



MacColl Institute at
Group Health Cooperative

Establishing Patient and Family Advisory Councils in the Medical Home

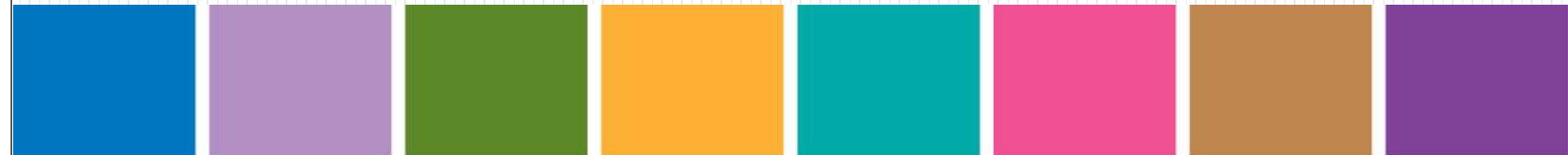
Moderators:

Nicole Van Borkulo, MEd, Qualis Health

Judith Schaefer, MPH, MacColl Institute for Healthcare Innovation at Group Health

Speaker:

Juliette Schlucter, Bridgekeeper



BRIDGEKEEPER



Partnerships for quality healthcare

Establishing Patient and Family Advisory Councils in the Medical Home

Juliette Schlucter

Patient and Family-Centered Care Consultant

We had a moment last year when patients were instructors at a collaborative learning session for a day and everyone was asked “Think what isn’t going well.” Everyone came up with essentially the same list. Then they asked, “What would help it get better?” Patient and family advisors came up with things like a list of questions to prepare for the visit, taking notes during the visit, and making sure everyone is on the same page. You could see the light go on in the clinicians and see their acceptance of patient voice not as critic, but as partner, take hold.”

Alan Glaseroff, MD
Humboldt IPA

Our Objectives

- 1. Define strategies for creating a collaborative council including the recruitment, training and mentoring of patients and families to serve in advisory roles.
- 2. Discuss how to integrate the patient and family perspective in system-wide operational goals.
- 3. Share ideas for goal setting, agendas and implementation strategies to move the collaborative process forward.

Key Elements in Engaging and Sustaining Patient Advisor Programs

- A clear purpose.
- Infrastructure for recruitment, preparation and supporting of advisors.
- Facilitating the collaborative process.
- Actionable goals.
- Broad sharing of accomplishments.
- Honoring partnerships.

(In patient and family feedback) there were things like, “I want to know, if my provider has changed, who my provider is for that day when I walk in the door. Really simple things, important things.

Debra Rosen, QI Manager
Northeast Valley Health Corporation

Clear Purpose

- “Our organization values a model of shared decision making between patients, families and health care professionals to guide individual interactions and for the design and implementation of care delivery.”
- The logistics of how, who and when will change over time but the commitment to this purpose should not.

