Developing Patient and Family Partnerships in Practice Transformation

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Objectives |

- Discuss how to transform primary and ambulatory care practices into high quality and satisfying experiences through partnership with patients and families at the point-of-care and at beyond.
- Explore the roles that patient and family advisors can play to improve quality and safety.
- Share best practices demonstrated across primary and ambulatory care programs, their success and challenges.



"People will forget what you said. People will forget what you did. But people will never forget how you made them feel."

~Maya Angelou

Scenario A

"You need to freeze your eggs."

"You are 18

- this is

your last

visit."

"We need the room for another patient."



Outcomes of Clinic Visit

Young Adult Patient

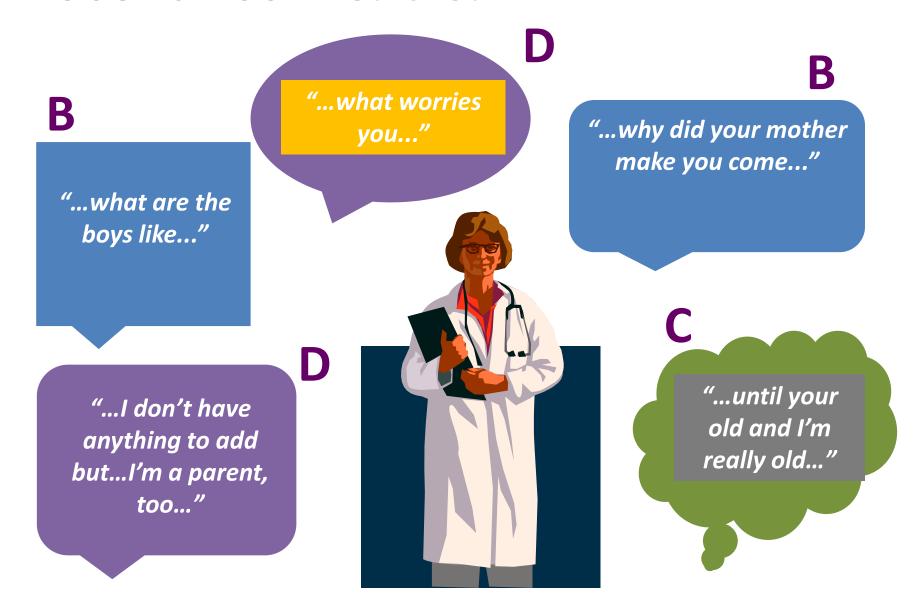
- Confused
- Humiliated
- Unimportant
- Closed-mouthed
- "I am done..."

Mom

- Disrespected
- Angry
- Minimized
- Failure
- "We are done..."

"Doctor was only in the room for a couple of minutes."

Scenarios B & C & D



Outcomes of Clinic Visits

Patient

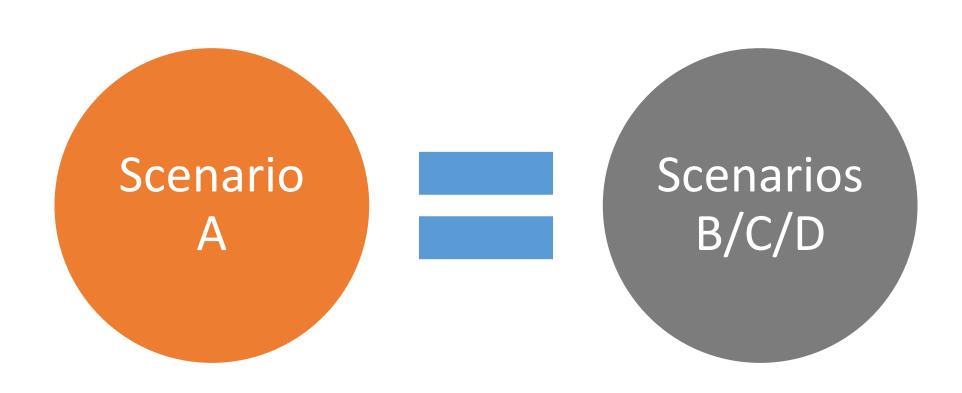
- Felt like a kid not a disease
- Felt reassured
- Felt listened to
- Felt the compassion
- "I liked him/her..."

Mom

- Validated
- Respected
- Hope
- "A good mom"
- "I would recommend..."

"Doctors took all of the time that they needed to take with us."

In all reality... TIME does not have to be limiting





What is Patient- and Family Centered Care?

Partnerships based on Respect & Dignity, Information Sharing, Participation, and Collaboration







Patient- and family-centered care is working "with" patients and families, rather than just doing "to" or "for" them.



Patient- and family-centered care provides the framework and strategies to **transform organizational culture** and improve the experience of care, and enhance quality, safety, and efficiency.



Transforming Healthcare: A Safety Imperative

"We envisage patients as essential and respected partners in their own care and in the design and execution of all aspects of healthcare. In this new world of healthcare:

Organizations publicly and consistently affirm the centrality of patient-and family-centered care. They seek out patients, listen to them, hear their stories, are open and honest with them, and take action with them.

... Continued

Leape, L., Berwick, D., Clancy, C., & Conway, J., et al. (2009). Transforming healthcare: A safety imperative, *BMJ's Quality and Safety in Health Care*. Available at: http://qshc.bmj.com/content/18/6/424.full



Transforming Healthcare: A Safety Imperative (cont'd)

The family is respected as part of the care team—never visitors—in every area of the hospital, including the emergency department and the intensive care unit.

Patients share fully in decision-making and are guided on how to self-manage, partner with their clinicians and develop their own care plans. They are spoken to in a way they can understand and are empowered to be in control of their care."





