

6 PATIENT AND STAKEHOLDER ENGAGEMENT

Engaging participants is foundational to the work of PEDSnet and extends beyond patients and families to clinicians, researchers and health systems.

6.1 GUIDING PRINCIPLES

Guiding principles include:

- Patients and families are partners in all phases of the research process including: formulating research questions; defining essential characteristics of study participants, comparators, and outcomes; identifying and selecting outcomes for the population of interest, conducting and monitoring the research and disseminating and implementing the results;
- Patients are involved in network leadership positions; and,
- Patients are involved in decision-making about network participation in proposed studies.

6.2 FINANCIAL RECOGNITION

Many parent and stakeholder participants will be motivated by a desire to improve the research base and care processes that affect child health. How this is recognized is an important issue and in some cases, those engaged in a PEDSnet project will be recognized financially. Patients who contribute to PCORnet at large and to Network leadership roles are compensated if the participation requires sustained work effort.

6.3 ENGAGEMENT RESOURCES AND TRAINING

PEDSnet will develop the tools, training and support to enable patients, families, clinicians, researchers and health system leaders to interact throughout the research and implementation process. The initial focus of activities will be prioritizing resource development to support the needs of projects that are using PEDSnet resources. We anticipate that will include the research prioritization process, engagement design studios, training for patients and families in research, training for clinicians and researchers in co-production with patients and families, and training in community building to engage communities of individuals interested in PEDSnet.