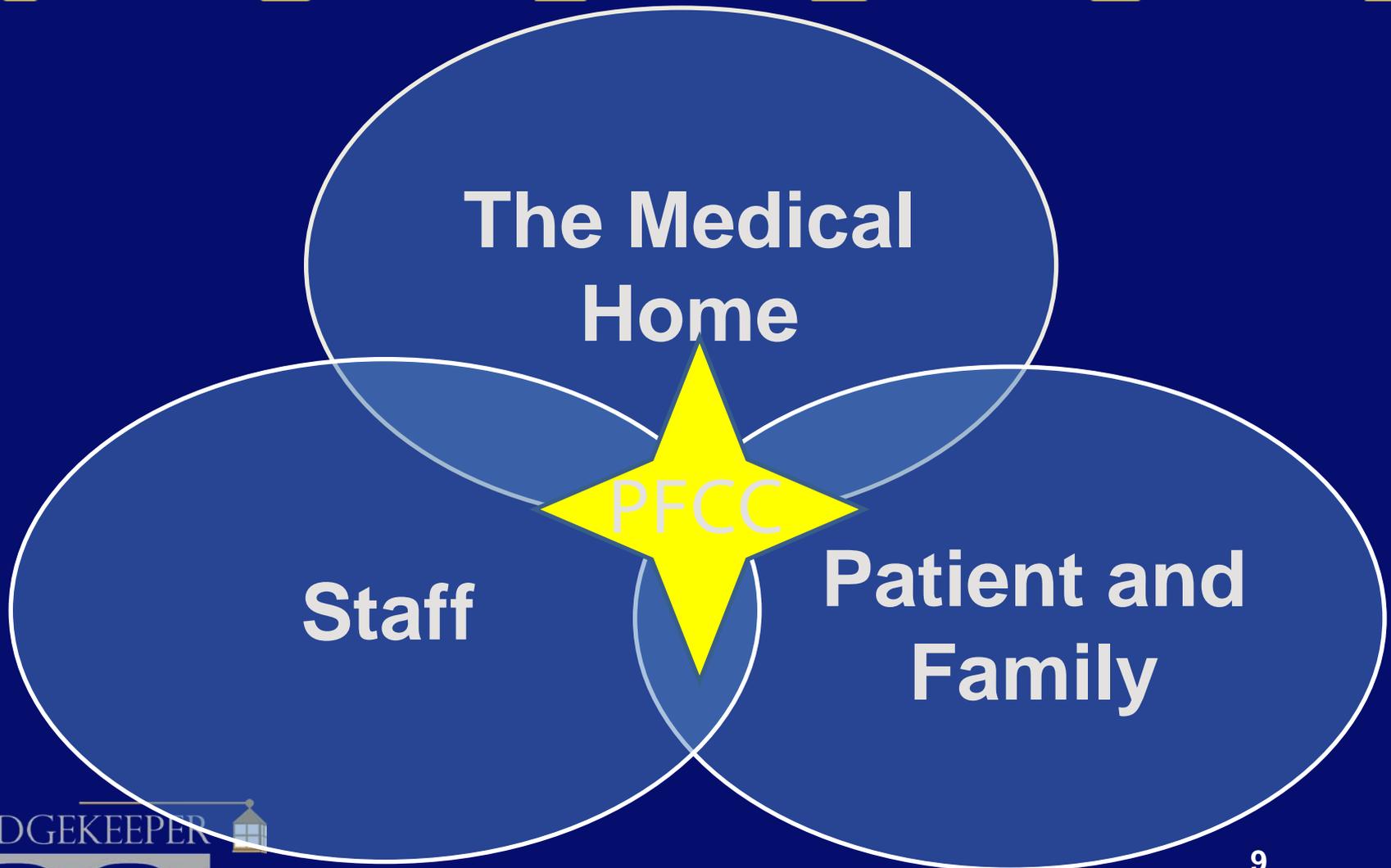
Why Patient and Family Advisors?

- Essential partners for creating the ideal patient/family/staff health care experience.
- Critical to shaping a PFCC culture.
- Provide patient and family perspective from lived experiences.
- Authentic voice marries the rhetoric with reality.

Patient and Family-Centered Care

- Patient- and family-centered care places emphasis on **mutually beneficial partnerships** between patients, families and healthcare professionals.
- It acknowledges that families, however they are defined, are essential to patients' health and well-being and are allies for quality and safety within the health care system.
- Core Concepts:
 - Respect and Dignity
 - Information Sharing and Communication
 - Participation
 - Collaboration

Model of Collaboration to Advance Patient- and Family-Centered Care



Acknowledges Unique Pressures

Patients & Families

- Diagnosis
- Lack of Sleep
- Worry
- Medical Jargon/World
- Uncertainty
- Staff
- Environment

Staff

- Time
- Resources
- Education
- Safety
- Bandwidth
- Families
- Administrative responsibilities
- Internal dynamics

Organization

- Budget constraints
- Staffing
- Juggling multiple high priorities
- Community Needs vs. Individual or Group
- Long vs. Short Term
- Regulations

3 Keys to Effective Collaboration

- Common purpose or goal
 - A shared and articulated vision
- Equal Voice
 - Fair and balanced – “an even playing field”
 - As important for staff as well as patients and families.
- Laboring together for the best solution
 - Validation of challenges
 - Finding overlapping interests
 - Relational thinking – “how will this feel to other stakeholders?”

Barriers to Successful Collaboration

- The right people are not in the room
- Ineffective meeting facilitation
- Lack of leader/decision maker involvement
- Stakeholders are in the dark
- Moving too slowly

Comments/Questions/Experiences

I think what our patient and family liaisons did well was to frame everything in terms of an opportunity for patient and family advisors to expand their own skills. They found a facilitation guide about how to facilitate your own meetings. They framed it as an invaluable skill you can use in your own life and the patient advisors we have are very interested in that.

