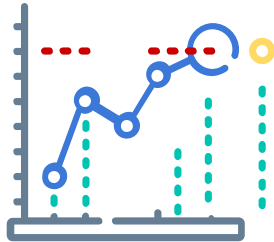
- Generation of data for research
- Electronic health records and associated data
- Commercial data



CHOICE

Opting out is often a false choice

- Participation in research drives potential benefit
- Use of technology and services no longer truly voluntary



RISK

Nature, consequences, and likelihood are contextual and rapidly changing

Still (mostly) focused on the individual

- Privacy, security, safety
- Individual benefit/risk

SOCIAL (GROUP) HARMMS



LATENT ISSUES:

STIGMA, BIAS, AND DISCRIMINATION

How do we measure and report on stigma, bias, and discrimination?

Who gets to decide what does and does not constitute stigmatizing research?

Is there any way to determine social harm prior to the research?

How do we separate intent and future use?

What are appropriate vehicles to regulate potential group and social harms?

How do we navigate conflicting interests, rights, and responsibilities?

How do we educate data users about, and hold them accountable for, their social responsibilities?

THANKS

*All of Us Research Program Policy Office
and ELSI Lab*

NIH Office of Science Policy
National Library of Medicine
NIH Stigma Special Interest Group
NIH Department of Bioethics
GA4GH REWS Workstream

ANY QUESTIONS?

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