

## Embracing Patient and Family Centered Care:

Recognizing the Driving Forces Across all Healthcare Settings

Sponsored by Clarity Group, Inc.  
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## A New Healthcare Agenda

- **New Healthcare Goal:** Population Health
- **New Healthcare Impetus:** Value Based Reimbursement/Non-payment for certain Healthcare Acquired Conditions
- **New Healthcare Delivery Configuration:** Amass the resources from Cradle to Grave services – expand the geographical reach
- **New Healthcare Challenges:**
  - **Clinical Integration:** Coordination of resources, standardized practices, patient registries, shared data, cost analysis, complex fee distribution ... across the system of care
  - Single culture focused on quality and safety – *Excellence!*



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## How is it Going to Look in the Future?

- ACOs and similar configurations are focused on outpatient networks of care to improve access and reduce cost of care
- Outcomes of the new healthcare reform go beyond the hospitals walls, beyond a particular event or even the organization
- There is a shift in what physician alignment means today and in the future



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## How is it Going to Look in the Future?

- Care delivery networks need to be organized in different ways
- New concepts emerging for managing the anticipated growth in patient volumes
- Working together to support cohesive quality improvement by starting with defining what is meant by ambulatory quality and hospital quality for the population



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## But What's Missing?

- What we know about healthcare reform
  - Expand access, improve the quality and safety of services and reduce costs



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## The Patient's Voice!

- Shift our way of thinking: Focusing on the patient's experience and integrating their viewpoint into the culture across *all systems of care*...



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## Objectives for Today

- Develop a shared understanding of the core concepts of patient- and family-centered care and how these concepts enhance quality, safety, efficiency and the experience of care
- Describe effective ways to partner with patients and healthcare providers to transform the patient-caregiver relationship into a collaborative partnership
- Describe strategies to inspire patients and healthcare providers to transform the patient-caregiver relationship into a collaborative partnership



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## Evolution of the Patient- and Family-Centered Care

- Concept of "patient-centered medicine" first introduced in 1969
- Family-centered changes within maternity care in 1960s and 1970s
- 1987, U.S. Surgeon General, the Maternal and Child Health Bureau (MCHB) of the U.S. Department of Health and Human Services, the Association for the Care of Children's Health
- 1989 MCHB changed its mission statement



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## Evolution of the Patient- and Family-Centered Care

- Principles of “Patient-Centered Care” presented by the Picker Commonwealth Program for Patient Centered Care in 1987
- Eight dimensions
  - Respect for patients’ values, preferences and expressed needs
  - Coordination and integration of care
  - Information, communication and education

“Principles of Patient-Centered Care.” *Picker Institute*. The Institute for Patient- and Family-Centered Care, n.d. Web. <<http://pickerinstitute.org/about/picker-principles/>>.



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## Evolution of the Patient- and Family-Centered Care

### Eight Picker Principles of Patient-Centered Care, cont.

- Physical comfort
- Emotional support and alleviation of fear and anxiety
- Involvement of family and friends
- Transition and continuity of care
- Access to care



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## Evolution of the Patient- and Family-Centered Care

1992 Institute for Patient- and Family-Centered Care was founded

### Institute for Patient- and Family-Centered Care describes the concept in this way:

*“Patient- and Family-Centered Care (PFCC) is an approach to the planning, delivery and evaluation of healthcare that is grounded in mutually beneficial partnerships among healthcare providers, patients and families. It redefines relationships in healthcare.”*

“Frequently Asked Questions.” *IPFCC*. Institute for Patient- and Family-Centered Care, 29 Dec. 2010. Web. <http://www.ipfcc.org/faq.html>.



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## Evolution of the Patient- and Family-Centered Care

### • Core Concepts of PFCC

- Respect and Dignity
- Information Sharing
- Participation
- Collaboration

“Frequently Asked Questions.” *IPFCC*. Institute for Patient- and Family-Centered Care, 29 Dec. 2010. Web. <http://www.ipfcc.org/faq.html>.



