




**INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE**

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**Proven Practices for Developing Patient and Family Advisors and Leaders**


Beverley H. Johnson  
*Leading the Way: Patients and Families as Leaders in Health Care Transformation*  
 Portland, OR  
 January 19, 2012

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**In our time together . . .**

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- ▼ Identify ways to improve health care by investing in patient and family advisors or member advisors.
- ▼ Discuss the infrastructure necessary to ensure effective, sustained involvement of patient and family advisors or member advisors.



**Patient- and Family-Centered Core Concepts**

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- ▼ People are treated with **respect and dignity**.
- ▼ Health care providers communicate and share complete and unbiased **information** with patients and families in ways that are affirming and useful.
- ▼ Patients and families are encouraged and supported for **participation** in care and decision-making at the level they choose.
- ▼ **Collaboration among patients, families, and providers occurs in policy and program development and professional education, as well as in the delivery of care.**




**A Key Lever for Leaders . . . Putting Patients and Families on the Improvement Team**

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*In a growing number of instances where truly stunning levels of improvement have been achieved...*

*Leaders of these organizations often cite—putting patients and families in a position of real power and influence, using their wisdom and experience to redesign and improve care systems—as being the single most powerful transformational change in their history.*

Reinertsen, J. L., Bisagnano, M., & Pugh, M. D. *Seven Leadership Leverage Points for Organization-Level Improvement in Health Care*, 2<sup>nd</sup> Edition, IHI Innovation Series, 2008. Available at www.ihi.org.




**Collaboration**

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“Collaboration means that no one interest group is always right. It means taking what you think, and what I think, and what someone else thinks, and coming up with something that works for everyone.”

Bev McConnell Crider  
 From: *Essential Allies: Families as Advisors*



### Leadership Best Practices

- ▼ Create the expectation for partnerships with patients and families in all settings as a quality and safety strategy . . . AND involvement in change and improvement initiatives from the beginning.
- ▼ Appoint a staff liaison for collaborative endeavors, an individual with strong facilitation skills and access to organizational leaders.
- ▼ Ensure that there is a comprehensive plan to recruit, orient, and prepare advisors and the staff working with them.
- ▼ Create a variety of ways for patients and families to serve as advisors.
- ▼ Invest in patient and family leadership development.
- ▼ Ensure that there is a system in place to track collaborative initiatives and measure the impact.



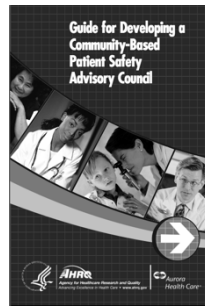
### Creating Medical Homes and Obtaining Certification and ACO's

Leaders Link Patient- and Family-Centered Care Advances and Related Partnerships with PCMH Certification Pathway and the Development of ACO's

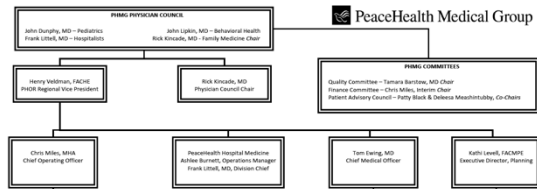


### Leaders Commit to Learning about Strategies for Effective Collaboration

<http://www.ahrq.gov/qual/advisorycouncil/>



### PeaceHealth Medical Group, Eugene, OR



Organization Chart refers specifically to the Patient Advisory Council and its reporting relationships



### MCG Neuroscience Pilot Unit and the Results 2004-2010

Patient Advisor Attends National Meetings with Staff Team



- ▼ Patient Satisfaction – 10th to above 90th percentile.
- ▼ Length of stay decreased – 50% in Neurosurgery.
- ▼ Reduction in medical error by 62% for 2004-2006; 65% for 2006-2010.
- ▼ Discharges (volume) increased 15.5%.
- ▼ Capacity for continuous improvement.
- ▼ Staff vacancy rate – 7.5% to 0%; 5-7 RN's on waiting list.
- ▼ Change in perceptions of the unit by doctors, staff, and house staff.



### The Province of Saskatchewan

In 2007, conducted *Patient First Review*, and in 2009, patient- and family-centered care became the standard of care for the entire province of Saskatchewan.

Health Ministry invested in education for patient- and family-centered practice across the province with patients/clients/residents and families part of the process.

