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Title

Enhancing patient engagement infrastructure to recruit maximum variation samples for health experiences research

Priority 1 (Research Category)

Qualitative research

Presenters

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Abstract

Background: Researchers and funders recognize value in engaged, multistakeholder research to successfully recruit diverse, representative patient participants. In the US, community health centers (CHCs) serve people regardless of their ability to pay, in populations with greater health inequities. As a CHC-focused practice-based research network, OCHIN has engagement infrastructure to promote inclusive participation among underrepresented communities. We describe infrastructure use, adaptation, and capacity building for in-depth qualitative patient interview recruitment in CHCs. Methods: In partnership with the Oregon Clinical and Translational Research Institute and Health Experiences Research Network, OCHIN applied an established, robust methodology to understand people's lived experiences of specific health conditions. Condition topics include 30-50 interviews synthesized and disseminated via publicly available web modules developed with module-specific stakeholder advisory boards; raw data are archived for future use. OCHIN partnered on 3 modules to lead CHC clinic-based and digital community recruitment. Results: Our first module on childhood cancer had low clinic recruitment return as a condition managed outside CHCs and difficult to identify for outreach. Digital recruitment return was high, especially when partnered with a community network. We scaled our community-partnered digital recruitment approach for an adolescent and young adult cancer module while taking an intensive clinic-based approach for a module on medications for opioid use disorder. Both approaches necessitated tailoring: enhanced relationship building, community champions, tool development, technical support, and problem-solving. We successfully completed interviews with 75 people comprising a wide range of identities, social and demographic characteristics, healthcare coverage, condition experiences, and treatment trajectories. Module advisory boards included OCHIN patient participants and CHC service providers. Communicating our approach and developing shared understanding and expectations with our research partners was essential in maintaining the time, resources, and relationships needed for effective engagement and recruitment. Conclusion: Adaptive, sufficiently resourced, relational engagement approaches built on existing

infrastructure facilitated inclusion of people who could share a wider variety of stories for more representative, inclusive health experience modules.