

2019 OHRP EXPLORATORY WORKSHOP

Privacy & Health Research in a Data-Driven World

Live Webcast

Thursday, September 19, 2019 | 8:15 AM - 4:15 PM EDT

Webcast is open access and free of charge. A link will be provided closer to the event.

SESSION I

8:25 AM – 10:30 AM



Is Privacy a Casualty of Advancing Research?

The goal of this session is to explore the problem of privacy protection in a data-rich world, the tensions that exist between the societal good that could come from big data research and the real and perceived risks to individuals, as well as the public's perspectives about broad data sharing. Invitees will discuss the ethical considerations related to large-scale open data sharing including questions about data ownership, the types and goals of big data research that might be pursued, what needs to be done to maintain public trust in health research, and who are the people responsible.

SESSION II

10:55 AM – 1:00 PM



Approaches to Protecting Privacy & Confidentiality

Speakers representing diverse stakeholders in the research enterprise will discuss policies, techniques, and technologies for controlled use, data protection, and informed consent as ways to protect individual privacy and data confidentiality. The goal of this session is to explore the challenges of privacy protection for health-related big data research conducted on a variety of platforms and in various settings. Invitees will also consider the ethical and practical challenges posed by data-sharing across cultures and boundaries.

SESSION III

2:00 PM – 4:10 PM



Protecting Privacy & Confidentiality: A Shared Responsibility

The goals of this session are to discuss some of the challenges facing IRBs and institutions in the review of proposed data sharing options for research that falls under the Common Rule, and explore ethical oversight of big data research that falls outside the scope of the Common Rule. Invitees will explore the possible roles of a variety of stakeholders for supporting responsible conduct of research involving big data in addition to potential approaches to ethical evaluation of proposed big data research.

www.hhs.gov/ohrp/education-and-outreach/exploratory-workshop/2019-workshop/index.html

Videos of each session will be available on the OHRP website after the event



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