Provincial annual strategic plans with targets and expectation developed by the Health Ministry and its partners.

Conveyed expectation for the establishment of steering committees with patient and family advisors to develop a 10-year implementation plan for acute and non-acute care settings across the province.



## Contra Costa Regional Medical Center and Health Centers, Martinez, CA

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Patients and families influenced the entire process —from the initial decision to focus on behavioral health, to the timing of changes, to developing ideas for rapid cycle improvements.

*"There was a prevailing concern that bringing patients and families into the room would change the conversations. This is true; it has changed the conversations for the better, a centering force that grounds us in reality. We are engaging in discussions that were out of reach for our organization previously."*

Anna Roth, CEO



## Getting Started

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## Involving Patients and Families as Advisors

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*"Get started before you are ready."*

Jim Anderson  
Former President and CEO  
Cincinnati Children's Hospital Medical Center



Recipient of the 2006 AHA McKesson  
Quest for Quality Prize



## Why involve patients and families as advisors?

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- ▼ Bring important perspectives.
- ▼ Teach how systems really work.
- ▼ Keep staff honest and grounded in reality.
- ▼ Provide timely feedback and ideas.
- ▼ Inspire and energize staff.
- ▼ Lessen the burden on staff to fix the problems... staff do not have to have all the answers.
- ▼ Bring connections with the community.
- ▼ Offer an opportunity to "give back."



## Address the Mental Barriers — Challenges for Leaders

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- ✓ We don't have time for this.
- ✓ Patients, families, and members will hear the negatives about our organization.
- ✓ We don't want to air our dirty laundry.
- ✓ This is nice to talk about, but...
- ✓ Patients/families and members just don't understand our system.
- ✓ They will want things that cost too much and we'll have to tell them "no."
- ✓ We are not a hotel; we are here to save lives.
- ✓ We need to be better organized.



## Wellspan's 2<sup>nd</sup> Patient-Centered Medical Home Collaborative with AF4Q Community Practices

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The Overarching Goal is to advance toward NCQA Certification . . .

- ▼ Learn PCMH competencies.
- ▼ Learn Lean concepts.
- ▼ Work QI projects such as improving diabetes or pulmonary outcomes.
- ▼ Develop Patient Partners.

Karen E. Jones, MD, FACP, Medical Director of Quality and Innovation, WellSpan Medical Group, WellSpan Health and assisted by AF4Q Patient Partners Coordinator, Kathy Hutcheson



### Wellspan's 2<sup>nd</sup> Patient-Centered Medical Home Collaborative with AF4Q Community Practices

Summer of 2011

- ▼ Gave guidance to practices for identifying two Patient Partners to join each practice team in the collaborative.
- ▼ Suggested that each practice have a staff liaison for these partnerships.
- ▼ Had phone conversations with each of the nominees.
- ▼ Provided Patient Partners with 1/2 day orientation on a Saturday on PCMH and Lean.
- ▼ Shared concerns expressed by practices with Patient Partners — "Patient Partners will see us at our worst; this collaboration will slow us down."

... continued



### Wellspan's 2<sup>nd</sup> Patient-Centered Medical Home Collaborative with AF4Q Community Practices (cont'd)

- ▼ Following orientation with Patient Partners, held a conference call with practices. Updated them on progress, and shared Patient Partner concerns— Patient Partners were worried that they would have nothing to contribute.
- ▼ There are five Learning Session dinners throughout the year of the collaborative. Patient Partners attended the September Learning Session and will attend future dinners.
- ▼ Monthly calls are held with practices... (didn't include the Patient Partners in first call, and realized right away they should have).



### Wellspan's 2<sup>nd</sup> Patient-Centered Medical Home Collaborative with AF4Q Community Practices (cont'd)

- ▼ Monthly calls held with Patient Partners for support and clarification.
- ▼ Monthly meetings with coaches, practices, and the Patient Partners are now ongoing.
- ▼ Patient Partner Dinner recently held in preparation for the 2<sup>nd</sup> Learning Session Dinner.



### Recruiting Patient, Family, and Member Advisors



At the beginning . . .

Identify some initial, tangible ways to involve patients and families before beginning a formal recruitment process.