'Blockbuster Drug' Patient Engagement

"Engagement, broadly defined, is an active partnership among individuals, families, health care clinicians, staff, and leaders to improve the health of individuals and communities, and to improve the delivery of health care."

Health Affairs, 32(2) 2013



Collaborative Patient and Family Engagement

Collaborative patient and family engagement is a **strategy for building a patient- and family-centered system of care**. It is a priority consideration and essential to health reform at four levels:

- ➤ At the clinical encounter—patient and family engagement in direct care, care planning, and decision-making.
- At the practice or organizational level—patient and family engagement in quality improvement and health care redesign.
- ➤ At the community level—bringing together community resources with health care organizations, patients, and families.
- At policy levels—locally, regionally, and nationally.



Drivers: Essential to Achieving TCPI Aims

TCPI AIMs/Goals

- 1) Practice Transformation. Evidence of a culture of quality where the vision is clear and data is used to drive continuous improvement in quality, outcomes, cost of care and patient, family and staff experience.
- 2) Effective solutions moving to scale. Evidence of practice spreading effective improvement strategies to full scale for the entire population under its care
- 3) High Clinical Effectiveness: Practice is effective in bringing all patient segments to their health status goals.
- 4) Reduced Avoidable Hospital Use: Rates of readmission and unnecessary admissions for practice's patients have been reduced.
- 5) Reduced Unnecessary Testing & Procedures: Practice demonstrates a reduction in unnecessary testing and in the use of the ED by its patient population.
- 6) Reduced costs: Practice controls its internal costs as well as other elements of total cost of care.
- 7) Documented Value: Practice can articulate its value proposition and increases participation in available value-based payment agreements.

Primary Drivers Secondary Drivers 1.1 Patient & family engagement 1.2 Team-based relationships 1.3 Population management **Patient and Family-**1.4 Practice as a community partner **Centered Care Design** 1.5 Coordinated care delivery 1.6 Organized, evidence based care 1.7 Enhanced Access 2.1 Engaged and committed leadership Continuous. Data-2.2 Quality improvement strategy supporting a culture of **Driven Quality** quality and safety **Improvement** 2.3 Transparent measurement and monitoring 2.4 Optimal use of HIT 3.1 Strategic use of practice revenue **Sustainable Business** 3.2 Staff vitality and joy in work **Operations** 3.3 Capability to analyze and document value 3.4 Efficiency of operation

Change The Assumptions



Assume *patients* are the *experts* on their own experience and that they have information *you* need to hear and act on.

Know that **families** are **primary partners** in a patient's experience and health.



Partnering with Patients and Families at the Point-of-Care

What do Patients and Families Expect...

- To receive high-quality, safe care
- To be listened to, taken seriously, and respected as a care partner
- To have full and timely access to medical information
- To have coordination among all members of health care team across all settings
- To always be told the truth with full explanations, transparency and apology
- To be supported emotionally as well as physically

Challenges of Patients and Families

- Cognitive
- Emotional
- Social
- Financial
- Spiritual



Learning Through Surveys e-Advisor Survey, 2014

What do families want at clinic appointment?

- Ample time spent with physician
- Short wait to get to exam room.
- Short wait to see physician.
- Pleasant and helpful greeting.

"I did appreciate the note on the board stating how far behind the doctor was running. It was a long wait but we appreciated having the heads up."

Learning Through Surveys e-Advisor Survey, 2010

What makes an unpleasant clinic appointment?

- Long waits (over an hour)
- Not being heard
- Lack of follow through
- Repeating story multiple times
- Needing to go to multiple locations to see different people when scheduling surgery
- Unpleasant or rude greeting
- Leaving the clinic with no plan
- Driving a distance only to have minimal time with the physician

Learning Through Surveys e-Advisor Survey, 2010

What Makes a Positive Check-in Experience?

- Responsive staff who are friendly, pleasant, and sincere (appropriate smile and eye contact)
- Prepared greeter staff who know who you are and why you are there.
- Staff that do not make us feel that you are inconvenienced by us.
- Staff who listen to our concerns.
- For pediatric patients, staff who talk to our child and/or are ready with distraction activities.

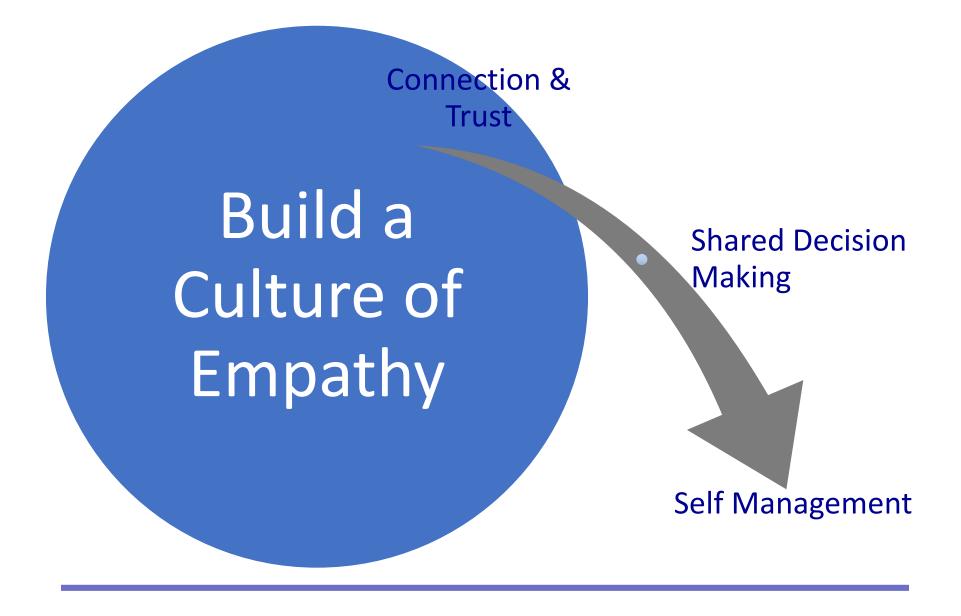
"First impressions mean a lot."

