A New Era of Innovations in Person- and Family-Centered Care
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.
Session Objectives

- Describe innovations from around the world to significantly promote genuine partnerships between clinicians and individuals and their family members.

- Identify practical strategies for adapting and adopting innovations to advance person- and family-centered care.
Session Faculty

- **Maureen Bisognano**  President and Chief Executive Officer of the Institute for Healthcare Improvement (IHI)

- **Helen Haskell**  President, Mothers Against Medical Errors, Board member, Institute for Healthcare Improvement (IHI)

- **Patricia A. Rutherford**  Vice President, Institute for Healthcare Improvement (IHI)
Innovations in Person- and Family-Centered Care

Maureen Bisognano, President and CEO, IHI
The Triple Aim

The IHI Triple Aim

Ask “What’s the matter” in addition to “What matters to you?”
New Design Principles

- Change the balance of power
- Standardize what makes sense
- Customize to the individual
- Collaborate/cooperate
- Eliminate walls
- Assume abundance/return the money
- Make it easy
- Move knowledge, not people
- Create wellbeing
- Create joy in work

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

http://www.childrenshospital.org/care-coordination-curriculum/care-mapping
Organizations Learning from Patients

The Old Way

- Ryhov Hospital in Jönköping had traditional hemodialysis and peritoneal dialysis center.
- But in 2005, a patient, Christian, asked about doing it himself.
Christian taught a 73-yr-old woman how to do it…

…and they started to teach others how to do it.
The New Way

- Now they aim to have 75% of patients to be on self-dialysis
- They currently have 60% of patients
Lessons to Date

From Christian (patient):

- “I have a new definition of health.”
- “I want to live a full life. I have more energy and am complete.”
- “I learned and I taught the person next to me, and next to her. The oldest patient on self-dialysis is 83 years old.”
- “Of course the care is safer in my hands.”
Lessons to Date

From Anette (nurse leader):

- Surprised at design differences between patients, family, and staff
- Managing at 1/2 – 1/3 less cost per patient
- Evidence of better outcomes, lower costs, far fewer complications and infections
- “We brought in the county’s employment, helped the patients make or update the CVs, and trained them for a new career.”
Update

- Now calculated costs at 50% of costs in other hemo-dialysis units
- Complications dramatically reduced and subsequent expensive care avoided
- Measuring success by “number of patients working”
If your kidneys fail, dialysis can save your life.

But, dialysis is not just a medical treatment.

It can also affect every aspect of your lifestyle.

This tool will help you choose the right treatment for you, so you can feel your best and live the way you want to.

Get Started

What matters to you?

Check the values that matter most to you.
For each value you select, you’ll be able to rate how each treatment option fits your life.
We’ll show you a summary when you’re done.
What matters to you?

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Lifestyle Values
- I need to be able to work or go to school
- I need to be able to travel
- I want to be able to eat and drink what I like
- I love to swim and/or take tub baths
- I will NOT give up my pets
- I want to feel well from one day to the next
- I worry about how much dialysis will cost
- I need to feel in control of my time and my life
- I don’t want a dialysis machine in my home
- I’m terrified of needles
- I want professionals to take care of me

Health Values
- I want to be able to sleep as well as I can at night
- I want the best chance for a kidney transplant
- I want to avoid taking pills as much as I can
- I want to protect my bones, joints, and nerves
- I want to protect my heart
- I want to stay out of the hospital
- I want to live as long as I can

Partner & Family Values
- My sex life is important to me
- I want to have (or father) a child
- I want to take care of a child or a disabled or elderly person
- I don’t have a care partner to help me
- I want to spend as much time as I can with my family
- I don’t want to be a burden on my family

Continue
I need to be able to work or go to school

You CAN work or go to school on dialysis — IF you choose a work-friendly option. Work-friendly treatments fit YOUR schedule. They give you more energy and mental focus. And, they help you stay out of the hospital, so you miss less work.

Rate how well each treatment fits this value

**Peritoneal Dialysis & Work/School**
- You can do PD with a pump at night while you sleep
- You may be able to do PD at work
- You can take PD with you on work trips

**Standard Hemodialysis & Work/School**
- You may be able to get a treatment shift in a clinic before or after work or school
- You can do standard home HD on your own schedule

**Daily Hemodialysis & Work/School**
- You can do your treatments before or after work or school
- More treatment for more energy
- You can take a small (70 lbs) HD machine with you for work trips

**Extended Hemodialysis & Work/School**
- Can be done at night while you sleep — no time out of your work or school day
- Most treatment for most energy

**But...**
- You must keep your PD peritoneal clean, as your nurse will teach you
- Your doctor may give you limits on how much weight you can add or lose during the week
- Average of 1.7 hospital days per year. (NOTE: This number includes those who switched options during the year)