Ellen Chen, MD
San Francisco General
Family Medicine



Recruitment and Training of Patient and Family Advisors and Mentoring the Collaborative Process

Qualities to Look For

- Thoughtful and collaborative nature.
- Representative of the families you serve.
- Ability to share their story in ways that are respectful and affirming.
- Sensitive to other points of view
- Respectful of staff, fellow advisors and the mission of the council.
- Relevant experience.

Recruitment

- The benefits of starting small.
- The pros and cons of open recruitment vs. staff referrals.
- Seek range of diagnosis and use of medical home services.
- Seek diversity of race, culture, gender and family composition.

3 Key Questions for Application and/or Interview

- Describe a day-in-the-life of a recent visit to the Medical Home.
- Describe something that works well for you at our medical home.
- Describe something that does not work well for you and share with us how you would improve it.

The Advisor Interview

- **What staff needs to know:**
 - The Advisor's medical home experience; what worked well, what would have improved the experience.
 - The Advisor's commitment and motivation.
 - Special needs of advisors
- **What Advisors need to know:**
 - Goals and standards of program.
 - The value they will bring to Council.
 - Commitment required of them and support they can expect from you.
 - Honorarium and other benefits (parking, child care)

Council Membership

Staff

- Leaders
- Multi-discipline
- Clinical and non-clinical
- Front-line representation
- Nursing
- Physician

Patients and Families

- Diversity considerations:
 - Culture
 - Socio-economic
 - Gender
 - Diagnosis
 - Services Used
 - Family Position (sibling, grandparents)
 - Language needs

Ideas for Training Advisors

- Opening remarks from Senior Staff member
- Mission and vision
- Program goals and standards
- Key concepts of Patient and Family-Centered Care
- What makes for good collaboration
- Describing A Day-in-the-Life of a Patient and a Healthcare Professional at the Medical Home.
- Other training ideas

The Work of the Council Is...

- Based on patient and family perspective and...
- The medical home's current operational goals and priorities...
- To advance patient safety, quality, and a culture of patient and family-centered care.

"We have had a patient advisory council at Inner City Health Center for a little over 1 year now. Our group is made up of about 10 individuals from multiple ethnic backgrounds: (Caucasian, African American, Mexican, Pakistani, Argentinean, Russian, and Ethiopian) We also have a member who is physically disabled and wheelchair dependant. The group discusses many issues related to the services and access at Inner City Health Center. They give both positive and negative feedback and suggestions for improvement which we try to act on as a health center. They were recently involved in giving input to our patient satisfaction survey. They have given us input about how to better "advertise" our services and have offered to and in some significant cases, served as ambassadors for Inner City Health Center to help with both fundraising and helping future patients learn of the services we provide. Developing a Patient Advisory Council took a considerable amount of effort in choosing our council members and learning how to best utilize them, but it has paid off abundantly in giving us new insights into our services as well as discovering a cadre of enthusiastic volunteers!"

Heather Cutillo RN, CDE
Diabetes Care Coordinator
Inner City Health Center

The Council Is

- Not a support group
- Not a grievance committee
- Not a staff meeting
- Not a “show and tell” forum

Typical Meetings

- Monthly
- Two to two and a half hours in length
- Typically early evening (5:00 to 7:00)
- Meet over dinner
- Prepared agenda
- Paid parking and in some cases stipend/honoraria.

Meeting Guidelines

- Maintain blend of sharing perspectives and staying focused on an outcome.
- Limit agenda to two to three items.
- Articulate objectives for each agenda item.
- Use a “parking lot” to capture great ideas for future meetings.
- Finish on-time!!

Setting Agendas

- Staff share priorities, pressures and resources of the medical home.
- Advisors share perspective, experience and priorities.
- Transparent view of patient/family/staff satisfaction.
- Ensure time for problem solving.
- Create opportunities for innovation...blue sky approach.

Openly Share Strategy, Operational Goals and Limitations with Staff, Patient and Family Leaders

- You can not be an effective collaborator if you are in the dark.
- Organization must commit to transparency about goals, and limitations.
- Be mindful of hidden agendas.
- Make it safe for all to share experiences, ideas and explore solutions.

Patient and Family-Centered Care Meeting

Date: _____

Start / End Time: _____

Meeting: _____

Location: _____

Facilitator: _____

Recorder: _____

PARTICIPANTS:

Agenda Topic	Discussion Goals	Action / Follow-Up	Responsible Person(s)

Examples of Collaborative Work on a Council

- Effective Team Communication
- Infection Control
- Improving the Waiting Experience

Mentor Collaboration During the Meeting

- Be sure everyone knows who is in the room.
- If possible, send written materials including agendas ahead of meeting so participants can prepare.
- Use the agenda as your facilitators guide to:
 - Clarify goals.
 - Stay “on task”
 - Confirm next steps
- Make sure everyone has an opportunity to share their point-of-view.