### Qualities and Skills of Successful Patient and Family Advisors



- ▼ The ability to share personal experiences in ways that others can learn from them.
- ▼ The ability to see the "big" picture.
- ▼ Interested in more than one agenda issue.
- ▼ The ability to listen and hear other points of view.
- ▼ The ability to connect with people.
- ▼ A sense of humor.
- ▼ Representative of the patients, families, and members served by the hospital, clinic, or health plan.

### Recruiting Patient and Family Advisors

- ▼ Ask staff and physicians for suggestions.
- ▼ Contact support groups and community organizations such as Rotary, Kiwanis, fire stations, and religious organizations.
- ▼ Ask current patient and family advisors.
- ▼ Call or send a mailing to patients and families.
- ▼ Ask patients/families during an ED or clinic visit or during a hospital stay when appropriate.
- ▼ Post signs/brochures on bulletin boards in waiting areas, corridors, and lobbies.
- ▼ Place notices in the clinic's, hospital's, or nursing home's publications, websites, and TV systems.
- ▼ Post information on [Twitter](#) and [Facebook](#).



### Share Your World!



- Participate in improvements for patients and their families
- Share your personal perspective
- Improve the pregnancy and childbirth experience for UWMC patients




*Be a Patient or Family Advisor!*

To Learn More:  
Contact Hollis Ryan at 206-598-2697 or pfcc@uw.edu

LW Medicine  
UNIVERSITY OF WASHINGTON  
MEDICAL CENTER

### Patient & Family Advisors Needed!

I value your perspective and our partnership. I'd like you to consider becoming a Patient/Family Advisor. Advisors volunteer to help us with program/policy review, review education materials and forms, provide input on quality and safety efforts as well as facilities planning. We are also using patient advisors to help design better processes of care.

Would you be interested in volunteering to be on a Patient Family Advisory Council? Please contact Sheila Miller at 687-6283 to get more information about this unique opportunity.


Sincerely,

**Peace Health Medical Group**


### Peace Health Medical Group Eugene, OR

### A Recruiting Tool


<b>Qualities of an Advisor:</b> <ul style="list-style-type: none"> <li>• Shares insight and experience in productive ways</li> <li>• Sees beyond his/her own personal experience</li> <li>• Respects diversity and differing opinions</li> <li>• Listens well</li> <li>• Collaborates on solutions</li> <li>• Has passion for enhancing the healthcare experience of all</li> </ul>	<b>Important Considerations:</b> <ul style="list-style-type: none"> <li>• Current PeaceHealth Medical Group patient and/or family member</li> <li>• Make commitment for 1 year at minimum</li> <li>• Willingness to attend information session to learn more in mid-September</li> <li>• Ability to attend monthly meetings on the fourth Thursday from 5:30 - 7:30 pm, starting in October</li> </ul>
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### Patient, Family, and Member Advisors Prepared for Success



### Statewide Patient Experience Conference



Oswalda Davila, Patient Advisor, on a panel in a plenary session for a Statewide Conference sponsored by the California HealthCare Foundation — January 2011



### NEVHC Preparing and Supporting Patient and Family Advisors

"I want to thank the Council for having me part of this work. When I share information about the changes we are making at the clinic with my family and friends in the community, I feel better about myself as a diabetic trying to manage my condition."




Oswalda Davila, Patient Advisor

### High Plains Research Network (HPRN) Community Advisory Council, Colorado

- ▼ Since 2003, the Community Advisory Council has participated in all aspects of the HPRN research.
- ▼ An all day “boot camp” is held prior to working on a project. Projects have included:
  - Testing to Prevent Colon Cancer in Rural Colorado
  - Asthma Toolkits and Community Asthma Integration and Resources (AIR) (Asthma awareness and management)
  - Under-insurance
  - Patient-centered medical home
  - Patient harm/medical mistakes
- ▼ For further information: Westfall, J. M., VanVorst, R. F., Main, D. S., & Herbert, C. (2006). Supplemental case report: Community involvement in a practice-based research network. *Annals of Family Medicine*, 4(1), 8-14. Retrieved from <http://www.annfammed.org/cgi/data/4/1/8/DC1/>

### High Plains Research Network (HPRN) Community Advisory Council, Colorado (cont'd)



Connecting with the Gun Club . . .

### High Plains Research Network (HPRN) Community Advisory Council, Colorado (cont'd)

“The Community Advisory Council has made our research ten times better, much more relevant to the communities we serve. In addition, it’s a lot of fun to work with the Community Advisory Council.”