Provider-Family Partnerships Improve Care

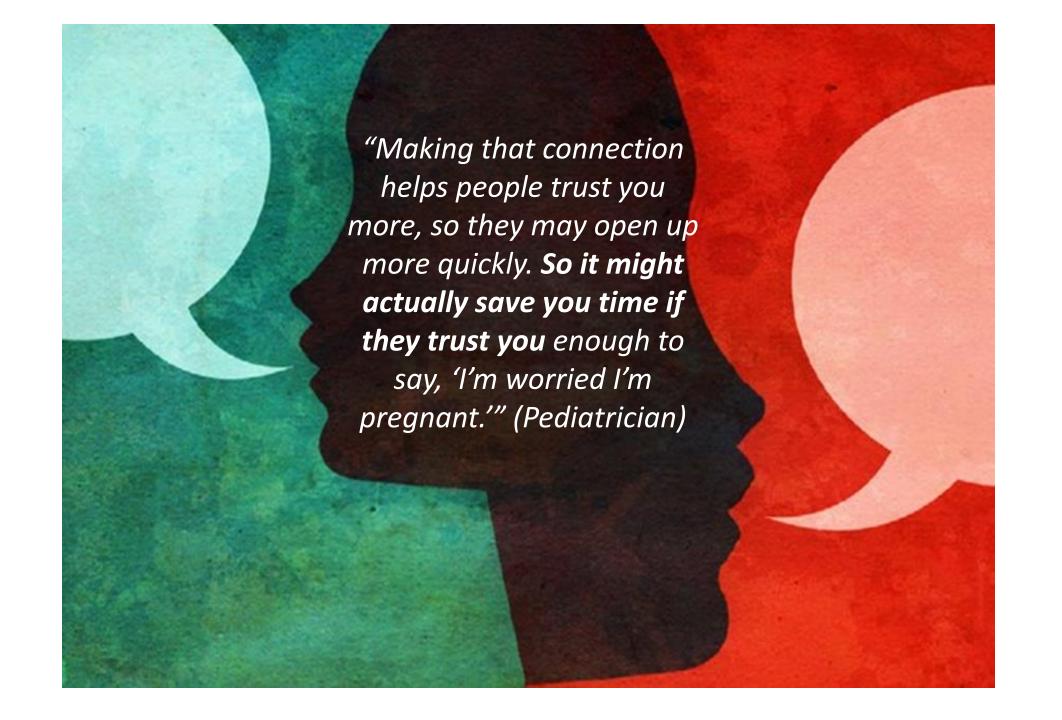
Families who reported never or only sometimes feeling like a **partner** were

- ~10 times more likely to be dissatisfied with services
- ~4 times more likely not to get needed specialty services
- ~2 to 3 times more likely to have unmet needs for either child or family

Denboba, D. et al. Achieving Family and Provider Partnerships for Children with Special Health Care Needs. Pediatrics. 2006; 118(4): 1607-1615.



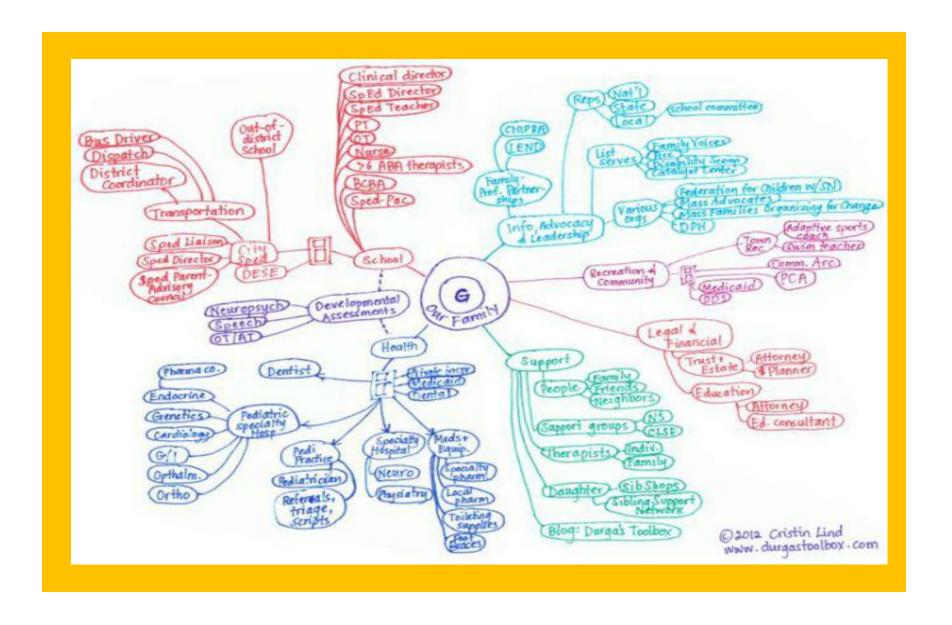
If you build it, the scores will come.