Role of Leaders and Staff

- Share medical home strategy, operational plans and priorities with staff and patient and family advisors.
- Identify available resources.
- Create an expectation that projects, policies and plans move forward more effectively through collaboration with patients and families.
- Close the loop on next steps.
- Share collaborative work broadly with colleagues.
- Think out-of-the box.

Role of Patients and Families

- “Be the patient/family.”
- Be able to reflect on and establish priorities from a patient/family point of view.
- Prepare as much as possible for meetings in advance.
- Think out-of-the-box.
- Mentor new patient and family advisors.

Concerns Advisors May Have

- “Will change really happen?”
- “How will decisions be made?”
- “What is the ‘Group Think’?”
- “How will I contribute?”
- “Will my voice matter?”

Concerns Staff May Have

- “I studied family theory...I have years of experience with patients, I’ve been a patient...Why can’t I represent the point of view of the patient and family?”
- “We invited patients before and it turned into a grievance session?”
- “Who will make the decisions?”
- “Will my voice matter?”

Sharing Multiple Points-of-View

- Give voice to all members
 - “Tell me how this would feel to you?”
 - “What would improve the experience?”
 - “What concerns would this raise?”
- Make sure meetings are jargon-free
- Support the debate

What Not To Say

- Avoid drawing lines between you and other stakeholders: “Us vs. Them”
- Avoid large generalizations: “No one cared.” “No one communicated.” “The nurses here...” “Families never....”
- Avoid using a specific person or department’s name when offering an example about something that didn’t go well.

Guidelines and Boundaries

- Confidentiality
 - What you hear and learn about staff, patients and families is always maintained as confidential.
- Wearing two hats --
 - Dynamics can feel different when you come to the Medical Home as a patient or family and the day before you were in meetings with the very people now providing care for you or your loved-one.
 - Everyone needs to make a commitment to respect the complexity of those two roles.
- We all have boundaries for what we are willing to share. It is OK to say “I am not prepared to talk about that today” or “I don’t think I am the best person to answer that question.”

Sharing the Council and Sustaining Success

- Broadcast work of the Council
 - In staff publications
 - In patient and community publications
- Incorporate bringing work to the council in performance measurement and goals.
- Honoring Advisors
 - Annual luncheon
 - Certificates, small tokens.
 - Press release to advisors' local papers.

Comments/Questions/Experiences

(In patient and family feedback) there were things like, “I want to know, if my provider has changed, who my provider is for that day when I walk in the door. Really simple things, important things.

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Northeast Valley Health Corporation



Make Things Happen!

Plan Thoughtfully but Act Swiftly

- Swift action
 - Create tangible results for effort as early on as possible. Especially for “low-hanging fruit.”
 - The easy and obvious.
- Longer term projects
 - Illustrate incremental progress along the way.
 - Openly share the complexity of issues and justification for delays.
- Document Progress
 - Use monthly progress reports to track accomplishments.

Creating Momentum

- Share accomplishments with internal and external communities.
- Use every opportunity, verbally and in print, to underscore the collaborative process is “how business is done.”
 - “Patients, families and staff evaluated this policy and together recommend these guidelines...”
 - “Patients, families and staff developed these communication tips...”

Benefits of Collaboration for Advisors

- Opportunity to “give back” to a care center and community.
- Ability to use your first-hand experience to improve quality of care, safety and services for future patients and families.
- Opportunity to develop leadership and collaborative skills.
- Ability to serve as a role model/mentor for new patient and family advisors and the community.

Benefits of Collaboration to Medical Home

- Permanent and strategic partnership with patients and families.
- Ongoing access to patient perspective.
- Shared decision making positively impacts patient/family and staff experience.
- Meets IOM goals for health care in the 21st Century.

Value of Patient and Family-Centered Collaboration

- Improved patient safety
- Improved quality outcomes
- Improved experience of care
- Decrease in malpractice litigation
- More effective utilization of resources
- Improved staff experience

Keys To Sustaining Collaborative Culture

- Execute!
- Tie collaboration to vision and values of medical home.
- Have collaboration be a part of staff goals and performance.
- Document administrative details and create programmatic infrastructure including role of staff advisor liaison.
- Broadcast work and success.

When aligned around shared values and united in a common mission, ordinary people accomplish extraordinary results.

Ken Blanchard

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