Person and Family Centered Care

Martha Donovan Hayward
IHI Lead for Patient and Public Engagement
IHI’s Strategy to Improve Health and Health Care Worldwide

Transforming health care will require:
- Reliable systems for providing safe, harm-free, evidence-based care
- Patients and families empowered to be genuine partners in their care
  - New models for high-quality, high-value care
  - Building improvement capability at all levels
- Proving health, improving care, and lowering per capita cost (Triple Aim)

Accelerate the pace of improvement in health care

AND

Innovate and partner with organizations and communities to improve health

Creating a culture of health will require:
- Health care systems optimized for “health” and “care”
- Bridges between health care, community, and public health
- Healthy communities initiatives
- Creating enabling conditions
- Peer-to-peer supports
- New mindsets

Supporting our customers wherever they are on the journey

Working in Five Focus Areas

Leveraging IHI’s Core Strengths

- Innovating new models and methods
- Convening globally to harvest, share, and spread learning
- Partnering with others to accelerate the pace and scale of improvement
- Driving measurable results worldwide within health care and across communities

October 2014
Person- and Family-Centered Care

Our Goal:
Usher in a new era of partnerships between clinicians and individuals where the values, needs, and preferences of the individual are honored; the best evidence is applied; and the shared goal is optimal functional health and quality of life.
Terminology matters

- Consumer centered Care
- Patient and Family Centered Care
- Public and Patient Engagement
- Person Centered Care
“I am not a consumer of my disease.” K. Dudley, patient

Patients are ‘in’ the system. Not a time to learn.

Families – as defined by the patient are our best partners

When we are in our ‘public’ state we can plan, consider, decide and learn in order to manage our health

‘Person’ includes staff, clinicians, patients, the well.
What ‘Patient-Centered’ Should Mean

Patients and family members say:

“They give me exactly the help I need and want, exactly when and how I need and want it.”

-- Don Berwick, MD, MPP
Patient Experience Defined

The sum of all interactions, shaped by an organization's culture, that influence patient perceptions across the continuum of care.

THE BERYL INSTITUTE
The Doctor’s View
The Patient’s View
All models are wrong and some are useful.

George E. P. Box
Framework for Public/Patient Engagement

P/F Broadcasting the need, progress and awareness in our communities

P/F Making organizations accountable
Policy, Leadership

P/F engaged in Improvement Science, process design

P/F engaged at improving their own care
Hospital /Clinic/ Office/ Home

Conversation Project
Patient Family Advisory Councils
Always Events
Med rec/white boards, goal setting, shared decision making
What Matters to You?

Enhancing conversations between patients and clinicians from -- “What’s the matter?” to also including “What matters to you?”

Shared Decision Making — The Pinnacle of Patient-Centered Care

Michael J. Barry, M.D., and Susan Edgman-Levitan, P.A.

n engl j med 366;9 nejm.org march 1, 2012
What matters to you?

- Lifelong well-being v. looks
- A 12 year old wants WIFI
- What is your greatest worry or concern right now?
  - My dog
  - My 40th anniversary
  - My husband
What Matters: A Call to Action

What if every clinician, staff member and community health worker routinely asked “what matters to you?” and listened attentively at every encounter with individuals and their family members?

What would we learn? How would this understanding enhance our ability to develop genuine partnerships with patients to co-create a more customized plan to meet their expressed needs, values, and preferences?

www.ihi.org/whatmatters
To
For
With
Doing To

You know you are *doing to* when:

- We set visiting hours
- We control all schedules
- We determine what and when you eat
- Information is not shared in the patient’s presence
- Information not understandable
- There is helplessness – when the patient/family say:
  - I don’t know what happens next
  - I don’t know who is in charge of my care
  - I don’t feel like you know me
Doing For

You know you are *doing for* when:

- Family presence is defined by the patient
- You keep the patient in mind when designing or improving programs – then they are asked to react to program or facility design
- Service Lines - design services that match the patient journey across organizational boundaries – but without the patient
- There are dedicated efforts to improve the patient experience
- We manage your expectations about waiting
- Patients have options in schedule and food
- Information is openly shared with patients
Doing With