**But...**
- Standards in-center HD may take time out of your work or school day
- You may feel washed out like you have the flu for less than 3 hours to 6 hours after each treatment
- Average of 4.7 hospital days per year for standard in-center HD. (NOTE: This number includes those who switched options during the year)
- One small study found 1.3 fewer hospital days for standard home HD. The study did not look at days.
- You may not have as much energy
- You may not think as clearly
### Results

<table>
<thead>
<tr>
<th>My Values</th>
<th>PD</th>
<th>Standard HD</th>
<th>Short Daily HD</th>
<th>Extended HD</th>
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</tbody>
</table>

**Save or send your results**

Bookmark this page and come back later to see your chart again. Or, fill in your email address and we will send you the link.

We will only use your email address to send you your link. We will not keep it accessible.

**Help us improve!**

**How helpful did you find this tool?**

- Not at all helpful
- Not very helpful
- Mixed
- Somewhat helpful
- Very helpful

**How could we make it better?**

Submit
Centering Pregnancy

- Boston Medical Center
Norah

- Young woman from Boston – 24 weeks pregnant with her first child.
- Her husband is still back in Nigeria and she’s hoping he’ll be here for the birth.
Norah, like all the young women who participate in the group visit, takes her own vital signs, weighs herself, and enters all the info into her record.

She shares the record with the physician and midwife – it’s flipped! – and then moves to the back of the room to be examined before the group portion of the visit begins.

While the exams are conducted, there is a lot of chatter, a lot of questions asked and advice given, and a lot of relationship-building.
What Matters to Norah

“I’m very afraid of labor. I’m terrible with pain. I’m scared. I don’t think I’ll be able to do it.” The midwife said, “those of you who have had babies before, what advice do you have for Norah?”

- Relaxed
- Ice cubes
- Confidence
Centering Results

- Reduced the risk of preterm birth by 33%\(^1\)
- Reduces Racial Disparities for Preterm Births
  - Hispanic women in Centering demonstrated lower preterm birth rates than those in traditional care models (5% vs. 13%)\(^2\)
  - Reduced the odds of preterm births by 41% in African American women\(^3\)
- Nearly twice the number of Centering Healthcare participants breastfed (46%) than those in a comparison study (28%)\(^4\)

\(^3\)Ickovics, et al. 2007
\(^4\)J of Midwifery & Women’s Health, 2004
Joy, even in sorrow
Ask “What’s the matter” in addition to “What matters to you?”
What Matters To Me

My name is Kendra. I am 7.
I don't like medicare by my

I can dress myself

With some help

I can do his

I love noise

24.10.2013

Toys
Lived Truth: Teaching with Patient Stories

Helen Haskell, President, Mothers Against Medical Errors, Board Member, IHI
Workload of Cristin Lind (Mother of a Child with Special Needs)

http://www.childrenshospital.org/care-coordination-curriculum/care-mapping
Paul Batalden

Every system is perfectly designed to get the results it gets.
Core Competencies

- Evolving to meet a changing healthcare environment
- Moving from a clinician-centered to a patient-centered model of care
- Changing from individual to team-based, with patient as part of the team
Traditional medical education

The design

- Intense scientific education
- Followed by intense clinical training

The results

- Students proficient in:
  - Medical Knowledge
  - Patient Care
- Focused on:
  - Clinician-patient relationship
Patient Stories

- The importance of learning from error
- The need for a new definition of patient engagement
- The need for responsiveness
- The need to understand the lived truth of others
Wisdom

... the ability to tell the story of your scars.
Patients’ stories of harm

- Cross boundaries, as the patients do
- Focus on relationships, as the patients do
- Show the importance of professional, interpersonal and communication skills in clinical outcomes
- Reveal “the rest of the story”
Core Competencies for HC Professionals

1. **Patient Care:** Provide patient-centered care that is compassionate, appropriate, and effective for the treatment of health problems and the promotion of health.

2. **Knowledge for Practice:** Demonstrate knowledge of established and evolving biomedical, clinical, epidemiological and social-behavioral sciences, as well as the application of this knowledge to patient care.

3. **Practice-Based Learning and Improvement:** Demonstrate the ability to investigate and evaluate one’s care of patients, to appraise and assimilate scientific evidence, and to continuously improve patient care based on constant self-evaluation and lifelong learning.
Core Competencies for HC Professionals

4. Interpersonal and Communication Skills: Demonstrate interpersonal and communication skills that result in the effective exchange of information and collaboration with patients, their families, and health professionals.

5. Professionalism: Demonstrate a commitment to carrying out professional responsibilities and an adherence to ethical principles.

