Engaging the Voice of the Patient and Family as partners in Collaborative Research

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Agenda

• Quick Overview of PFCC
• Lessons learned on the new, collaborative way of research design—participatory research with patients and families as partners
  – PCORNET and PPRN
  – Vasculitis Patient Powered Research Network
University of Michigan Health System
PFCC Program

Program aims to create partnerships between patients/families and faculty/staff from the examination room to the board room, and from the classroom to the lab.

Program direction influenced by “patient and family-identified needs” to improve:

- Patient and Family Experience
- Staff and Faculty Satisfaction
- Safety
- Clinical Outcomes
- Facility Design and Operational Efficiency

- Research Design:
  Better able to identify patient and family needs;
  Factors key to satisfaction & quality of life;
  Desirable clinical outcomes
Impact of Patient-Family Partners

They Bring

- Experience
- Passion
- Another set of eyes
- Brain & Voice
- Data
- Information
- KNOWLEDGE
Hardwiring PFCC in Research Design
PCORI was created to fund comparative clinical effectiveness research (CER) that will provide needed evidence to help patients and their caregivers make better-informed decisions.

To facilitate more efficient CER that could significantly increase the amount of information available to healthcare decision makers and the speed at which it is generated, PCORI has invested in the development of PCORnet: The National Patient-Centered Clinical Research Network.
Patient Centered Outcomes Research Network

What is PCORnet???
Patients and Families as Partners

Set Expectations

Training and Education

Defining Role

Demonstrate Inclusion

Avoid Check Box Mentality

Training and Education
COLLABORATIVE RESEARCH

✓ Participatory Research

✓ Knowledge is most relevant if it is generated with the involvement of people living the reality of the problem

✓ Conducting research with participants (vs. on participants)

✓ A partnership between participants and researchers

✓ Shared control over the production, use, and dissemination of knowledge
PATIENT & FAMILY AS PARTNERS

✓ Be involved in defining research questions, designing the study and surveys, interpreting results, formulating recommendations, and devising dissemination plans

✓ In particular,
  ✓ Defining elements of patient-centeredness important for patient-reported outcomes
  ✓ Patient needs and factors key to satisfaction and desirable clinical outcomes
Patient Partners in Clinical Study Networks

Seek Sponsor
Define Success (Endpoint)
Design Study
Ethics Review
Study Leadership
Communicate

Identify Problem
V-PPRN Promise to Patient-Partners

Patient-partners are to be...

- Provided opportunities to engage
  - Given appropriate training, orientation, and education
    - Empowered to share ideas and opinions
      - Kept informed and have all questions answered
Patients

- We need options when standard therapies fail
- We need options for children and adults
- We need faster results
- We are willing to help find solutions

Researchers: We need engagement of patients to generate evidence to support the development of novel therapies

FDA: How do we get patients to help with drug and device development?
Example of Partnership on a Research Project

Research Council Member Expectations

• Attend 2-4 meetings per year
• Take part in the discussion
• Provide honest feedback about research ideas based on experience as a patient or caregiver
• Provide feedback on the Patient & Family Research Council (PFRC) process
• Opportunity for continued involvement in funded research studies
PATIENT PARTNERING TO DEVELOP AND VALIDATE PATIENT REPORTED OUTCOME MEASURE FOR NS

Gipson, Selewski, Troost, 2014
Lessons Learned

• Patients can and want to be involved in the study pipeline

• Patients and Researchers
  – Often speak different languages
  – May need translators/facilitators until they learn to speak a common language
  – Negotiate a new type of relationship

• Both researchers and patients
  – Get better with practice
  – Need advice
  – May benefit from mentorship