You know you are *doing with* when:

- Build on Doing *for* and move beyond
- Patient/family advisors are on teams to design or improve programs that follow the patient journey
- All key decisions are mutual – patients/families are partners in care at every level
- All staff are viewed as caregivers and are skilled in respectful communication and teamwork
- Health Literacy is everywhere in patient care
- Senior leaders model that patient’s safety and well-being guide all decisions
- Staff, providers, leaders are recruited for values & talent;
Always Events
Picker Principles

- Respect for patients’ values, preferences and expressed needs
- Coordination and integration of care
- Information, communication and education
- Physical comfort
- Emotional support and alleviation of fear and anxiety
- Involvement of family and friends
- Transition and continuity
Why Always Events?

- Raise the bar on both provider and patient expectations
- Introduce a new organizing principle to help galvanize action and accountability
- Demonstrate how the AE concept can be implemented in practice
- Widely disseminate AE strategies for national replication
- Energize and expand the movement toward a more patient and family centered system
Always Events®

Always Events® are defined as “those aspects of the patient and family experience that should always occur when patients interact with healthcare professionals and the delivery system.”
Always Events®

Never Events
- Developed by the US National Quality Forum
- Events that should never happen
  - E.g. wrong-site surgery or fatal medication error
- IHI’s Always Events®
  - Provides a framework about what should always happen
  - Every person, every time they encounter the health care system
From Always Events® to Always Experiences

- Based on decades of research by The Picker Institute on the patient and family experience
- An Always Event® is a practice or set of behaviors that, when implemented reliably, can ensure progress toward an optimal patient and family experience and improved outcomes
- The goal of the process is an “Always Experience”; the Always Event® is a tool for achieving this goal
Criteria for Always Events®

- **Important**: Patients and families have identified the event as fundamental to their care

- **Evidence-based**: The event is known to be related to the optimal care of and respect for patients and families

- **Measurable**: The event is specific enough that it is possible to accurately and reliably determine whether or not it occurs

- **Affordable**: The event can be achieved without substantial capital expense
Why is this Different?

- Begins with what matters to patients and family members
- Recognizes the complexity of healthcare:
  - Many people – working across diverse disciplines
  - Towards a common purpose
  - In constant flux
  - Varied demands
  - Filled with ambiguity and workarounds
- Requires capacity to rapidly see and solve problems - as they happen
Why Now?

- Healthcare reliability is lacking
  - Harm, waste, poor experience for patients and those who care for them
- Increasing demands for better health, better care, lower costs
- We over-estimate our knowledge and skills for working in complex systems
  - Lack knowledge of how things *really* work
  - We assume we know
- Current approach not working
Always is so much better than Never

- Positive

- Patients experience what is…not what is absent

- Definable, visible, measurable
The Conversation Project

Ellen Goodman
July 31, 2014
Changing the Cultural Norm

**A national campaign**
encouraging everyone to have
a conversation about their
wishes for end-of-life care

**Collaboration to ensure health care systems are ready to receive and honor wishes for end of life care**
Setting the scene
Where we began

Roz Chast
The New Yorker

CAN'T WE TALK ABOUT SOMETHING MORE PLEASANT?

My parents and I never discussed DEATH...

So...do you guys ever think about...THINGS?

What kinds of things?

You know...THINGS.
PLANS.

I HAVE NO IDEA
WHAT YOU GUYS WANT!

Let's say something HAPPENED.

AM I THE ONLY
SANE PERSON HERE???

You know what?! Forget it. Never mind.

LATER THAT SAME DAY...

Whew!

Whew!

Whew!
The Talking Gap

90% of people think it is important to talk about their loved ones’ and their own wishes for end-of-life care.

27% of people have discussed what they or their family wants when it comes to end-of-life care.

