

PCOR Privacy and Security Research Scenario Initiative and Legal Analysis and Ethics Framework Development Home

Announcements

No announcements yet.

Initiative Overview

The aim of this initiative is to determine how health information derived from a wide variety of data sources can be used for PCOR and comparative effectiveness research (CER), consistent with principles of ethics and legal and regulatory requirements related to patient consent, privacy, and autonomy.

- **Phase 1:**
 - Develop 15-20 research data use scenarios that pertain to PCOR and CER
- **Phase 2:**
 - Assess the legal, regulatory, and policy environment governing the use of health information for PCOR/CER
 - Develop a legal and ethics framework for protecting patient privacy during conduct of PCOR/CER

As a member of the stakeholder group, you will participate in the activities related to **Phase 1**, including:

1. Identifying research data use scenarios that are patient-centric and encompass PCOR and CER;
2. Identifying necessary policies and requirements to enable data use in research;
3. Defining the gaps and needs in policies and ethical and legal requirements; and
4. Identifying instances where technical components intersect policy requirements, referencing relevant technical specifications as needed.

Project Contacts

Please reach out to the contacts below if you have any questions about the initiative.

Contact Information	
Prashila Dullabh, Project Director	dullabh-prashila@norc.org
Ioana Singureanu, Data Scenario Analysis and Facilitator	ioana@eversolve.com
Daniella Meeker, PCOR Research Lead	dmeeker@usc.edu
Helen Caton-Peters, ONC Staff Lead	helen.caton-peters@hhs.gov
Lauren Hovey, Project Manager	hovey-lauren@norc.org
Gagan Jindal, Collaboration Site Contact	jindal-gagan@norc.org
Katherine Donaldson, Stakeholder Liaison	donaldson-katherine@norc.org

Meeting Schedule

**NOTE: All times below are in Eastern Standard Time.*

Workgroup Meeting	Date and Time
Meeting 1 (Kickoff)	Tuesday, December 1, 2015 3:00pm-4:00pm EST
Meeting 2	Wednesday, December 16, 2015 1:00pm-2:00pm EST
Meeting 3	Wednesday, January 6, 2016 1:00pm-2:00pm EST
Meeting 4	Tuesday, January 19, 2016 1:00pm-2:00pm EST
Meeting 5	Wednesday, February 3, 2016 1:00pm-2:00pm EST

Meeting 6	Wednesday, February 17, 2016 1:00pm-2:00pm EST
Meeting 7	Wednesday, March 2, 2016 1:00pm-2:00pm EST
Meeting 8	Wednesday, March 16, 2016 1:00pm-2:00pm EST
Meeting 9	Wednesday, March 30, 2016 1:00pm-2:00pm EST
Meeting 10	Wednesday, April 6, 2016 1:00pm-2:00pm EST
Meeting 11	Wednesday, April 20, 2016 1:00pm-2:00pm EST
Meeting 12	Wednesday, April 27, 2016 1:00pm-2:00pm EST

Recent space activity



Anonymous

[Research Data Use Scenarios](#) updated Oct 14, 2016 [view change](#)

[Use of a Registry That Includes Patient Reported Outcomes](#) updated Oct 14, 2016 [view change](#)

[Use Sensor Data for PCOR](#) updated Oct 14, 2016 [view change](#)

[Use of Genetic Biomarkers for PCOR](#) updated Oct 14, 2016 [view change](#)

[Combining Claims and Birth Records](#) updated Oct 14, 2016 [view change](#)

Space contributors

- [Gagan Jindal](#) (Jun 24, 2016)