Health Experiences Research Initiative

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This five-year, qualitative study employs the Database of Individual Patient Experiences (DIPEx) approach to better understand patients’ experiences of pediatric oncology, congenital heart disease across the lifespan, and community experience with research. This methodology involves in-depth, patient interviews with a diverse sample of patients and caregivers. In addition to publishing results in peer-reviewed literature, findings are synthesized to produce web modules that include lay language summaries describing the range of patient experiences (illustrated with text, audio, or video clips of patient interviews) and raw interview transcripts are archived in a data repository of health experiences research. Thus, this project produces multiple tools that can benefit patients (patient education and support), providers (medical education) and researchers (data that can be used to support future research). The web modules can be accessed online at healthexperiences.org.

Potential Impact

By enhancing patient-centered research and improving the understanding of patient experiences, this study amplifies patients’ voices throughout the spectrum of clinical and translational research. In particular, the study engages those whose voices are less likely to be heard through the usual routes of engagement including children and the elderly; low-income patients; and racial/ethnic minorities. OCHIN has been included in this work to ensure safety net perspectives are included in the modules.

This study has the potential to provide information and support to patients and caregivers that is not otherwise available, and can serve as a unique resource for health care students and professionals, administrators, and policymakers.

In addition to public web modules, all qualitative data will be stored in a repository and can be utilized for secondary analyses (upon request). This information has the potential to inform current and future research.

Finally, this study seeks to build the infrastructure necessary to further expand the capacity of the U.S. Health Experiences Research Network (HERN) so that future health experiences modules can be developed.