1. Seeing the Person Behind the Patient and the Disease

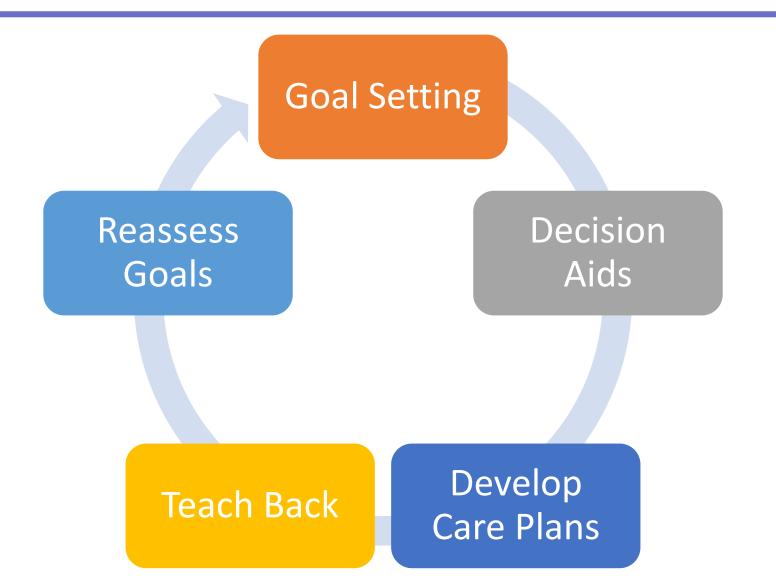
- Who is this person?
- How can I connect with this patient as a person?
- Who are the important people in the person's life?
- How does this person fit into her family, community, world?
- What is important to this person and her family?
- How has illness/injury impacted the patient's social identity?





Gabe's Care Map: Cristin Lind, Mom, Illustrates What It Takes To Raise One Boy With Special Needs, Huffington Post, January 18, 2013

2. Shared Decision Making



Words of Engagement

Encourage Patient to Speak Up

- "Tell me more. This is really helpful."
- "What do YOU think caused the problem?"
- "What are YOUR thoughts about how we should address this?"
- "What's worrying YOU most at this point?"

Invite Family to Share (with permission)

- "Would you mind telling me a little about your father?"
- "Please tell me about your mother's routine."

Growth Hormone
Test Story

3. Self Management

"Patients with the skills, ability, and willingness to manage their own health and health care—experience better health outcomes at lower cost."

- How confident do I feel to manage my health?
- What knowledge do I have about my conditions?
- What skills do I need that are necessary to maintain and improve my health?

Health Policy Brief, Health Affairs, February 14, 2013 Judith Hibbard, Patient Activation Measure, University of Oregon





Overcoming Barriers and Challenges

1. Balancing Productivity and the Patient Experience

How can I address emotional issues without lengthening the visit?

Does this "patient experience stuff" really apply to me?

How do I manage all of their questions and internet searches?

How can I teach to a full understanding?

How can I give patients more attention when I'm being pressured to see more of them?

The Privilege of Being Busy: Balancing Productivity & Patient Experience

Margaret Leaf, MS (mleaf@uwhealth.org) and Gregg Heatley, MD, MMM (gheatley@wisc.edu) - UW Health

High Productivity

High Patient Satisfaction

Humility & Learning

Navigate Challenges

Time Management

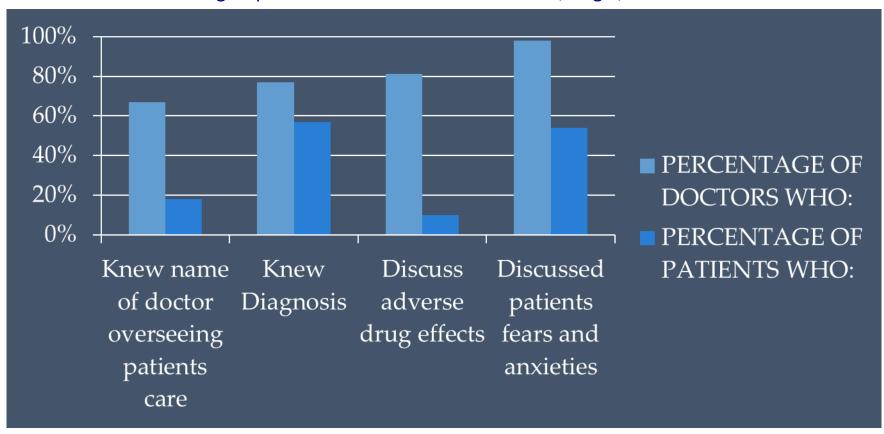
Teamwork

Patient Connection

Motivation & Reward

2. Doctor-Patient Communication Gap

"Researchers at the Yale School of Medicine asked 89 patients and 43 doctors about the patients' hospital experiences, and found startlingly different perspectives between the two groups." Archives of Internal Medicine, Aug 9, 2010



Consumers Report on Health. November 2010. Volume 22 Number 11 http://www.safepatientproject.org/pdf/CR%20Stay%20Safe%20in%20the%20Hospital.pdf

Communication Skills Maximize Efficiency

- Prepare for encounter both personally and clinically
- Rapport Building mindful practice/connect on something personal
- Up-front agenda Setting "what is most important"
- Maintain focus Steer conversation back
- Acknowledging Emotional Cues with Empathic Response
- Co-creating a plan review next steps

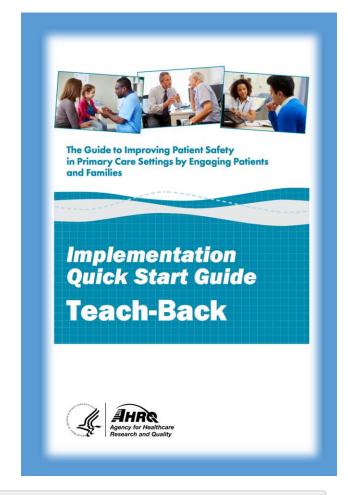
Adapted from Mauksch et al, Relationship, Communication, and Efficiency in the Medical Encounter: Creating a Clinical Model From a Literature Review; Arch Intern Med, 2008.