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## Evolution of the Patient- and Family-Centered Care

- In 2001, Institute of Medicine issued a report entitled, "Crossing the Quality Chasm: A New Health System for the 21<sup>st</sup> Century"
  - Six Quality Aims for Improving Care
  - 10 Rules for Redesign
  - Chain of Effects for Improving Healthcare Quality

Committee on Quality of Health Care in America. "Crossing the Quality Chasm: A New Health System for the 21<sup>st</sup> Century (Report Brief)." *Institute of Medicine. National Academy of Sciences*, 01 Mar. 2001. Web. <http://www.iom.edu/-media/Files/Report%20Files/2001/Crossing-the-Quality-Chasm/Quality%20Chasm%202001%20%20report%20brief.pdf>



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## Evolution of the Patient- and Family-Centered Care

- AHA 2004 -- collaborated with IPFCC and disseminated a toolkit on patient- and family-centered care to chief executive officers of every hospital in the United States
- IHI has made patient- and family-centered care an area of innovation and research



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## Evolution of the Patient- and Family-Centered Care

- World Health Organization launched World Alliance for Patient Safety -- "Patients for Patient Safety (PFPS)," one of six action areas is designed ensure perspectives of patients and families are central -- first workshop was held in 2005

*"A world in which patients are treated as partners in efforts to prevent all avoidable harm in healthcare. PFPS calls for honesty, openness and transparency, and aims to make the reduction of healthcare errors a basic human right that preserves life around the world." (London Declaration, 2005).*

"London Declaration: Patients for Patient Safety." *World Health Organization. WHO World Alliance for Patient Safety*, 17 Jan. 2006. Web. [http://www.who.int/patientsafety/information\\_centre/Final\\_London\\_Declaration\\_Feb06.pdf](http://www.who.int/patientsafety/information_centre/Final_London_Declaration_Feb06.pdf)



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## Evolution of the Patient- and Family-Centered Care

- 2006 JCAHO convened first patient and family advisory committee and published a book, "Patients as Partners: How to Involve Patients And Families in Their Own Care"
- National Committee for Quality Assurance -- physician practice recognition program that will reward medical groups for PFC practice design



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## Berwick's definition in 2009

"Copyrighted and published by Project HOPE/Health Affairs as [Donald M. Berwick. "What 'Patient-Centered' Should Mean: Confessions Of An Extremist." *Health Affairs*, 28, no.4 (2009):w555-w565. (published online May 19, 2009; 10.1377/hlthaff.28.4.w555)]. The published article is archived and available online at [www.healthaffairs.org](http://www.healthaffairs.org)“  
<http://content.healthaffairs.org/content/28/4/w555.abstract>



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## In other words...

Patient- and family-centered care is working **with** patients and families, rather than just doing TO or FOR them.



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## A Vision for Transformation, 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:

- Organisations 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.

“Transforming Healthcare: A Safety Imperative.” *BMJ Quality and Safety*. The Health Foundation, 13 Oct. 2009. Web. 07 June 2013.  
<http://qualitysafety.bmj.com/content/18/6/424.abstract?pid=52956258-5ec1-42e1-8472-a21ed72bd938>



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## A Vision for Transformation, a Safety Imperative

- 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.”



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## Patient- and Family-Centered Care versus Traditional Care

- Patient-centered care needs to be assessed by patients' perceptions
- Not a patient autonomy model or paternalistic model
- Control vs. collaboration
- Blind obedience versus equal partnership
- Information and skills taught based on provider's agenda vs. patient's agenda



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## Embracing the Patient and Family Experience

- Need to shift focus away from disease and back to patient
- More than one reasonable path forward exists
- Shared decision making, addressing the barriers
- Need to recognize creating ongoing sustainable partnerships requires profound changes in culture and leadership behaviors
- Need to have midlevel managers feel empowered to explore and lead rather than mandate and force education



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## Embracing the Patient and Family Experience

- We need to attempt to move from “What’s the matter?” with the patient to “What matters to the patient?”



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## Misconceptions

- Patient- and family-centered care is not just “being nice.” It is not just the “soft stuff.”
- Patient- and family-centered care is not the same as customer service, service excellence or service recovery.
- Patient- and family-centered care is about partnerships and patient and family engagement.



