Henry Ford Health System

Patient-Engaged Research Center (PERC)

Johnson (PI) 1R24HS022417-04
Personalizing Care for Obese Patients in an Urban Health System

Agency for Healthcare Research and Quality
Advancing Excellence in Health Care
Overview

• Henry Ford’s
  • Patient Engaged Research Center
• Models for Engagement
• Patient Family Advisory Councils (PFAC*)
  • Head & Neck Cancer Clinic
  • Henry Ford Cancer Institute
  • Transplant Living Community
Engaging Patients and Caregivers in Care Redesign & Research
In 2014, Henry Ford received an 5 yr. /$5 million AHRQ grant to develop the infrastructure for Patient Centered Outcomes Research (AHRQ‐R24 HS022417).

Developed a 4 point Strategic Plan for the Center.
Who are Patient Advisors?

• Any role in which those who receive care work together with health care professionals to improve care for everyone.

• Advisors share insights and perspectives about the experience of care and offer suggests for change and improvement.
4 Patient Advisor Roles

- **Focus Group Advisors**: Participate in Focus Groups to share opinions on specific topics.
- **Research Advisors**: Partners in Research Question Development, Methods, Data Analysis and Dissemination.
- **E-Advisor**: Insights Virtual Community.
- **Henry Ford Advisors**: Bring Patient and Caregiver views/voices to Councils & Teams.
Flexible Model for Patient Engagement
Models for Patient Engagement

**Individual Advisors**

- 1-2 patients to join work team
- HFH employees lead and set agendas
- Patients are active members of team
- Agenda is set by HF Team with Patient Advisor input

**Patient and Family Advisory Councils (PFAC)**

- 15+ patient and family advisors create a new local or System team
- Patients lead team with HFH Champion to set agendas for work
- Agenda priorities are driven by patients
Patient and Family Participation with Providers

3 Clinical / Disease Based Councils
- Head & Neck Cancer
- Transplant
- Brain Tumor

5- Research Based Councils
- Head & Neck Cancer
- Transplant Community
- Precision Medicine
- LGBTQ Community
- NIH All of Us Research Program

3- Hospital Focused Advisory Councils

4 System Wide Councils
- Care Transitions
- Care Experience
- Cancer Center
- Education Hub

Patient Advisors on 24 Teams including: Quality, Ethics, Nursing Councils, Boards of Trustees.
Patient & Family Advisory Council Stories
Head & Neck
Patient & Family Advisory Council
Merging Clinical Improvement & Research

HFHS Advisors

**ENT Advisory Council**
- ~20 member PFAC
- 1st Meeting December 2014
- Planning & Charter
- Created a new patient resource guide
- Survivorship Clinic
- Access to Dental Resources
- Revised Care Flow
- Bio-Repository Consent

Research Advisors /Funding

- “What’s the SCOOP? Discovering Quality of Life Outcomes That Matter to Squamous Cell Carcinoma of the Oropharynx (SCOOP) Patients and Their Families”
- Pipeline to Proposal Award from Patient-Centered Outcomes Research Institute (PCORI)
- Comparative Effectiveness Research
  - Quality of Life
  - Rad. vs. Surgery/Chemo
  - Sentinel Lymph Node
Henry Ford Cancer Institute PFAC
Engaging a Patient/Family Advisory Council
Meaningful Work & Research

• The Cancer PFAC meets monthly and has a membership of 20 people representing:
  • Various cancer types and stages of treatment & remission
  • Both Patients and Caregivers are members
  • All committed to enhancing the Cancer patient experience

• Meeting Topics to date:
  • PFAC Strategic planning – setting the direction and identifying priorities
  • Cancer Building vision including discussion around wayfinding, arrival experience and first impressions.
  • Selection of Supportive Oncology Services
  • Developing a PCORI Precision Medicine research grant application

• Future Meeting Topics:
  • Care Pathways
  • Developing care roadmap
  • Building construction
Engaging a Patient/Family Advisory Council

Meaningful Work & Research

Strategic Planning Exercise and Insights:

- Patient Education Resources
- Patient/Caregiver Navigator
- A Place of “Zen”
- Personalized Medicine
- Roadmap to Care for each patient and their caregiver

PCORI: Eugene Washington Cancer Precision Medicine Award
TLC = Transplant Living Community
Developed by Patients-Lifestyle Management
Play Your “ACES”℠

• **Attitude**
  • Maintain a fighting spirit and positive outlook

• **Compliance**
  • Follow doctor’s orders and take medications as prescribed

• **Exercise**
  • Walk to stay healthy as part of your regular routine

• **Support Team**
  • Develop a team of family, friends, and community
Patient Centered Care Committee (PCCC) \(\rightarrow\) Patient/Family Advisory Council (PFAC)

- PCCC Established in 2010
  - Staff driven with participation of patients
  - Founding dynamics:
    - Collaborative responsibility for success
    - Communication pathway
    - Evolutonal growth and partnerships
    - TLC integrated with multiple care teams
    - Favorable patient/family satisfaction report
    - Complementary care continuum dynamics with sustained culture change

- Patient Engaged Research Center (PERC) helped re-structure PCCC
  - Charter creation, approval and signing
  - Name changed from PCCC to PFAC
  - Reinvigorated TLC group with purpose
  - Defined patient advisor roles
  - Brought core concepts from PCCC to life
  - PFAC shift was more patient-driven, patient-centered
PCORI Funding: “Transforming the Gift of Life into a Transplant Living Community”

**Tier I Goal:**
To formalize TLC by creating a PFAC to engage with Henry Ford Transplant Institute personnel and community stakeholders to facilitate patient/family engagement and implement patient-driven concepts. We aimed to identify strategies that are most effective and broadly applicable to a variety of chronic diseases in order to facilitate other programs with PFAC implementation.

**Tier II Goal:**
Build on our Tier I outreach and engagement success and expand our stakeholder outreach to regional groups in order to conduct a participant survey, “What I Wish I Knew,” to inform the creation of comparative clinical effectiveness research questions and then conduct a literature search on key topics from the survey data.
Summary

• A Strategic Plan & Senior Leadership Support are key to creating a framework for success

• Collaboration with patients and families leads to innovative solutions and opportunities to both redesign care and conduct research
  • Creating formal PFACs validates the importance of including the patient and caregiver perspectives

• A flexible patient advisor engagement model meets the needs of all stakeholders (patients, families, researchers, providers and senior leadership)
Acknowledgements

Patient Engaged Research Center
• Chris Johnson, PI
• Heather Olden, Engagement Core Coordinator
• The Patient Engaged Research Center Team

The Head and Neck Patient and Family Advisory Council
• Steven Chang, MD FACS, Physician Champion
• Amy Williams, Staff Psychologist
• Sue Hill, Registered Dietitian

The Henry Ford Cancer Center Patient and Family Advisory Council
• Becca Blanken, Champion

The Transplant Living Community / Henry Ford Transplant Institute Patient and Family Advisory Council
• Elizabeth Rubinstein, Patient Advisor, TLC Leader
• Kelly Collins, MD, Physician Champion