AGENDA-SETTING ALGORITHM Build rapport: Use the patient's name; greet all persons in the room; use a short, non-medical social interaction; smile; make eye contact; sit down. Transition to agenda setting: "I understand you are here for _____, but before we get into that, is there something else you would like to discuss today?" NO YES Ask about refills and forms, and Complete the agenda: Ask "Is there something else?" add your own agenda items: Consider heath maintenance until the patient comes up issues and lab results. with no new items. Are there too many items for the time available? NO YES Ask the patient which Prioritize problems and negotiate the agenda: Ask the problem he or she wants to start with today. patient which problem he or she wants to start with today. Explore the problem with an open-ended statement: "So, tell me about _

Family Practice Management®

This tool was developed by Egnew TR, Tacoma Family Medicine, Tacoma, Wash. Copyright © 2012 Thomas R. Egnew. Physicians may photocopy or adapt for use in their own practices; all other rights reserved. http://www.aafp.org/fpm/2014/0700/p25.html.

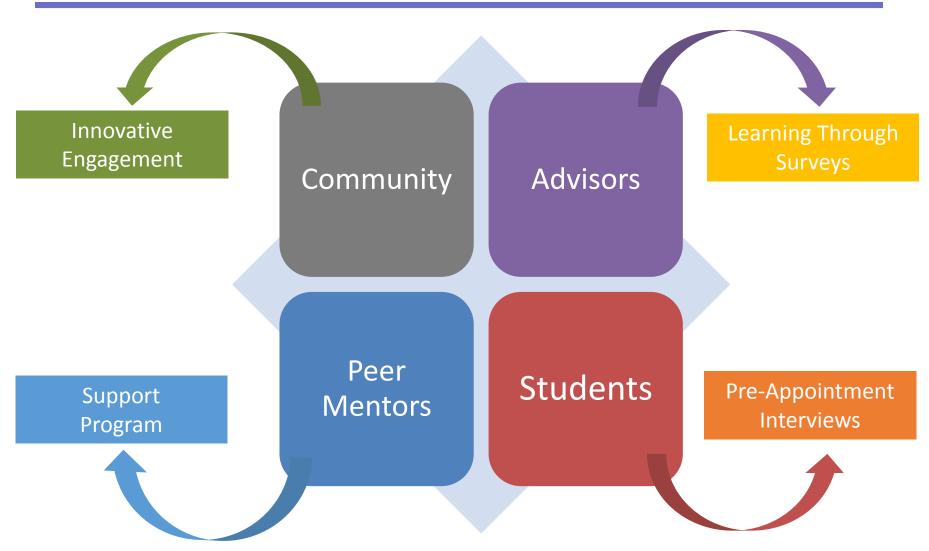
3. AHRQ Teach-Back Strategies Help Primary Care



Patient and Family Engagement in Primary Care

Research shows that when patients are engaged in their health care, it can lead to measurable improvements in safety and quality. To promote stronger engagement, the Agency for Healthcare Research and Quality (AHRQ) is developing a guide to help patients, families, and health professionals in primary care settings work together as partners to promote improvements in care.

4. Engage "the Village"



Peer Support – Lucile Packard Children's Hospital at Stanford

- Making the most of a clinic visit
- How to schedule multiple appointments
- How to manage medications
- Partnering with healthcare providers
- Coordinating care between Packard and community services
- How to parent in the hospital
- Who's who on your health care team

- Learning about your child's health condition
- Effective ways to communicate with care providers
- Understanding legal rights
- Working with the schools



Lucile Packard Children's Hospital Stanford

Compliments of Karen Wayman, PhD

Congregational Health Network Methodist Le Bonheur Healthcare

- <u>Background</u>: Partnership with 400 churches to support the transition from hospital to home.
- Intervention: A trained church member liaison visits the patient to provide psychosocial support and prepare for post discharge support.

Results:

- Lower mortality nearly half that of peers not participating in program (n=472)
- Lower healthcare costs \$8700 saving/year/person (total: >\$4 million)
- Over a 27 month period admissions (159 to 101), readmission (37 to 17), patient days (1268 to 772), LOS (8 to 7.6) and hospital charges (\$127,922 to \$74,819) all fell after enrollment (n=50)
- Higher patient satisfaction among program participants



Special Needs

Anticipated" Discharge Fears	No. of #1 Rankings	Ranking in Top 3	Ranking in Bottom 3
Death of Loved One	11	16	9
Competence of Home Care Providers	6	17	10
Care Coordination	5	13	3
Infection/Clean Technique	4	24	3
Lack Knowledge of Needs	4	10	12
Ability to Reach Medical Providers	2	11	5
Knowing When to Return to Hospital	2	12	5
Finding a "New" Normal	1	1	18
Paying for Care	0	2	16
Loneliness/Isolation	0	0	26

After Discharge e-Advisors Survey 2013

- What came as a surprise?
 - Exhaustion
 - Balancing life and finding normal
 - Loneliness, isolation and burden of responsibility
 - Expectation that I should be an expert
 - Expenses

- What was your biggest need?
 - Respite, rest
 - Communication and care coordination
 - Confirmation that I was doing things correctly
 - Contact information –who to call and when



"Breaking bad news is actually a golden opportunity to deepen the patient-doctor relationship...For a doctor to be willing to be emotionally available is a tremendous gift for any patient."

Nila Webster, a stage four lung cancer patient

As Bad as or Worse than Death...