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## Why Improving the Patient and Family Experience is Vital

- Patient experience surveys -- payments to hospitals adjusted in part on how well they do on these surveys
- Mandate for health care entities to post quality and cost measures
- Increasing healthcare costs shifting to the patient
- Potential impact on referral patterns when patients have a choice



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## Why Improving the Patient and Family Experience is Vital, continued

- Leverage from national associations:
  - CMS initiatives
  - Local, regional and national Pay for Performance and Value-Based purchasing
  - NCQA Patient Centered Medical Home recognition program
- Rising consumer and patient expectations



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## Why Improving the Patient and Family Experience is Vital, continued

- Patients and families are the only team members always present through any episode of care
- Patients and families, when involved, improve adherence, outcomes and safety
- Reduction in malpractice risk:
  - Failure to understand patient's perspective
  - Poor communication of information or no communication at all
  - Feelings of desertion or abandonment
  - Basically devaluing the patient/family experience



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## Why Improving the Patient and Family Experience is Vital, continued

- Social isolation is a risk factor
- Individuals most dependent on hospital care are most dependent on families ...
  - The very young
  - The very old
  - Those with chronic conditions

Johnson, Beverley H. (2013, May 8). "Advancing the Practice of Patient- and Family-Centered Care: Partnerships for Quality and Safety." *NRQS Advisory Committee Meeting*, New Orleans, LA.



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## Why Improving the Patient and Family Experience is Vital, continued

- Improving the quality of work-life for healthcare providers and staff is an important piece in improving the patients' experience of care
- Reduces time and energy currently invested in "service recovery" or saying "I am sorry"



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## "We owe them journeys - not fragments"

Don Berwick, MD  
September, 2010



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## MCGHealth

- Incorporated PFCC into organization's strategic plan
- Human resources department ensures new staff possess attitudes and skills consistent with PFCC
- Behaviors for customer service have been defined and are included in position descriptions
- Offer a refresher course for physicians and staff
- Development of Senior VP of Patient and Family Centered Care position

"Profiles of Change [MCGHealth (MCG Medical Center and MCG Children's Medical Center), Augusta, Georgia]" *IPFCC: Institute for Patient- and Family-Centered Care*, 13 Aug. 2012. Web.  
<http://www.ipfcc.org/profiles/prof-mcg.html>



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## MCGHealth

- In 1998, the hospital created the position of Director of Family Services Development and hired a mother of a child with special health care needs. Julie served for nine years as part of MCG's senior management team; she was responsible for ensuring that patient and family perspectives were represented in all aspects of the health care experience for children and adults.



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## ***MCG Neurosciences Center of Excellence***

- Three members of the MCGHealth Partners Council who have neurological conditions had key roles in the development of this center.
- Patients and families contributed to the design process, assisted in the development of the philosophy for the unit and participated in interviewing center staff and physicians prior to the unit's opening.



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## ***MCG Neurosciences Center of Excellence***

- Patient satisfaction scores rose from 10<sup>th</sup> to 95<sup>th</sup> percentile
- Length of stay decreased by 50%
- Discharges (volumes) increased 15.5%
- Medical error rate fell by 62%
- Nursing staff vacancy rate fell from 7.5% to 0%



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## ***MCGHealth***

- Patient and Family Faculty Program was established in 2003 -- 25 families have agreed to share their stories with students and trainees
- Director of Patient and Family Centered Care at the Medical College of Georgia
  - Incorporated patient- and family-centered care into the curriculum of all academic programs



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## ***Cincinnati Children's Hospital***

### ***"A Dedicated Partner with Your Family"***

*"This team's purpose was to learn how to improve the care experience for patients and families as an integral step towards achieving the hospital mission, "to be the leader in improving child health."*

- The President/CEO, Chairman of the Board of Trustees, Chief of Staff, a Trustee from the Board's Patient Care Committee, Chief Nursing Officer and a Staff Nurse were among those chosen to participate at seminar on PFCC."

"About Cincinnati Children's," Cincinnati Children's Hospital Medical Center, N.p., n.d. Web.  
<http://www.cincinnatichildrens.org/about/about/>



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## Cincinnati Children's Hospital, cont.

- *"In the years since that seminar, this hospital has come far in its journey towards family-centered care. Cincinnati Children's is a learning organization that actively seeks out opportunities to work with others to achieve major goals. Each year since 1998, the hospital has sent interdisciplinary teams of families and professionals to the Institute's seminar creating a cadre of more than 150 change agents to further engrain patient- and family-centered care practices within this academic medical center."*



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## Cincinnati Children's Hospital, cont.

