Creating, sustaining and growing PFACs in NICU

Lelis Vernon - S.Q.I.L
Introduction
Lived experience: NICU mom, NICU family. Family Advisory Council 2008-12
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Definition

A patient and family advisory council (PFAC) is an organization of current and former patients, family members and caregivers that works together to advance best practices at a hospital or healthcare organization.
The functions of PFACs

**Advising**
Council members advise on projects, policies, and change initiatives presented by hospital staff.

**Implementing**
Council members identify and implement agreed-upon projects.

**Sustaining FCC in the NICU**
Scalable/ Self-sustaining provision of family voices to council

**Hybrid: A/I**
Council members advise on projects, policies, and change initiatives and implement Council-based projects
The values of PFACs

- Promote and sustain Patient- and Family-Centered Care pillars
- Patients and Families are essential allies for quality and safety
- Qualitative real-time feedback
- Provision of perspectives that differ from internal staff perspectives;
- Incorporation of the family experience into all aspects of health care operations;
- Creation of a venue to “walk the talk” of mission statements (i.e., “patients and families at the center of care”);
- Aid in the development of effective patient safety and quality initiatives;
- Creation of efficiencies in which FAC input identified “right-fit” policies and practices for patients and families.

Meanwhile, at today's meeting on feline healthcare...
Characteristics of PFACs

- **Venue**:
  - Hospital-Wide
  - Unit-Based

- **Authority**:
  - Parents Advise Multiple Perspectives
  - Parents Vote Recommendation
  - Members Vote Input Binding
  - Staff/Parents Vote Input Binding

- **Membership**:
  - Parent of a Current Patient
  - Parent of a Chronically Ill Child
  - Advisors Only
  - Advisors and Staff Members

- **Training**:
  - Hospital Orientation
  - One Time FAC Orientation
  - Monthly Training FAC Debrief
  - Tiered Advisory/Leadership Training
Challenges

- Budgeting, creating a niche for family leader
- Aligning family and administration expectations regarding function, scope, and authority;
- Sustaining family and provider interest in the work;
- Balancing staff and family input;
- Assuring equal voice among family participants;
- Assuring FAC engagement in meaningful work;
- Accommodating to the slow process of change in health care settings;
- Marketing the FAC within the unit
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Get ready!

Clinical

- Inform leadership of need for PFAC (bring the evidence! show the numbers!)
- Inform unit of PFAC formation
- Designate staff liaison
- Venue (NICU grads included?)
- Secondary liaison
- Media and tech tools

Family

- Identify/ welcome family
- Clear Family Partner (FP) with volunteer department
- Receive education/training (Unit based)
- Receive education/training (FP role)
- Hold "onboarding" meeting
- Feedback
- Meet with leadership/staff
Where are the FPs?

Brochures (advertise)
Interviews (EBCD?)
Focus Groups
Feedback
Customer-Facing Employees
NICU Reunions

Surveys
Phone calls
Reviews
Who are the FPs?

Families who had a NICU experience

- Are coping well with their NICU experience
- Are able to leave their NICU grad to attend meetings
- Are willing to talk about their experiences and can effectively share insights and information
- Demonstrate a passion for improving health care for others
- Have the ability to listen well, respect the perspectives of others, interact with many different kinds of people, and work in partnership
- Enjoy working with others, show a positive outlook on life, and bring a sense of humor
- Represent a broad cross-section of your hospital's population
Our FPQC family team
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Family Partners by the numbers

Volunteers: 55%
>5 years: 75%

Variations in:
- LOS
- Outcome
- Time lapse after d/c

Sustainability and Scalability:
- Engagement of community groups (post pandemic)
- "Virtual" expansion
- "Back to the Future" effect of COVID
Compensation

**VOLUNTEER**

Hospital PFAC Membership
(May include expense reimbursement)

- **$15/hour**
  - Select Hospital PFA Committee

- **$20-50/hour**
  - Working Groups and Webinars for Hospitals

- **$100-300 Gift Card**
  - Webinars, Workshops, Patient Panels

- **$175/hour**
  - Research Project Teams

- **$1,800 Stipend**
  - Measure Development Teams, Consulting Interviews, Focus Groups

- **$250/hour**
  - Co-Investigator Roles

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**Compensation Preferences**

65% of PFAnetwork members preferred cash or check compensation for Advisory efforts. Gift cards, food, and donations were also preferred.

Bar chart showing preferences:
- Cash or Check: Highest preference
- Gift Card
- Charitable Donations
- Meals

Prezi
IPFCC survey 2021

PFAC Prevalence

The majority of children's hospitals have at least one PFAC

- 88% Hospitals with at least one PFAC
- 8% Hospitals with a PFAC in development

Many hospitals have multiple PFACs

- 15% 1 PFAC
- 31% 2-4 PFACs
- 14% 4-5 PFACs
- 40% 6+ PFACs

PFAC History

Many children's hospitals have a long history with PFACs

In interviews, specific influential leaders often cited as forces behind PFAC development

- 51% < 1 year
- 24% 1 to 5 yrs
- 21% 6 to 9 yrs
- 4% 10+ yrs

PFAC Adaptations Due to COVID-19

- 86% Meeting virtually
  - 86% of PFACs had met at least once since March 2020
- 84% Meeting frequency
  - 84% of PFACs anticipated meeting as frequently as before the pandemic
- 72% Meeting attendance
  - 72% of PFACs reported attendance at meetings was the same as or better than before the pandemic
- 27% PFA involvement in COVID committees
  - 27% of hospitals involved PFAs on pandemic planning and response committees
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Thank you!

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