Rubin, Emily B, MD, et al. States notes than death among hospitalized patients with serious illnesses. \$\text{\$AMA}\$ Intern Med. Published online August \$21,201

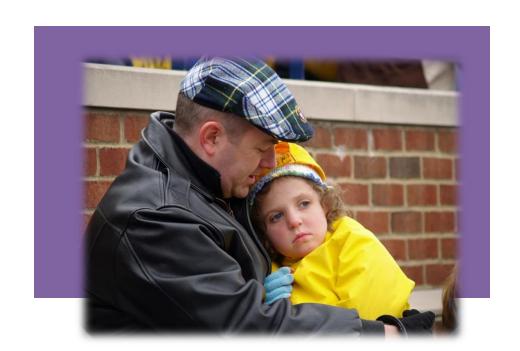
- Bowel and bladder incontinence, cited by about 70%.
- Reliance on a breathing machine, cited by about 70%.
- Inability to get out of bed, cited by about 70%...
- Being confused all the time, cited by about 60%.
- Reliance on a feeding tube, cited by about 55 percent of respondents.
- Needing around-the-clock care, cited by more than 50%.

Of Note:

- Patients may underestimate their abilities to adapt to certain healthcare states.
- The survey also found that a vast majority of respondents said that needing to be at home all day, being in moderate pain all the time, or needing to be in a wheelchair would not be preferable to death.

Remember the Caregiver

- Heroism
- Overwhelmed emotional and financial
- Exhaustion physical, mental and emotional
- Ambivalence
- New Normal



How Patient- and Family-Centered is Your Clinic?

- Does your patient education vision, mission, and philosophy reflect the principles of patient- and family-centered care?
- Do you inform patients and families how you expect them to engage in their care? Do you provide checklists?
- Are there systems in place to ensure that patients and families have access to complete, unbiased, and useful information?
- Do educational materials convey respect for families and their pivotal role in promoting health and well-being?
- Do you ensure communication that is understood by those with limited English proficiency, low health literacy and those who are hard of hearing?
- Do patients and families serve as advisors on committees and work groups involved in education efforts?



Patients and Families are Essential Partners for Innovation, Quality Improvement, and Health Care Redesign



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

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, 2nd Edition, IHI Innovation Series, 2008. Available at www.ihi.org.



Patients and Family Advisors

Any role in which those who receive care work together with health care professionals to improve care for everyone. Advisors share insights and perspectives about the experience of care and offer suggestions for change and improvement.





Why Involve Patients and Families as Advisors?

- Bring important perspectives.
- > Teach how systems really work.
- Keep staff 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."



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 bigger 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 and families served

Useful Framework for Participation

Depth of Engagement	Patients and Family Role	Things to Consider
Ad Hoc Input	Survey or Focus Group Participants	Ensure diversity and representation, validity
Structured Consultation	Council or Advisors- provides QI input	Early consult supports partnership model
Influence	Occasional Review/Consultants to project	Allows flexible ways to participate; requires background/orient.
Negotiation	Member of QI Group	Training in QI approach
Delegation	Co-Chair of QI Group	High level of expertise or skill
Advisor Control	Implementer or peer support role	Strong training component, mentoring and compensation

How Patient-Centered Practices Involve Patients in Quality Improvement

- ➤ Surveyed 112 patient-centered medical home clinics in 22 states.
- Nearly all solicited patient feedback.
- ➤ Only 32% involved patients as advisors on QI teams or councils.
- > Leadership commitment essential.



Han, E., et. Al., Survey Shows That Fewer Than A Third Of Patient-Centered Medical Home Practices Engage Patients In Quality Improvement Health Affairs, 32, no.2 (2013):368-375



Preparing Clinicians and Staff

Discuss issues and concerns before advisor join group

Reassure with confidentiality and selectice procedures

Share stories of benefits of patient and fa participation in QI



Preparing Advisors for Quality and Safety Committees

- Provide orientation on the quality improvement (QI) methodology & definitions
- > Share project background, especially data
- Discuss current topics & issues relevant to advisor's first meeting



AHA!

Preparing Advisors for Quality and Safety Committees (cont.)

- > Arrange a **pre-meeting** with the Chair of the committee
- Identify a mentor for the advisor who also serves on committee
- Share tips and tools developed by experienced advisors
- Provide opportunity to debrief first 3 meetings



Preparing Clinicians and Staff

Provide a bio sketch of advisor and a pictur

Foster a "listen first" approach

Encourage an acronym-free zone

Place advisors strategically close to chair o group facilitator



Fostering a Successful Beginning: Tips for Staff

- Explain how staff should be involved.
 - The importance of listening.
 - Effective approaches to meeting facilitation.
 - Act on advisors observations and recommendations when appropriate and provide information when not implemented.
- Be open to questions and challenges.
- >Try not to be defensive.
 - Respond/explain when questions are asked.





Exemplars Across the Continuum



PeaceHealth Medical Group - Eugene/Springfield, OR

For Patients and Families | Medical/Surgical Services & Treatment | Find a Doctor | Community, Health & Wellness

Eugene/Springfield, OR Locations > Patient Services > For New Patients

For New Patients

Home

Team Approach Introduction

Your Safety

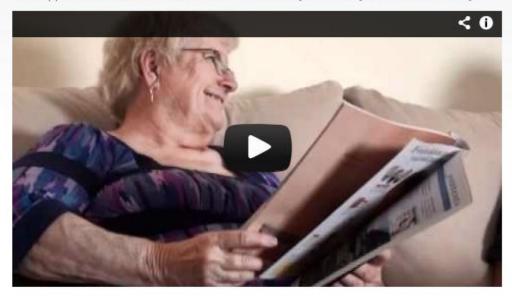
Your Medications

Your Medical Visit

Your Health & Wellness

Your Medications

It is important that your provider know all the medications you are taking including over the counter medications and supplements. Watch the video to learn more about your role in your medication safety.



