Patient & Family Advisory Councils (PFACs) at Academic Medical Centers and Research Engagement

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Funding Statement

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Road Map

- Project Overview.
- PFACs at other Academic Medical Centers.
- Engaging PFAC members in research:
  - Value
  - Barriers
  - Strategies and activities to support engagement.
HOMERuN sites:
15 hospitals, 9 states
Project Objectives

- Create Patient and Family Advisory Council (PFAC) for Hospital Medicine Research Network - HOMERuN.

- Specifically we want to engage patients, family members, caregivers throughout the research process so they can provide their perspective and their voice on HOMERuN’s research efforts and activities.

- Learn best practices for engaging PFAC members in research.
Sub-Study Aims

- Interview, focus group and observational qualitative study to:
  
  - Learn how Academic Medical Centers operationalize PFACs.
  
  - Describe the value and benefits of patient engagement in research.
  
  - Identify barriers and challenges to PFAC members engaging in research.
  
  - Identify activities to support engagement.
Study Methods

- Invited stakeholders from HOMERuN sites to participate.

- In-person site visits to Brigham & Women’s Hospital, Christiana Care and University of Pennsylvania to meet PFAC members/leaders and learn about PFAC structures.

- In–person outreach across UCSF PFACs (DGIM, Lakeshore, Palliative Care, Patient Experience).

- Focus groups and interviews conducted in-person or over the telephone.

- Interviews recorded and then professionally transcribed.
Study Participants

- 80 stakeholders participated from:
  - University of California San Francisco
  - Brigham & Women’s Hospital
  - Christiana Care Health System
  - University of Pennsylvania
  - Vanderbilt University Medical Center
  - University of Michigan
  - University of Chicago
  - University of Kentucky
  - University of Washington
Study Participants

- 80 stakeholders participated:
  - 45 PFAC members (patient, family members, caregivers)
  - 12 PFAC leaders
  - 12 patient experience/hospital leaders
  - 11 researchers
Participants and Data Collection

Focus Group #1
8 PFAC members
1 PFAC leader

Focus Group #2
3 PFAC members
1 PFAC leader
1 researcher

Focus Group #3
5 PFAC members
1 PFAC leader

Focus Group #4
9 PFAC members
2 PFAC leaders

Focus Group #5
7 PFAC members
1 PFAC leader

Focus Group #6
4 PFAC members

Focus Group #7
9 hospital leaders

Focus Group #8
9 PFAC members

19 Individual Interviews

7 PFAC leaders

3 Hospital Leaders

9 Researchers
PFACs at Academic Medical Centers
PFACs: Brigham & Women’s Hospital

- PFACs managed and PFAC members supported centrally by Center for Patients & Families.
Steering Committee

14 In-Person PFACs
- Hospital site
- Service line
- Condition specific

8 In-person Research PFACs
Study specific

Advisors-at-large
PFACs: Brigham & Women’s Hospital

- **Steering Committee** – overarching committee managing and supporting PFACs across institution. Members CMO, CNO, Director Center for Patients & Families, Senior Patient Advisor and 14 Patient Advisors.

- **In-person PFACs** – NICU, Emergency Department, Obstetrics, Women’s Health, General Medicine, Sleep Apnea, LGBTQ, hospital site specific, Patient and Family Nurse Education.

- **Research PFACs** – transition of care, falls study, research ethics, high risk surgery.

- **Advisors-at-large** - advisors on specific committee e.g. Hospital Medicine quality improvement, patient experience, ethics committee.
PFACs: Brigham & Women’s Hospital

- **Advisor Orientation** – volunteer services, vaccinations, badges.

- **Advisor Training** – overview of patient and family centered care, BWH philosophy, background of patient and family centered care at BWH, hospital tour

- At advisors first meeting accompanied by Senior Patient Advisor and Staff Liaison to help navigate and settle in to PFAC role.

- PFAC Annual Report including list of accomplishments and successes.
PFACs: Christiana Care

- Managed and Supported through Patient Experience Department
Patient Experience Department

- In-person PFACs
  - 9 PFACs

- E-advisors
  - >1000
PFACs: Christiana Care

- **In-person** – many self governing by patient and family advisors.

- **E-advisors** – online closed Facebook group where feedback and questions posed. Exploring other online forums.

- Volunteer training, vaccinations, badges.

- Patient Experience staff match PFAC advisors to research teams based on skills, experience and interest.

- PFAC Annual Report and list of accomplishments, celebrate successes.
PFACs: Vanderbilt University Medical Center

- Managed and Supported through Patient Experience Department
PFACs: Vanderbilt University Medical Center

- **Advisory Council Cabinet** - overarching committee
- **In-person PFACs** – hospital site specific, behavioral health, patient safety. C-suite leadership attend each in-person PFAC (rotating basis)
- **Advise Vanderbilt** – online e-advisors to engage more members of community
- **Patient Advisors-at-large** – involved range of committees (e.g. patient education council, food services, strategic directions)
- Advisors linked to research projects
- Orientation – volunteer services, vaccinations, badges
- Celebrate successes, annual reports and awards
PFAC: University of Pennsylvania
Single council

25 council members

Co-chairs = Penn employee and patient advisor (fixed term)
PFAC: University of Pennsylvania

- In-person – large group format
- Hospital wide issues, service line issues, operational issues
- C-suite and other high level management attendance
- Advisors consulted about research and quality improvement
- Orientation – volunteer services, vaccinations, badges
- Celebrate successes
Engaging PFAC members in research
Value of engaging PFAC members in research

- Makes research and research outcomes more patient centered.
- Increase relevance of research to patients in their health decision-making.
- Reveals psycho-spiritual-social determinants of health.
- Empowers patients.
- Moral obligation.
Codes

- Distrust of research
- Fears of feeling useless
- Tokenism
- Questioning value of research
- Eliciting individual voices
- Lack of skills and experience (patients)
- Lack of skills and experience (researchers)

Category

- Individual PFAC member reluctance
- Lack of skills & training
- Problems connecting with the right PFAC member at the right time
- Lack of diversity
- Issues with recruitment and sustaining engagement
- Time commitment
Codes

- Compensation for time and expertise
- Knowledge of PFAC members skills and interests
- Consistent and ongoing engagement
- Equalizing roles
- Building community
- Being authentic and building trust
- Information in clear, plain language
- Expectation setting
- Being specific with required tasks
- PFAC member and researcher training

Category

- Creating an environment where PFAC members make a unique and meaningful contribution
- Building community between PFAC members & researchers
- Best practice activities for researchers to facilitate engagement
- Tools & training
Co-investigators:
UCSF – Andrew Auerbach, Wendy Anderson, Gina Symczak, Jim Banta, Sherry Chen, Jonathan Duong
BWH – Maureen Fagan, Martie Carnie, Jeff Schnipper, Celene Wong
Christiana Care – Edmondo Robinson
University of Michigan – Cathy Hanson
Reflections & Questions.....