Patient- and Family-Centered Care
What is it?
The Implications for Policy Makers

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What is Patient- and Family-Centered Care?
System-Centered Care
Patient-Focused Care
Family-Focused Care

Source: National Center for Family-Centered Care. (1990)
Patient- and Family-Centered Principles

▼ People are treated with respect and dignity.

▼ Health care providers communicate and share complete and unbiased information with patients and families in ways that are affirming and useful.

▼ Individuals and families build on their strengths through participation in experiences that enhance control and independence.

▼ Collaboration among patients, families, and providers occurs in policy and program development and professional education, as well as in the delivery of care.
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
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.”


http://qshc.bmj.com/content/18/6/424.full
How to Scale Up Primary Care Transformation: What We Know and What We Need to Know?

“Becoming a medical home is a radical change, requiring both a new mental model for primary care and the skills and resources to accomplish it.”

Homer, C. J., & Baron, R. J. (2010). How to scale up primary care transformation: What we know and what we need to know? Journal of General Internal Medicine, 25(6), 625-629.
Patient and Family Engagement . . .

“In our experience, the unique perspective that family members bring refocuses transformation efforts away from provider concerns and toward bringing value for families and patients.”

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.

Public Policy Implications

We must fund programs that bring people together—patients, families, clinicians, staff, and leaders of healthcare organizations as we . . .

♦ Redesign primary care

♦ Reach out to the public to encourage support patient and family engagement in care and decision-making and the management of chronic disease.

♦ Change the concept of families as visitors in hospitals to one where they are allies for quality, safety, and for the transitions to home.

♦ Develop a workforce with strong communication and collaboration skills.
Support is needed for learning how to collaborate in health care redesign

“Now the round table symbolizes our equality, while my fancy chair and golden crown signify that perhaps I’m just a smack more equal.”
Sharing Stories
“Facts bring us to knowledge, Stories bring us to wisdom.”

Rachel Remen
My Experience of Care
DIABETES . . . 23.6 million adults and children in the United States have diabetes — 7.8% of the population

Public Policy Implications

Patient- and family-centered medical home . . . patient and family engagement . . . collaborative self-management . . . Information technology that supports patient- and family-centered care are essential to cost efficiency and achieving the best clinical outcomes.

Patients and families are partners in building this system of care.
Redesign of Primary Care and the Management of Chronic Conditions

**DIABETES SELF MANAGEMENT**

NAME: ___________________  DOB: ___________________

Diabetes is a very serious disease that may cause damage to the blood vessels and nerves leading to the brain, eyes, heart, kidneys, toes and feet.

You, the patient, are the most important person to manage your diabetes. Your health care team will assist you and offer support as you manage your diabetes. The following goals will help you gain and maintain diabetic control to reduce damage to your blood vessels and nerves.

Please choose goals you are willing to work on to better manage your diabetes:

<table>
<thead>
<tr>
<th>Goal</th>
<th>Description</th>
<th>Date Set</th>
<th>How Ready</th>
<th>How Confident</th>
<th>Date Met</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>I will lower my current HbA1c value. My goal HbA1c is ________%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>I will check my feet daily. If I notice a sore or irritation, I will seek medical attention.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>I will visit the Podiatrist yearly or as advised.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>I will take a baby step in or extra-control sugar every day.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td>I currently smoke ______ cigarettes per day. I will take action to stop smoking.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td>I will have a dilated eye exam every year or as indicated by my eye doctor. On ______</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.</td>
<td>I will check my blood sugar as instructed and will call if the results are consistently below ______ or above ______</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

http://www.newhealthpartnerships.org
http://www.chcf.org/topics/patient-self-management

Collaborative Self-Management Support
- Information Sharing
- Goal Setting
- Action Plans
- Follow-Up Support
Patient Advisory Roles in Self-Management Support

“A Lay Leader”

This patient advisor participated on a QI team, taught classes in the Healthier Living Series, and trained peer support group facilitators.

Humboldt Del Norte IPA
Eureka, CA
Recovery Model of Care for Mental Health Services — SAMHSA and the Veteran Affairs Standard of Care
Mame’s Story

A vibrant dynamic 94-year old breaks her left shoulder, left hip, and right hand on February 18th. This bilateral involvement imposes total dependence for 5 weeks.
Mame’s Story

- Every person except one in the community hospital introduces themselves upon entering her room.
- No signs about visiting hours.
- The patient room has a family bed that functions as a bed, a desk, and a dining room table.
- Patient and family pre-op conversation with the surgical team.
- The transition to the rehab hospital . . . When requested, the discharge summary is provided to the family . . . the nurse asks the family to help in its completion.
- EMR supports sharing a medication list with the patient and family.
Mame’s Story

Opportunities for Improvement (cont’d)

♦ Discharge date set on a day impossible for family to help with transition to home.

♦ No flexibility to include the family in the rounds discussion with the physician.

♦ Discharge instructions given at the moment of discharge to Mame with the nurse’s back turned to the family member and blocking the view of the medication list.