http://www.peacehealth.org/phmg/eugene-springfield/eugene-springfield-locations/patient-services/for-new-patients/Pages/your-medications.aspx

Offer Variety in the Complexity of Projects

Easy	Moderate	Difficult
Providing input on wayfinding to practices, offices, exam rooms	Mentoring other advisors and recruiting for diversity within council	Participated in content and filming of a new patient experience model of care
Review of health information and media materials	Participating in organizational learning opportunities	Designed and Produced DVD on patient safety that was used as a model of the impact of advisors
Artwork selection for lobbies and waiting rooms	Establishing PAC award to providers/departments who embrace PFCC Principles	Patient Centered Medical Home transformation
Providing feedback on Patient Portals	Participating on New Nurse Panels on chronic illness from a patient's point of view	Service for Excellence Plan - Agenda Setting - piloted with new Medical Home In Adult and Family Medicine
Participating in Employee and Provider Appreciation Days	Sharing personal stories on experience of care	Collaborated in designing course content for front office staff training
Feedback on surveys	Serving on organizational committees - Clinical Councils, Quality Councils, Patient Safety Councils	Participate in interview panels for new Adult and Family Medicine Chief (key physician leader)
Promote visibility of PAC partnerships by random site visits to thank staff	Collaborated on Welcome Brochures	Help mentor and orient new physicians and managers to the practice







Executive PFAC Meetings 4 Step Process

- 1- Staff present on current projects related to patient experience
- 2- Patient & Family Advisors brainstorm and come up with ideas for improvements
- 3- Ideas are used as projects and programs move forward to incorporate the patients' perspective
- 4- Follow-up with Patient & Family Advisors on projects and how their ideas are being used

AVS Subcommittee



- ✓ 5 monthly 2-hour meetings
 - ✓ 7 Patient & Family Advisors,
 - ✓ Sr. Regional Medical Director,
 - ✓ Health Educator, Provider Educator
 - ✓ Program Coordinator
- ✓ AVS Data collected for baseline
- ✓ Poster created
- ✓ Communication plan developed

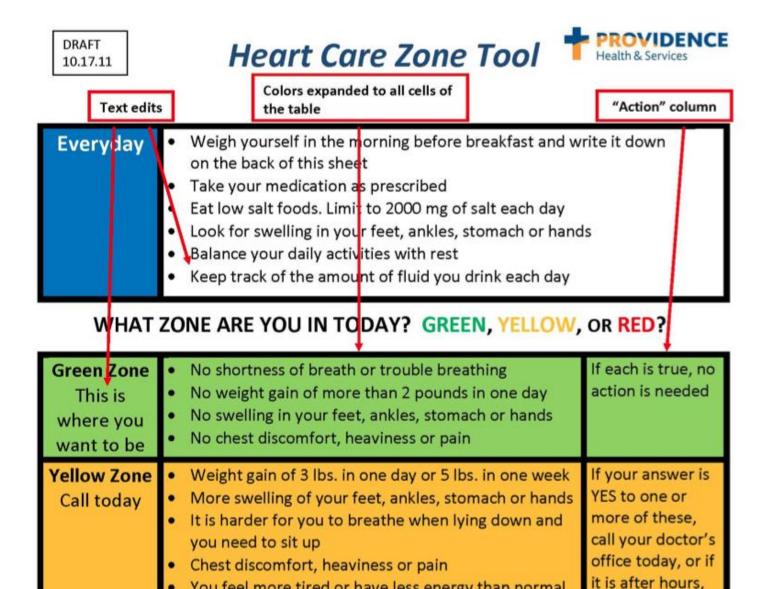
As a Result...

Patient & Family Advisors presented to leadership, all clinic managers and medical directors, 3 months later the increase in the issue rate was 29.29%

"This is remarkable work! It shows the power of engaging our patients in quality improvement work as partners." - Dr. Ben LeBlanc CMO



Making Information Clearer – Patient Input Makes the Difference!







Patient Advisor: Marc Blanco Patient Experience Project

Other activities:

- Recruiting for another clinic location
- Online Advisory Group
- Advisors using IPADs to survey patient and family input in clinic



Silver Exchange (Advisory Council)
Recent projects: revision of patient letters, waiting room improvements, logo contest