Source: The Conversation Project National Survey (2013)
The Conversation Project

A national public engagement campaign dedicated to assure that everyone’s wishes for end-of-life care are:

*Expressed* and *Respected.*
TCP’s Strategy for Creating Cultural Change

- Awareness: National media campaign and community engagement events

- Accessible: Tools to help people get started

- Available: Bringing TCP to people where they work, where they live, and where they pray
You tell each other everything.

When it comes to end-of-life care, talking matters.

Sharing your wishes for end-of-life care can bring you closer to the people you love. Visit TheConversationProject.org for inspiration, personal stories, and a step-by-step guide to get you started.
Accessible: Our Tools

- Conversation Starter Kit
- How to Talk to Your Doctor Starter Kit
- Pediatric Starter Kit
- Families of People With Dementia
Available

Reaching people where they:

- Work..
  - Dow, Goodyear
- Live…
  - 200 groups in 42 states
- Pray…
  - Conversation Sabbath
Learning to Date

- Universality of issue
- Starter kit is very accessible
- Having the conversation makes a major difference in peoples’ lives
- Not every conversation is perfect, need to start…..
- Not everyone wants to have the conversation
- Major impact on health care providers
- Economics and Humanity
- It always too early until it is too late!
HAVE YOU HAD THE CONVERSATION?

Help get it out in the open.
I want mine to be...

Share how you want to live the end of your life.

1,230,176 people have spoken. Join them.

WHAT it's all about
Hear from co-founder Ellen Goodman about what The Conversation Project is, what we're asking people to do, and why she got involved.

WHY it's important
60% of people say that making sure their family is not burdened by tough decisions is "extremely important"
56% have not communicated their end-of-life wishes
One conversation can make all the difference.
Source: Survey of Californians by the California Health Foundation (2013)

HOW to get started
Explore our Starter Kit for tools and tips to help you have the conversation.

Everyone has a story

"At that point I decided not only to honor my mother's wishes, but also to give her the best possible death."

Have you had the conversation with a loved one?
We want to hear how it went.

CONNECT WITH US:

SHOW YOUR SUPPORT
The Conversation Project depends on foundation grants, corporate sponsorships and individual contributions to support its work. Please consider a gift to honor a loved one's memory.

DONATE NOW
The Starter Kit: Get Ready

Now, think about what you want for end-of-life care.

**What matters to me is _____.**
Start by thinking about what’s most important to you. What do you value most? What can you not imagine living without?

Now finish this sentence:
What matters to me at the end of life is___________________________________________.

Sharing your “What matters to me” statement with your loved ones could be a big help down the road. It could help them communicate to your doctor what abilities are most important to you—what’s worth pursuing treatment for, and what isn’t.
The Starter Kit: Get Set....

Where I Stand scales
Use the scales below to figure out how you want your end-of-life care to be.
Circle the number that best represents your feelings on the given scenario.

As a patient...

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>I only want to know the basics</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I want to know as much as I can</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ignorance is bliss</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I want to know how long I have to live</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I want my doctors to do what they think is best</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I want to have a say in every decision</td>
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</tbody>
</table>


The Starter Kit: Go

Mark all that apply:

Who do you want to talk to? Who do you trust to speak for you?

- [ ] Mom
- [ ] Partner/Spouse
- [ ] Doctor
- [ ] Dad
- [ ] Minister/Priest/Rabbi
- [ ] Caregiver
- [ ] Child/Children
- [ ] Friend
- [ ] Other: ________________

When would be a good time to talk?

- [ ] The next big holiday
- [ ] Before my next big trip
- [ ] Other: ________________
- [ ] At Sunday dinner
- [ ] Before I get sick again
- [ ] Before the baby arrives
- [ ] Before my kid goes to college

Where would you feel comfortable talking?

- [ ] At the kitchen table
- [ ] On a walk or hike
- [ ] Other: ________________
- [ ] At a cozy café or restaurant
- [ ] Sitting in a garden or park
- [ ] At my place of worship
- [ ] On a long drive
Learning Collaborative

- **Engage** with our patients and families to understand what matters most to them at the end of life.

