

**TITLE:** Amplifying patient and caregiver voices in health experiences research

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**STUDENT SUBMISSION:** No

**TOPIC/TARGET AUDIENCE:** Topic: patient voice, health experiences Target audiences: public health professionals, researchers

**ABSTRACT:** Background/Purpose: Developed in 2001 by researchers at Oxford University, the Database of Individual Patient Experiences (DIPEx) methodology utilizes rigorous qualitative research methods to understand patient experiences with specific health conditions. The U.S. DIPEx chapter, Health Experiences Research Network (HERN), was launched in 2014. Methods: We are conducting in-depth qualitative interviews with patients and caregivers to understand the experiences of childhood cancer, adolescent and young adult cancer, treatment for opioid use disorder, and firearm injuries among Veterans outside of military service. Each module will include 35-50 interviews representing a diverse range of experiences. Results: Noted modules are still in development with initial themes being identified across interviews. Findings will be shared publicly via the HERN website ([www.healthexperiencesusa.org](http://www.healthexperiencesusa.org)). The aim is to create a resource for patients, caregivers, and other stakeholders. Each web-based module includes summaries that are illustrated with interview clips synthesizing the range of experiences. Qualitative data (e.g. interview transcripts) will be archived in a repository that will be available for secondary data analysis. Conclusions: The DIPEx methodology offers a mechanism for utilizing a time-tested, research-based approach to improve understanding of patient experiences, illuminate patient preferences, and contribute to the design and conduct of patient-centered research.

**OBJECTIVE(S):** Identify potential opportunities for amplifying patient and caregiver voices utilizing the Database of Patient Experiences (DIPEx) methodology and/or collaborating with the Health Experiences Research Network (HERN).

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