4th Annual
Patient & Family Advisory Council (PFAC)
Conference
Strengthening Patient and Family Engagement in Massachusetts Hospitals

Join the conversation and tweet with us at @PFAC2016
This session

1. What we’ve learned about you
2. Panel Discussion
   What PFACs are doing
3. Pod Discussions
   How consumers are getting involved
Research “201”

What we learned...

Only 10% were familiar, but 42% were interested
Interviews conducted with 8 “research-engaged” PFACs

- Considerable variation
- Only two have systematic approach to selection
- Individuals serving (some “by accident”) and becoming sole consumer contact
- Research Advisory Council (no PFAC engagement)
- Little to no preparation for engagement
HCFA plans: Encourage Meaningful Engagement in Research

• At least 20% of PFACs will report individual and/or PFAC engagement in research-related activities (design, implementation and dissemination of research)
  
  • Create a Best Practices Guide (along with a self-assessment tool)
  • Provide consulting/coaching or training to 5-10 PFACs requesting services
    • Help identify their own goals for research engagement
    • Provide samples of meaningful research engagement via website resources.
  • Maintain lists of hospitals’ ongoing research in order to encourage involvement
  • Host webinar on research activities
  • Host 2 sessions at the PFAC conference on research activities
PFAC learns about research being conducted/results

PFAC participates in occasional activities (surveys/focus groups)

PFAC regularly joins research project advisory committees

PFAC regularly engaged in design, implementation and dissemination of numerous research initiatives

PFAC engaged in concept, decision making in numerous research initiatives

Level 1
Low level of involvement and influence

Level 2

Level 3
Mid level of involvement and influence

Level 4

Level 5
High level of involvement and influence; joint decision making

Communicating

Listening

Consulting

Engaging

Partnering

Adapted from: Born K, Laupacis A. Public engagement in Ontario’s hospitals—opportunities and challenges. Health Q. 2012;15 Spec No:16-20
Working Criteria for Meaningful PFAC Engagement

**Systematic** - a process by which
- member(s) are chosen as potential consumer representatives to study
- PFAC helps researchers identify qualified and interested advisors
- members report back to the PFAC about their work
- PFAC staff help orient and prepare PFAC members

**Ongoing** - involvement is not isolated to one activity or event on the study

**Meaningful** - engagement goes beyond attending meetings, and includes specific activities in
- Planning the study
- Conducting the study
- Disseminating the study results
Consumer Engagement in Research: How are PFACs Engaged in Improving Research at their Institutions

Anna G. Symington, Alexis Snyder, Celene Wong
Objectives

- Define three critical components of PFAC engagement in research
- Begin to plan ideas for PFAC engagement in research
Consumer Engagement in Research

Anna G. Symington
Consumer Engagement in Research

Alexis Snyder
How Our PFAC Became Engaged in Research

Integrated PFAC into hospital projects and committees which enhanced components of PFAC engagement that aligned with core values of PCOR

- Collaboration
- Communication
- Reciprocal Learning
- Trust and Transparency
Establishing Strong Engagement with Leadership Led To:

Discussion with Research Director

Council Members Asked To Partner in Research

Successful Submission of PCORI Engagement Award

Active Participation and Full Partnership on Project
Success
True Partnership on Current Project

- Design, implementation and dissemination

- Co-learning between researchers and patients

- Collaboration on new proposal/addition of youth partner

Challenge
Integrating PFAC Beyond PCORI
- Including PFAC in research that may not require patient/caregiver engagement
Recommendations

Build Strong Engagement in Hospital Activities and Committees

Reach Out and Explore Current Research at Hospital: Express Support and Ask How PFAC Can Play a Role Now and/or on Future Projects
Consumer Engagement in Research

Celene Wong
Why Involve Patients in Research?

- Brings important perspectives from end users
- Inspires and energizes research staff
- Keeps research staff grounded
- Provides iterative process to aims and research question
- Brings connectivity of lived experience to the research question
- Offers opportunity for qualitative analysis in addition to existing quantitative methods
- Contributes to dissemination process & education of general public and/or relevant patient populations
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Research 201: How are Patients and Family Representatives Advising Researchers in Massachusetts?

• You will be able to attend 3, 12-minute discussions
• There are 7 tables in total
• At the end of each discussion, please move to a new table
• Three types of involvement (different tables will focus on different aspects)
  • Design
  • Implementation
  • Dissemination
Research 201: How are Patients and Family Representatives Advising Researchers in Massachusetts?

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<th>STAGE</th>
<th>Name</th>
<th>Design</th>
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