

Engaging Stakeholders to Develop a Patient-Centered Research Agenda for Chronic Kidney Disease in Delaware

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More than 20 million people over the age of 20 in the U.S. have Chronic Kidney Disease (CKD). These patients have multiple comorbid conditions and see numerous healthcare providers, making it difficult to manage the condition and delay disease progression. In order to promote coordination of care and improve patient outcomes, a CKD registry in development in Delaware seeks to join electronic health records of multiple sources. To support these aims, a team of patients, clinicians, and researchers will collaborate to gather information and facilitate Patient-Centered Outcomes Research (PCOR) based on the CKD registry.

This work is supported by a Eugene Washington PCORI Engagement Award from the Patient-Centered Outcomes Research Institute (PCORI). The award will fund two conferences and a community academic workgroup. The two-year project will inform outcomes of interest and additional data needs as well as solicit feedback on research designs, privacy issues and data sharing in the context of PCOR from patients, payers, and physicians in the CKD community.

The leadership team includes one patient, one dialysis nurse, one representative of a federally qualified health center serving a vulnerable population, one representative of the Delaware Academy of Medicine and two academic researchers. Patients and other stakeholders will be engaged in each phase of conference and workgroup development and implementation. The Value Institute at Christiana Care is the lead institution for this project. Other institutions include the Delaware Academy of Medicine, Henrietta Johnson Medical Center, Dialysis Patient Citizens, and the Delaware Chapter of the American Nephrology Nurses Association.

The first conference, “Partners in Research: Developing a Patient-Centered Research Agenda for Chronic Kidney Disease (CKD)” will be held at the Christiana Care Ammon Education Center on September 16, 2016. The conference will bring together stakeholders in the registry to discuss research questions and outcomes that matter to patients and stakeholders for the ultimate goal of improving outcomes for patients with CKD. Registration for the free conference is currently open, and all stakeholders are encouraged to attend. Transportation can be arranged if needed and breakfast and lunch will be served. The day will feature both speaker presentations and interactive working groups. The morning’s events include speakers highlighting the state of CKD both nationally and in Delaware, disparities in CKD, innovations in case management of chronic disease, and the importance of PCOR and community engagement in order to improve care. Working groups in the afternoon will focus on outcomes and research needs related to the registry.

For more information about the registry project, visit our website www.delaware-ckd.org.

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