6. Systems-Based Practice: Demonstrate an awareness of and responsiveness to the larger context and system of health care, as well as the ability to call effectively on other resources in the system to provide optimal healthcare.
7. **Interprofessional Collaboration:** Demonstrate the ability to engage in an interprofessional team in a manner that optimizes safe, effective patient- and population-centered care.

8. **Personal and Professional Development:** Demonstrate the qualities required to sustain lifelong personal and professional growth.


Planetree Focus Groups

Top three concerns cited by patients

- Dismissal/trivialization of the patient voice
- Absence of caring attitudes from providers
- Lack of continuity in care

Three patient stories

- Linda, an American orthopedic patient
- Nick, a Canadian surgical patient
- Claudine, a French pain patient
The Silence of the Hospital

Lessons on supporting patients and staff after an adverse event
A Cascade of Small Events

Learning from an unexpected postsurgical death
Lost

A chronic pain patient’s search for answers
My Name is Kendra

What Matters To Me

I have Autism

I can't speak
So I won't be able to tell if it hurts

I can make noises

I can't have grapes
And it makes me bloated

I am very fast and will put things in my mouth and can make a run for it

I can dress myself with some help

I can do my hair with some help

I love cuddles to reassure me

I don't like medicated by my mouth "so watch out I will struggle";

I love to feel peoples hair, it is my way of saying hello

I will bang my head and bite my hand when I am frustrated

Some time my hair gets tangled and I'm rubbish at doing my hair "needs a lot of help"

I love noise and toys

I can't do my hair

My Mum's name is Deborah Day

My Dad's name is Martin

24.10.2013
Lessons

- Continuity of care
- Joy and meaning in work
- Compassion, respect, and honesty
- The patient’s voice
- Listening
Lessons

Patients have the answers.

-Carolyn Canfield

If you want to serve, you need to begin with the stories.

—President Bill Clinton
Practical Strategies for Wide-Spread Adoption of Innovations

Pat Rutherford, Vice President, IHI
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: 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
Asking “What Matters?”

Example of a Bedside White Board

Any concerns or worries about going home (or to next care setting)?

What matters to you today? “1st and Last 5 Minutes”

HOME CARE SERVICES CSI
Switch: How to Change Things When Change Is Hard
Chip Heath and Dan Heath, New York: Broadway Books, 2010
The Rational Mind - which often likes change and understands it is good

The Emotional Mind - which fights change because it’s easier to stay the same

This is easy, but it doesn’t often work

Human Brain

This is harder, but is more likely to bring about change

"Knowing something isn’t enough to cause change. Make people feel something"
Framework for Change

Direct the Rider
• Provide crystal-clear direction

Motivate the Elephant
• Provide emotional reasons to change

Shape the Path
• Make the change easy
• Workflows, systems, habits
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.”
Criteria for Always Events®

- **Important**: Patients and family members have identified the events as fundamental to improving their experience of care.

- **Evidence-based**: The events are known to contribute to the optimal care of and respect for patients and family members (either through research or QI measurement over time).

- **Measurable**: The event is specific enough that it is possible to determine whether or not the process or behaviors occur reliably.

- **Affordable**: The event can be achieved without substantial capital expenditures.
Understand “What Matters to Patients?”

Co-Design an Always Event® to Address “What Matters?”

Test the Components and the Composite of the Always Event®

Translate the Always Event® into Standard Work Processes

Co-Design an Always Event®

Reliably Implement Standard Work Over Time

**PLAN**

Communicate Standard Work Processes

Use Process Measures to Assess Progress

**DO**

Implement Standard Work

**STUDY/ACT**

Observe & Redesign Standard Work as Needed to Increase Reliability
Getting Started

- Choose a pilot unit, clinical program or population
  - Where there is will to improve patient/family experiences
  - Where there leadership capacity to test and implement an Always Events
  - Where there are no other major change initiatives underway
- Engage patients and family members
- Engage a clinical team
- Convene a launch meeting
- Discern a specific focus for improvement (partnership between the clinical team and patients and family members)
  - Create an aim statement (how good, by when?)
Translate the Always Event® Ideas into Standard Work

1. Identify and co-design the Always Event (composite of successful change ideas that were tested)
2. Specify the care setting and the patient segment
3. Outline the work process within the care setting
   -- Specify process segment or step for the initial focus
4. Change the work to assure reliable occurrence of the Always Event
   -- Use the Model for Improvement
   -- Apply reliable process design strategies, engaging the point of care team in co-design of the work re-design
Nursing Assessment of What is Most Important to Patients

Yawkey 7 Nurses- GI Infusion
(p-chart 3-sigma)

Mean Compliance Rate

Lower Control Limit (LCL)  Upper Control Limit (UCL)

Time Period

Monday Tuesday Wednesday Thursday Friday
wk 0 wk 1 wk 2 wk 3 wk 4 wk 5