♦ Two different medication lists provided, neither consistent with Mame’s list upon admission or the bottles at home.
<table>
<thead>
<tr>
<th>MEDICATIONS</th>
<th>HOW MUCH</th>
<th>HOW OFTEN</th>
</tr>
</thead>
<tbody>
<tr>
<td>NORVASC</td>
<td>10 MG</td>
<td>DAILY</td>
</tr>
<tr>
<td>TENORMIN</td>
<td>50 MG</td>
<td>DAILY</td>
</tr>
<tr>
<td>AZELASTINE HCL</td>
<td>2 DROPS BOTH EYES</td>
<td>TWICE DAILY</td>
</tr>
<tr>
<td>OSCAL/VIT D</td>
<td>2 TABS</td>
<td>WITH SUPPER</td>
</tr>
<tr>
<td>COLACE</td>
<td>100 MG</td>
<td>TWICE A DAY</td>
</tr>
<tr>
<td>COZAAR</td>
<td>100 MG</td>
<td>DAILY</td>
</tr>
<tr>
<td>LOPETREDNOL ETABONATE</td>
<td>1 DROP RIGHT EYE</td>
<td>DAILY</td>
</tr>
<tr>
<td>MULTIVITAMIN</td>
<td>1 TAB</td>
<td>DAILY</td>
</tr>
<tr>
<td>TRIAMCINOLONE ACETONIDE</td>
<td>1 APPLY BOTH LEGS</td>
<td>TWICE A DAY</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>START MEDICATION</th>
<th>DOSE</th>
<th>RTE</th>
<th>FREQ</th>
<th>SCH/RATE</th>
<th>LAST ADMIN</th>
</tr>
</thead>
<tbody>
<tr>
<td>02/29/08 AMPHODIPINE BESYLATE</td>
<td>10 MG</td>
<td>PO</td>
<td>EVERY DAY</td>
<td>SCH</td>
<td>03/27/080014</td>
</tr>
<tr>
<td>02/29/08 ATENOLOL</td>
<td>50 MG</td>
<td>PO</td>
<td>EVERY DAY</td>
<td>SCH</td>
<td>03/27/080014</td>
</tr>
<tr>
<td>02/28/08 AZELASTINE HCL</td>
<td>2 DROPS</td>
<td>REV</td>
<td>TWICE A DAY</td>
<td>SCH</td>
<td>03/27/080014</td>
</tr>
<tr>
<td>02/28/08 CALCIUM CARBONATE/VITAMIN 2 - OPTIVAR 0.5%</td>
<td>PO</td>
<td>WITH SUPPER</td>
<td>SCH</td>
<td>03/26/080019</td>
<td></td>
</tr>
<tr>
<td>02/28/08 DOCUSATE SODIUM</td>
<td>100 MG</td>
<td>PO</td>
<td>TWICE A DAY</td>
<td>SCH</td>
<td>03/27/080014</td>
</tr>
<tr>
<td>02/29/08 ENOXAPARIN SODIUM</td>
<td>40 MG</td>
<td>SC</td>
<td>EVERY DAY</td>
<td>SCH</td>
<td>03/27/080014</td>
</tr>
<tr>
<td>02/28/08 LOSARTAN POTASSIUM</td>
<td>100 MG</td>
<td>PO</td>
<td>EVERY DAY</td>
<td>SCH</td>
<td>03/27/080014</td>
</tr>
<tr>
<td>02/28/08 LOTEPREDNOL ETABONATE</td>
<td>1 DROP</td>
<td>NEY</td>
<td>EVERY DAY</td>
<td>SCH</td>
<td>03/27/080014</td>
</tr>
<tr>
<td>02/29/08 MULTIVITAMIN THERAPEUTIC 1 - THERAPEUTIC MULTIVITAMIN</td>
<td>PO</td>
<td>EVERY DAY</td>
<td>SCH</td>
<td>03/27/080014</td>
<td></td>
</tr>
<tr>
<td>02/28/08 PANTROPYDROL SOD SIQUEHY 40 MG</td>
<td>PO</td>
<td>WITH BREAKFAST</td>
<td>SCH</td>
<td>03/27/080014</td>
<td></td>
</tr>
<tr>
<td>03/18/08 TRIAMCINOLONE ACETONIDE</td>
<td>1 APPL</td>
<td>TO</td>
<td>TWICE A DAY</td>
<td>SCH</td>
<td>03/27/080014</td>
</tr>
<tr>
<td>02/28/08 ACETAMINOPHEN (TYLENOL)</td>
<td>1-2 TABS</td>
<td>PO</td>
<td>EVERY 4 HRS AS NEEDED</td>
<td>FRN</td>
<td>03/26/0801279</td>
</tr>
<tr>
<td>02/28/08 BISACODYL</td>
<td>10 MG</td>
<td>PR</td>
<td>TWICE A DAY AS NEEDED</td>
<td>FRN</td>
<td>03/21/0801900</td>
</tr>
<tr>
<td>02/28/08 DOCUSATE SODIUM</td>
<td>100 MG</td>
<td>PO</td>
<td>TWICE A DAY AS NEEDED</td>
<td>FRN</td>
<td>03/21/0801111</td>
</tr>
</tbody>
</table>
Mame’s Story

Mame . . . celebrating her 97th birthday with some of her great grandchildren and her son-in-law.
“Why the Nation Needs a Policy Push on Patient-Centered Health Care”

“Patient-centered care depends on three factors:

- An informed and engaged patient and family;
- Receptive and responsive health professionals who can focus on disease and know the patient; and
- A well-coordinated and well integrated health care environment that supports the efforts of patients, families, and their clinicians.

Policy makers’ support for patient-centered care must include all three legs of this stool.”

Across the age continuum and in all settings — primary care, acute care, rehabilitation, and long-term care — we need patients and families as partners.

The Time is Now

“If health and/or healthcare is on the table, then the consumer (public, patient, family member) must be at the table, every table, NOW!”

Lucian Leape Institute, 2008
References and Resources


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- Institute for Patient- and Family-Centered Care: www.ipfccc.org.
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