

CDT To Bring Privacy Expertise to Consortium Coordinating New National Patient-Centered Clinical Research Network

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Deven McGraw, Director of the Health Privacy Project at CDT

The Center for Democracy & Technology (CDT) is part of the consortium selected by the Patient-Centered Outcomes Research Institute (PCORI) Board of Governors to serve as the Coordinating Center for a new national data network designed to enhance the nation's ability to conduct patient-centered comparative effectiveness research (CER). CDT will lead the privacy work for the consortium, which is led overall by the Harvard Pilgrim Health Care Institute.

"CDT is incredibly grateful to the Harvard Pilgrim Health Care Institute for including us in their proposal and to PCORI for selecting our consortium to carry out this important work," said Deven McGraw, Director of the Health Privacy Project at CDT. "Patients suffer most from a health care system that too often costs too much and delivers poor quality care. Robust, patient-centered comparative effectiveness research is key to reversing these trends. However, it will be essential to move forward with this research in a way that protects the privacy and security of sensitive patient data."

According to the [release from PCORI](#) [1], the Coordinating Center will provide technical and logistical support to the proposed new [National Patient-Centered Clinical Research Network](#) [2]. The initiative's goal is to improve the nation's capacity to conduct CER efficiently and learn from the healthcare experiences of millions of Americans by creating a large network of health data representative of patients from across the country.

PCORI, an independent non-profit organization authorized by Congress in 2010, plans to develop the national data network through the creation or expansion of up to eight health system-based Clinical Data Research Networks (CDRNs) and up to 18 Patient-Powered Research Networks (PPRNs) organized by groups of patients interested in participating in clinical research.

The directors of the Coordinating Center will be Richard Platt, MD, MS, Professor and Chair of the Harvard Medical School Department of Population Medicine at the Harvard Pilgrim Health Care Institute in Boston, and Robert Califf, MD, Vice Chancellor for Clinical and Translational Research, Director of the Duke Translational Medicine Institute, and Professor of Medicine in the Division of Cardiology at the Duke University Medical Center in Durham, N.C.

Other organizations that are part of the consortium are AcademyHealth, Brookings Institution, Center for Medical Technology Policy, Group Health Research Institute, Johns Hopkins University and America's Health Insurance Plans.

More information on the National Patient-Centered Clinical Research Network and the role of the Coordinating Center can be found on the [PCORI website](#) [3].

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[1] <http://pcori.org/2013/pcori-awards-9-million-contract-to-harvard-group-to-coordinate-national-patient-centered-clinical-research-network/>

[2] <http://pcori.org/funding-opportunities/improving-our-national-infrastructure-to-conduct-comparative-effectiveness-research/>

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