Engaging patients to inform health policy research within a practice-based research network

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TOPIC/TARGET AUDIENCE: Researchers, Community Leaders, Citizens

ABSTRACT: The OCHIN (not an acronym) Practice-based Research Network has an established Patient Engagement Panel, which facilitates patient advising on grant proposal development, electronic health record tool innovation, and research activities. Building on this structure, OCHIN has developed a Patient Investigator role by designating individual patients as advisers on multi-year grant-funded research projects. Currently, OCHIN supports Patient Investigators on three projects evaluating the impact of Affordable Care Act Medicaid expansion on health insurance, healthcare utilization, health outcomes, and cost. The objective of this presentation is to describe a model for patient engagement in data-only studies not involving clinical intervention.

We developed a framework for multi-year engagement, including drafting a role description, reviewing and completing the Collaborative Institutional Training Initiative's research training, and developing a budget with appropriate compensation. Patient Investigators helped identify strategies to overcome barriers to their engagement during the preliminary data analysis phase of the projects, including: (1) ongoing training about the research process; (2) collaboration with research team about data analyses challenges, data interpretation, and manuscript development; and, (3) dissemination of research aims through presentations, audio interviews, and blogging. Through collaboration with Patient Investigators, we have identified engagement strategies that are effective in data-only studies.

OBJECTIVE(S): Define the Patient Investigator role and identify specific strategies to facilitate engagement in data-only studies. Describe challenges faced with the inclusion of Patient Investigators and solutions that worked for engagement in OCHIN research projects.

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