- Families are no longer visitors, units are open 24/7
- Families are encouraged to be present for rounds which are linked to discharge goals
- Discharge goals are printed daily for the patient and family
- Orders are written in patients' rooms during rounds on a laptop
- Residents review orders out loud so everyone can verify them



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## Cincinnati Children's Hospital, cont.

- Some quality improvement data from CCH
  - Patients are being discharged sooner
  - Medical order entry error rates have been reduced from 7% to 1%
  - Faculty report that patient- and family-centered rounds are a more effective way to teach



"A Roadmap for the Future." IPFCC: Institute for Patient- and Family-Centered Care, Jun. 2006. Web. <http://www.ipfcc.org/pdf/Roadmap.pdf>

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## A Sampling of Accomplishments of the CCH Family Advisory Council include:

- **National Seminar** -- Cincinnati Children's Hospital hosted the Institute for Patient- and Family-Centered Care's Hospitals Moving Forward with Family-Centered Care Seminar. Among the 86 Cincinnati Children's participants were two family members and eight staff members who presented personal perspectives.
- **Inpatient Parent Handbook** -- Family Advisory Council members critiqued the drafts and provided pointers and recommendations regarding content and usability during development of an inpatient parent handbook.



"Profiles of Change [Cincinnati Children's Hospital Medical Center]." IPFCC: Institute for Patient- and Family-Centered Care, 29 May 2013. Web. <<http://www.ipfcc.org/profiles/prof.cinn.html>>

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### A Sampling of Accomplishments of the Family Advisory Council include:

- **Surgical Waiting Room Renovation** -- Patients' families were a driving force in making this project a reality. They came in after hours to meet with the architects and had amazingly creative ideas about its function and appearance. Working with Perioperative Services and construction staff, Family Advisory Council members provided input for designing the "ideal" surgical waiting room.
- **Newborn Intensive Care Unit** -- Members participated in development of renovation plans for the Regional Center for Newborn Intensive Care Unit (RCNIC) Family Waiting Area, Parent Care Rooms, and a parent handbook.



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### A Sampling of Accomplishments of the Family Advisory Council include:

- **Parking Committee** -- Family Advisory Council members collaborated to minimize confusion in the visitor parking garage and to make special needs parking more accessible.
- **Billing Task Force** -- In order to make billing statements easier to understand, Family Advisory Council members and the Billing Department collaborated to develop and launch a family-friendly billing system. The task force redesigned paper billing statements, as well as new online billing management systems. The Billing Task Force also created tips for families on how to handle and organize medical bills and information, as well as a downloadable "billing contact record."



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### A Sampling of Accomplishments of the Family Advisory Council include:

- **Media Task Force** -- Family Advisory Council members lead the change to allow only family-friendly TV stations be available in all waiting rooms.
- **The Family Faculty Program** -- created to incorporate family-centered care philosophies and experiences into the resident teaching curriculum at Cincinnati Children's.



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### Patient Centered Medical Home

- First introduced in 1967 by The American Academy of Pediatrics.
- Primary care medical home provides health care that is relationship-based with an orientation toward the whole person.
- Partnering with patients and their families requires understanding and respecting each patient's unique needs, culture, values, and preferences.
- The medical home practice actively supports patients in learning to manage and organize their own care at the level the patient chooses.

"Defining the PCMH." PCMH. Patient Centered Medical Home, n.d. Web. [http://pcmh.aahrq.gov/portal/server.pt?community=pcmh\\_home/1483/PCMH\\_Defining%20the%20PCMH\\_v2](http://pcmh.aahrq.gov/portal/server.pt?community=pcmh_home/1483/PCMH_Defining%20the%20PCMH_v2).



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## Patient Centered Medical Home

- Access to care
- Communication
- Coordination
- Comprehensive care
- Shared decision making
- Whole person orientation
- Self management support
- Focus on quality and safety



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## Innovative Team Roles in Private Practice

- The practice team consists of 2 primary care physicians, 1 nurse practitioner, 1 registered nurse, an office manager, 6-7 patient representatives and 4 medical assistants
- Patient representatives -- 4 distinct functions: telephone work, greeter, scheduler and in-basket manager
  - Role works because of intensive training for an average of 6 weeks

Bodenheimer, Thomas, M.D. "Building Teams in Primary Care: 15 Case Studies." *Chief*, California HealthCare Foundation, July 2007. Web. <http://www.chcf.org/~media/MEDIA%20LIBRARY%20Files/PDF/B.PDF> Ps:30BuildingTeamInPrimaryCareCaseStudies.pdf.