Evin, his family and staff from the Silver Ave Clinic

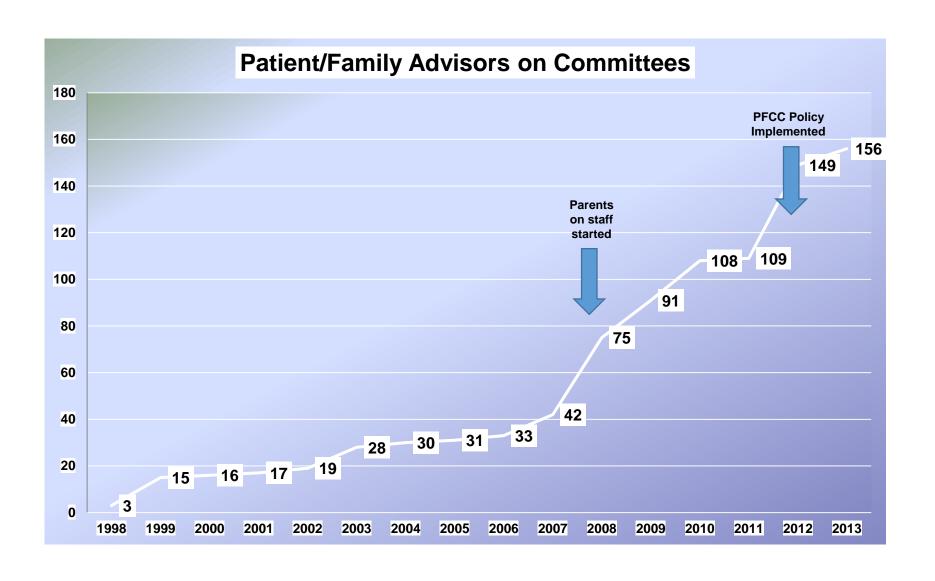
Collaboration Beyond Advisory Councils



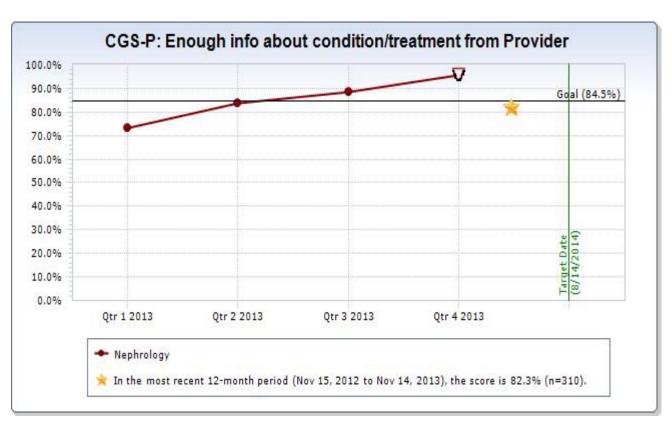
- Invite patients with a chronic condition to participate in a clinic team working on improving educational materials or programs to that population of patients.
- ➤ Identify patients new to the clinic to participate in a "photo walk-about" to take pictures of ways the clinic is welcoming and places where the messages could be more positive or where way-finding is confusing.
- Ask patients and family what is one change we could make that would improve your experience? Collect the responses and form a clinic team with advisors to follow-up on suggestions.



Patient/Family Advisors on Committees



The Power of the Parent in the Clinic Patient Satisfaction Results



Score N Size Q1 2013 73.2% 82 Q2 2013 84% 81 Q3 2013 88.4% 86 Q4 2013 96.3% 80

Benefits of Advisors on QI Teams

- Health care professionals & staff make fewer assumptions about what patients or families "want".
- Advisors "see things differently" and ask "why do you do it this way?"
- Advisors challenge what's possible.
- Advisors offer hope, assistance, and support.





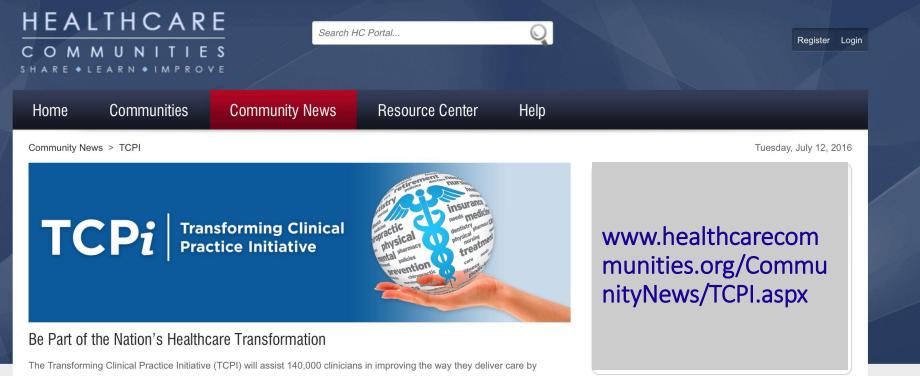


"Trust the Process"







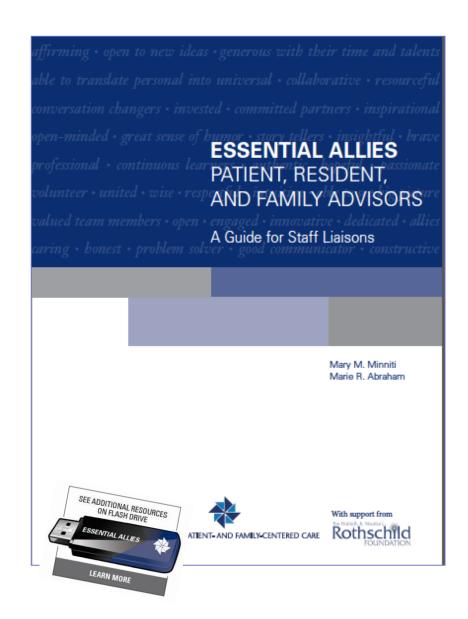


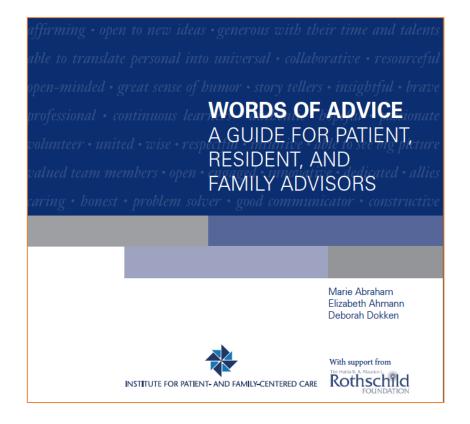
The Transforming Clinical Practice Initiative (TCPI) will assist 140,000 clinicians in improving the way they deliver care by providing technical assistance support for integrating quality and process improvement, and by building on and spreading existing change methodologies, practice transformation tools, published literature, and technical assistance programs. Clinicians that will be supported by TCPI include primary and specialty physicians, nurse practitioners, physician assistants, clinical



Consider:

- Share your story of partnership in ambulatory or primary care
- Become a PFAC Network Member





Available from IPFCC





Questions



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