- **Steward** this information as reliably as we do allergy information.

- **Respect** people’s wishes for care at the end of life by partnering to develop shared goals of care.

- **Exemplify** this work in our own lives so that we understand the benefits and challenges.

- **Connect** in a manner that is culturally and individually respectful of each patient and their family.
Big News!

- Medicare rules changing
- Normalizing the conversation for people in all states of health
- Engaging families
- Identifying proxies
- Training health care providers to have the conversation
Soul Doctor and Jazz Singer
Engaging With Patients

Part II
The voyage of discovery is not in seeking new landscapes but in having new eyes.

Marcel Proust
Storytelling
What is your story?

- What story(ies) are told in your family?
- What do they say about the culture of your family?
- What influence do they have on you?

Notes for 3 – Share for 3 mins each (15)
Transformational Learning: 1st Reflection

- Think of a time in your life (situation or incident) where you were vulnerable.
  - Where were you?
  - Who was involved?
  - What happened?
  - What made you feel vulnerable?
  - Make note of your feelings

- What advice did you or would you have liked to give those who influenced your experience?
Transformational Learning: 2nd Reflection

Think of a time in your life when someone provided you genuinely “helpful” help.
• What was your experience?
• What did you feel?
• Describe the characteristics of “helpful” helping

Think of a time when someone provided you some “not-so helpful” help.
• What was your experience?
• What did you feel?
• Describe the characteristics of “not-so helpful” helping

Developed by Jane Taylor and Pat Rutherford
Why we tell stories

- Connect to process
- Engages head and heart
- Enables empathy
- Return to ‘why’
- Demonstrate the humanity of our work
- Reflects culture
Where

- Clinical interaction – one on one – deep listening
  - Saves time
  - Provides vital information
  - Builds trust
- Team Interaction
  - Provides focus and meaning to process
  - Engages hearts and minds
  - Enhances improvement
- Leadership
  - Inspires
  - Models meaning in work
  - Offers a reference point
Brené Brown

“Maybe stories are just data with a soul”
Rolling 12-month Serious Safety Events expressed per 10,000 adjusted patient days

SSER August 2008: 0.41
Average Days between events: 14 days (CY08 Sept YTD)
19 days (CY07)
37 days (CY06)
Another View of the Same Data for the Last 3 Months

<table>
<thead>
<tr>
<th>Name</th>
<th>Date</th>
<th>Event</th>
</tr>
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<tbody>
<tr>
<td>John L.</td>
<td>9/27/2008</td>
<td>HAI</td>
</tr>
<tr>
<td>Tammy F.</td>
<td>11/17/2008</td>
<td>Post Procedure Death</td>
</tr>
<tr>
<td>Ralph H.</td>
<td>9/12/2008</td>
<td>Fall</td>
</tr>
<tr>
<td>Juanita D.</td>
<td>10/25/2008</td>
<td>Fall</td>
</tr>
<tr>
<td>Roberta A.</td>
<td>10/13/2008</td>
<td>Delay in Diagnosis</td>
</tr>
<tr>
<td>Frank H.</td>
<td>10/03/2008</td>
<td>Delay in Treatment</td>
</tr>
<tr>
<td>Baby C.</td>
<td>10/13/2008</td>
<td>Fall</td>
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<tr>
<td>Harold C.</td>
<td>10/5/2008</td>
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<td>Donald C.</td>
<td>9/26/2008</td>
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</tr>
<tr>
<td>Baby D.</td>
<td>11/1/2008</td>
<td>Wrong Pt. Procedure</td>
</tr>
<tr>
<td>James A.</td>
<td>9/06/2008</td>
<td>Wrong Pt. Procedure</td>
</tr>
<tr>
<td>George P.</td>
<td>11/07/2008</td>
<td>Fall</td>
</tr>
<tr>
<td>Herman D.</td>
<td>11/17/2008</td>
<td>Retained Foreign Obj.</td>
</tr>
<tr>
<td>Joe E.</td>
<td>9/23/2008</td>
<td>Wrong Site Surgery</td>
</tr>
<tr>
<td>Johnny R.</td>
<td>10/08/2008</td>
<td>Delay in Diagnosis</td>
</tr>
<tr>
<td>Mark G.</td>
<td>11/17/2008</td>
<td>Fall</td>
</tr>
<tr>
<td>Nick S.</td>
<td>1/4/2008</td>
<td>Delay in Dx</td>
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Safety Behavior Training Begins: September 11, 2008
Employee Training Ends: September 17, 2008
Medical Staff Training Ends: October 1, 2008