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## Innovative Team Roles in Private Practice

- Greeter
- Scheduler
  - Providers schedule own follow-up visits, lab tests and simple x-rays in the exam room
- Managing clinician's in-baskets
- Medical Assistants
  - Take patient to room, collect vital signs, a more detailed history and medication reconciliation



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## Innovative Team Roles in Private Practice

- Registered Nurse
  - Chronic disease management
- Team Meetings
  - Morning huddles, one hour weekly meetings, occasional afternoon closure for team-building
- Leadership and training are vital to success



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## National eHealth Collaborative

- “All the good HITECH legislation is accomplishing in shifting our focus from adoption to meaningful use of information technology will be limited if patients are not engaged in their own care.”
- Meaningful use Stage 2
- Variety of interventions to stay in constant contact with patients and try point them in direction of self management

Glaser, John. "Expanding Patients' Role in Their Care." *H&H: Hospitals & Health Networks*, 11 June 2013. Web. <http://www.hhnmag.com/hhnmag/HHNDaily/HHNDailyDisplay.d.html?id=7280003149>.



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## National eHealth Collaborative

- Strategies to strengthen patient engagement through new technology tools
- Inform Me, Engage Me, Empower Me, Partner with Me, and Support My e-Community
- Main Line Health-patient-directed daily care plan (Inform Me) to help educate patients and their families on tests and treatments they will receive



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## National eHealth Collaborative

- New York-Presbyterian Hospital patient portal led to 42% increase of appointments scheduled while lowering no-show rates from 20% to 12%
- Using patient engagement to address obstacles with technology
- Technology is only part of the equation



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## The Journey starts with a long-term commitment:

Belief that their participation is essential in delivery of optimum care.

- Here are some starting points:
  - Start by educating all senior leadership and include patient and family at the start
  - Assess current state of patient- and family-centered care, patterns of care, access to information, etc.; see IPFCC website for tools
  - Develop an action plan, integrate strategies into the organization's mission, vision, philosophy and definition of quality



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## The Journey starts with a long-term commitment:

- Here are some starting points:
  - Appoint a family steering committee and leaders from the organization to the same committee; find the right staff member to serve as liaison; identify staff members and physicians for informal workgroups
  - Start out with general areas to be addressed such as what works well, what doesn't and address the issues through a collaborative process



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## The Journey starts with a long-term commitment:

- Here are some starting points:
  - As group gets comfortable over time, branch out in more specific areas such as assessing policy and procedure development. Other various committees can extend the membership to include patients and families
  - Develop ongoing education programs to support patient/family and staff
  - Monitor change, evaluate processes, measure the impact and celebrate the successes



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“That’s what scares me: to be made helpless before my time, to be made ignorant when I want to know, to be made to sit when I wish to stand, to be alone when I need to hold my wife’s hand, to eat what I do not wish to eat, to be named what I do not wish to be named, to be told when I wish to be asked, to be awoken when I wish to sleep.”

Don Berwick

Mahar, Maggie. “What Does Don Berwick Mean by “Patient-Centered” Care? (Ezra Klein Confuses the Enemy).” *Health Beat*. N.p., 09 July 2010. Web. <http://www.healthbeatblog.com/2010/07/what-does-don-berwick-mean-by-patient-centered-care-ezra-klein-confuses-the-enemy-summary-don-berwick-who-still-act>



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## Transformation

“The easiest way to make transformational change happen is to have families be part of the process because:

- Having families included in this process gives energy and urgency for improvement;
- Having patients and families on teams helps focus on the key priorities;
- Having families involved means that you don't spend time on things that are unimportant.”

*Uma Kotagal, MD, Director of Health Policy and Clinical Effectiveness at Cincinnati Children's Hospital Medical Center*

“Profiles of Change [Cincinnati Children's Hospital Medical Center].” *IPFCC*. Institute for Patient- and Family-Centered Care. 29 May 2013. Web. <<http://www.ipfcc.org/profiles/prof-cin.html>>



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Thank you for your time!  
Any questions?

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