Jack Westfall, MD, MPH

### New Zealand Preparing Advising for Collaboration in Improvement

Tools and Practical  
Guidance for  
Collaboration



### Fostering a Successful Beginning: Orienting Patient and Family Advisors

- ▼ Mission, Values, Priorities of the QI Team, Unit, Clinic, or Hospital
- ▼ Speaking the Language—Medical Jargon 101
- ▼ Who’s Who in the Organization or on the QI Team
- ▼ Hospital/Clinic Tour
- ▼ “Day in the Life”
- ▼ Council Meeting Attendance Expectations
- ▼ Roles and Responsibilities
  - Patient, Member, and Family Advisors, Staff

### Fostering a Successful Beginning: Orienting Patient, Family, and Member Advisors

- ▼ How to be an effective advisor
  - How to ask questions
  - What to do when there is a disagreement
  - Listening and learning from other’s viewpoints
  - Thinking beyond your own experience
  - Sharing your story
  - Telling “negative” stories in a positive way
  - The impact of anger

### Fostering a Successful Beginning: Orienting Staff

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- ▼ Designate someone to serve as a connection/ liaison for other staff and advisors.
  - Able to answer questions and support advisors in their new roles.
  - Assist in communicating activities of the advisors to other staff and leaders.
- ▼ Be a patient- and family-centered “champion.”



### Fostering a Successful Beginning: Orienting Staff (cont'd)

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- ▼ Explain how staff should be involved.
  - The importance of listening.
  - Effective approaches to meeting facilitation.
- ▼ Be open to questions and challenges.
- ▼ Try not to be defensive.
  - Respond/explain without being defensive.
  - Defensiveness usually has a negative effect.




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### Keeping Collaborative Endeavors Active, Growing, and Successful



### Conducting Effective Meetings

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- ▼ Spend extra time on introductions.
- ▼ Begin some meetings with patient and family stories.
- ▼ Discuss the concept of collaboration explicitly at the beginning of a new endeavor and assess how it is working at the end of meetings.
- ▼ Stay on the agenda.
- ▼ Avoid using jargon.
- ▼ Encourage the participation of patient and family advisors, validating their role as committee members.
- ▼ Plan proactively for challenging situations.
- ▼ Establish ground rules for conducting meetings.



### What keeps collaborative endeavors active, growing, and successful?

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- ▼ Advisors feel they are being listened to.
  - If something cannot be done, they are told why.
- ▼ Advisors feel they are making a difference. They are involved in specific projects.
- ▼ Staff and other patients and families are aware of these collaborative activities.
- ▼ Skills and talents of advisors match the needs of the organization and it's work.



### What keeps collaborative endeavors active, growing, and successful?

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- ▼ Meetings are enjoyable and productive.
  - Agendas are not too long.
  - Meetings are of substance and value.
  - Real work occurs and constructive changes are made.
- ▼ Leaders recognize and value the contributions.
- ▼ Genuine openness and transparency exists.
- ▼ Organization celebrates successes.



## What keeps collaborative endeavors active, growing, and successful?

- ▼ Invest in leadership development of patient and family advisors and member advisors.
  - Provide mentors or co-facilitate meetings with advisors learning new skills.
- ▼ Send them to meetings and conferences for continuing education.
  - Include them on teams with health care professionals or send them to meetings that are primarily consumer-led.
- ▼ Invite them to participate in organizational meetings where they will learn about policy, programmatic, and strategic issues.
- ▼ Debrief with advisors following key meetings.



## Cambridge Health Alliance Cambridge, MA



### Celebrating and Thanking Patient and Family Advisors

This organization, serving the immigrant gateway communities near Boston, holds a Thanksgiving turkey dinner with all the trimmings to celebrate and thank patient and family advisors.



## Chatham-Kent Health Alliance Chatham, Ontario



CEO participating in the Annual Celebration of patient and family advisors, their work, and their annual report



## Changing the Culture of Health Care Within an Organization and Across the Continuum of Care . . .

A Journey, not a Destination

Partnering with Patients  
and Families is Key

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- Reinersten, J. L., Bisognano, M., & Pugh, M. D. (2008). Seven leadership leverage points for organization-level improvement in health care (2<sup>nd</sup> ed). Cambridge, MA: Institute for Healthcare Improvement. (Available at [www.ihl.org](http://www.ihl.org))
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