

# 2019 OHRP EXPLORATORY WORKSHOP

## Privacy & Health Research in a Data-Driven World

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

Live Webcast from Bethesda, Maryland

[www.hhs.gov/ohrp/education-and-outreach/exploratory-workshop/2019-workshop/index.html](http://www.hhs.gov/ohrp/education-and-outreach/exploratory-workshop/2019-workshop/index.html)

### AGENDA

Time	Sessions
8:15 AM – 8:25 AM	<b>Welcome and Introduction (OHRP)</b>
8:25 AM – 10:30 AM	<p><b>Session I: Is Privacy a Casualty of Advancing Research?</b>  <b>Moderator:</b> Jodi Daniel, J.D., M.P.H.; <i>Cromwell &amp; Moring LLP</i></p> <p>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. Panelists 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 responsible parties.</p>
8:25 AM	<p><b>Session I Introduction</b>            Jodi Daniel, J.D., M.P.H.; <i>Cromwell &amp; Moring LLP</i></p>
8:30 AM	<p><b>Reconsidering Research Ethics in Big Data Research</b>            Jacob Metcalf, Ph.D.; <i>Data &amp; Society Research Institute</i></p>
8:50 AM	<p><b>Striking a Balance: Benefit-Risk Analysis for Big Data Research</b>            Jules Polonetsky, J.D.; <i>Future of Privacy Forum</i></p>
9:10 AM	<p><b>Public Perspectives on Data Sharing and Privacy</b>            Cinnamon Bloss, Ph.D.; <i>University of California, San Diego</i></p>
9:30 AM	<b>Panel Discussion for Session I</b>
10:30 AM – 10:55 AM	<b>Break</b>
10:55 AM – 1:00 PM	<p><b>Session II: Approaches to Protecting Privacy &amp; Confidentiality</b>  <b>Moderator:</b> Mark Barnes, J.D., LL.M.; <i>Ropes &amp; Gray, LLP</i></p> <p>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. Panelists will also consider the ethical and practical challenges posed by data-sharing across cultures and boundaries.</p>
10:55 AM	<p><b>Session II Introduction</b>            Mark Barnes, J.D., LL.M.; <i>Ropes &amp; Gray, LLP</i></p>
11:00 AM	<p><b>Transforming Health Measurement and Care Delivery Through Patient-Generated, Permissioned Data from Daily Life</b>            Deborah Kilpatrick, Ph.D.; <i>Evidation Health</i></p>

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11:15 AM	<b>CMS Data Products</b> Andrew Shatto; <i>Centers for Medicare and Medicaid Services (CMS)</i>
11:30 AM	<b>The Vivli Experience in Sharing Clinical Trial Data Globally</b> Rebecca Li, Ph.D.; <i>Vivli</i>
11:45 AM	<b>The Use of 'Differential Privacy' as a Statistical Method for Protecting Confidentiality in Data Publications</b> Simson L. Garfinkel, Ph.D.; <i>US Census Bureau</i>
12:00 PM	<b>Panel Discussion for Session II</b>
<b>1:00 PM – 2:00 PM</b>	<b>Lunch Break (60 minutes)</b>
<b>2:00 PM – 4:10 PM</b>	<b>Session III: Protecting Privacy &amp; Confidentiality: A Shared Responsibility</b> <b>Moderator:</b> Elizabeth Buchanan, Ph.D.; <i>University of Wisconsin-Stout</i>  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.
2:00 PM	<b>Session III Introduction</b> Elizabeth Buchanan, Ph.D.; <i>University of Wisconsin-Stout</i>
2:05 PM	<b>IRBs and Big Data Research</b> Michael Zimmer, Ph.D.; <i>Marquette University (as of August 1)</i>
2:20 PM	<b>A Framework for Ethics Committees for Reviewing Research Protocols with Privacy and Confidentiality-Related Risks in Electronic Environment</b> Adarsh K. Gupta, D.O., M.S., FACOFP; <i>Rowan School of Medicine</i>
2:35 PM	<b>Facing the Future: Operational Solutions to the Regulatory Challenges of Big Data Research</b> Megan Kasimatis-Singleton, J.D., M.B.E., CIP; <i>Johns Hopkins University School of Medicine</i>
2:50 PM	<b>Ethical Considerations for the Review of Big Data Research Beyond the Common Rule</b> Jules Polonetsky, J.D.; <i>Future of Privacy Forum</i>
3:00 pm	<b>Shared Responsibility in Ethical Big Data Research</b> Jacob Metcalf, Ph.D.; <i>Data &amp; Society Research Institute</i>
3:10 pm	<b>Panel Discussion for Session III</b>
<b>4:10 pm – 4:15 pm</b>	<b>Closing</b>