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Lived Experience in Health Care and Health Systems Research Handbook Provides an Advanced Roadmap for Meaningful Collaborations

Aurora, Colo (Aug. 17, 2023) – Partnerships between researchers and people with lived experience can lead to important, meaningful, and relevant research. It's important to ensure that research partnerships are a meaningful experience for everyone involved.

The Children and Youth with Special Health Care Needs National Research Network (CYSHCNet) published a free handbook aimed at helping researchers, families, and patients work collaboratively on research studies. This “how to” guide highlights the needs of patients and families and helps to ensure projects are co-created by a team where everyone’s input is valued and necessary.

Topics include:

- What are lived experience partners and why do we need them?
- Power dynamics in research partnerships
- Engaging, recruiting, and retaining diverse, underrepresented, and/or underserved children with special health care needs in clinical research
- Family-driven research and design, co-production, and project management
- Evaluations, ethics, and more!

This handbook is aimed at health systems research, yet written broadly to encompass any research that would benefit from including people with lived experience as co-investigators. Its intent is to help individuals form better partnerships within their research teams.

The handbook is available for free download here:

<https://cyshcnet.org/lived-experience-handbook/>

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About CYSHCNet:

CYSHCNet brings academic researchers and lived experience partners together to study the health care system issues that matter most to CYSHCN and their families. The national network is based in Aurora, Colorado. Learn more: <https://cyshcnet.org/>.

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