Events:
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Good storytelling moments

- Kick starting a new idea
- Socializing new members
- Sharing wisdom, best practices, new behaviors
- A call to action
“Stories not only teach us how to act—
they inspire us to act”

• Marshall Ganz
Workload of Cristin Lind (Mother of a Child with Special Needs)

http://www.childrenshospital.org/care-coordination-curriculum/care-mapping
Model for Improvement

Engaging patient and family advisors in the work of improvement

Martha Donovan Hayward
Lead for Public/Patient Engagement
Institute for Healthcare Improvement
Don’t do more.
Do better.
Why can’t you just........
Why can’t you just……..

- Teach staff to be nice
- Schedule my appointments together
- Treat me like a human being
- Let my family stay with me
- Spend more time with me
Let’s break that down
What are we trying to accomplish?

How will we know a change is an improvement?

What change can we make that will result in improvement?
What are we trying to accomplish?
- AIM

How will we know a change is an improvement?
- MEASUREMENT

What change can we make that will result in improvement?
- CHANGE/BEHAVIOR
What are we trying to accomplish?

How will we know that a change is an improvement?

What change can we make that will result in improvement?

Aim of Improvement

Measurement of Improvement

Developing a Change

Testing a Change

What Is The Role of a Patient/Family Advisor?

- Patient Activist
- Community Advocate
- Patient/Family Advisor
- Partner in Care
- Engaged Patient
- Speaker
- Leader
- Organizer
Formal Roles

- Support
- Policy
- Provide Assistance
- Executive Team
- Advisor
- Family Leader
- Customer Service
- Trainer
- Develop training for staff
- Voice of Patient & Family
- Represent Patient
- Hospital Volunteer on Unit
- Chair PFAC
- Train residents
- Recruit
- Sit on Committees
- Partner
- Market patient stories
- Activate patient
- Teaching peers
- Member of Patient Voices network
- Speaking
- Consumer Advisory Board
- Education staff on DME
- Access to Board
- Facilitate community groups
- Being assertive
- Share stories
- Teleconferences – share info
Informal Roles

- Bring urgency
- Compassion
- Cookies
- Dignity
- Non-threatening
- Listening
- Affirmation of patient experience
- Confirmation
- Comfort
- Sense of humor
- Hospitality
- Hope
- Balance & level headedness
- Empathy
- Humanity
- Framework for discussion
- Understanding
- Expertise
- Respect for all views
- Perspective
- Empower
- Caring
- Change
- Inform
- Engage
- Organize
- Truth teller
Who is Ready?

- A patient or family member in your setting with current experience
- Reached a state of healing – wants to make the world better for others
- Has a community outside health care that “holds” them; family, office, social, spiritual
- Ask a busy person.
Developing Health Care Team Members

- Remember – it is not just Patient/Family Partners who need development to work with healthcare team members!

- Most healthcare team members are not skilled in working in true partnerships with patients/families. We are used to being “in charge.”

- Specify listening behaviors to use in activities with Partners to assure their talents are being used effectively.
Resources

- **IHI**
  - Always Events
  - Model for Improvement
  - National Forum – December 6-9 – Orlando Florida
    - www.ihi.org

- **PFCC Partners**
  - By, for, and about patients and families
  - Programs to onboard PFAs
    - www.pfccpartners.com

- **Planetree**
  - 30 years of experience in Patient Centered Care.
  - Designation program
    - www.Planetree.org