



The Missing Voice: The Patient/Consumer Role in Payment Reform

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About Us



The National Partnership for Women & Families is a nonprofit, nonpartisan advocacy group dedicated to promoting fairness in the workplace, access to quality health care, and policies that help women and men meet the dual demands of work and family.

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What Do Patients Want?

Review

End-of-life care—what do cancer patients want?

Shaheen A. Khan¹, Barbara Gomes & Irene J. Higginson



RESEARCH ARTICLE

HEALTH AFFAIRS > VOL. 29, NO. 5 REINVENTING PRIMARY CARE

If You Build It, Will They Come? Designing Truly Patient-Centered Health Care

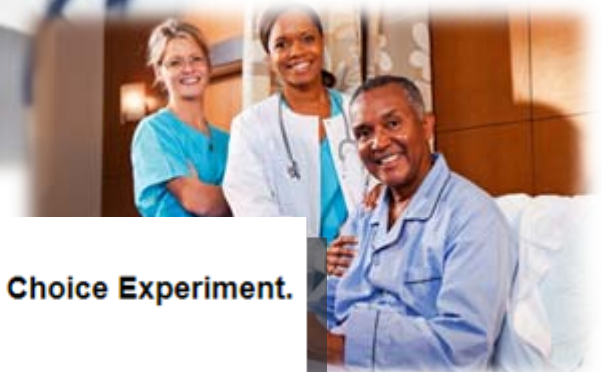
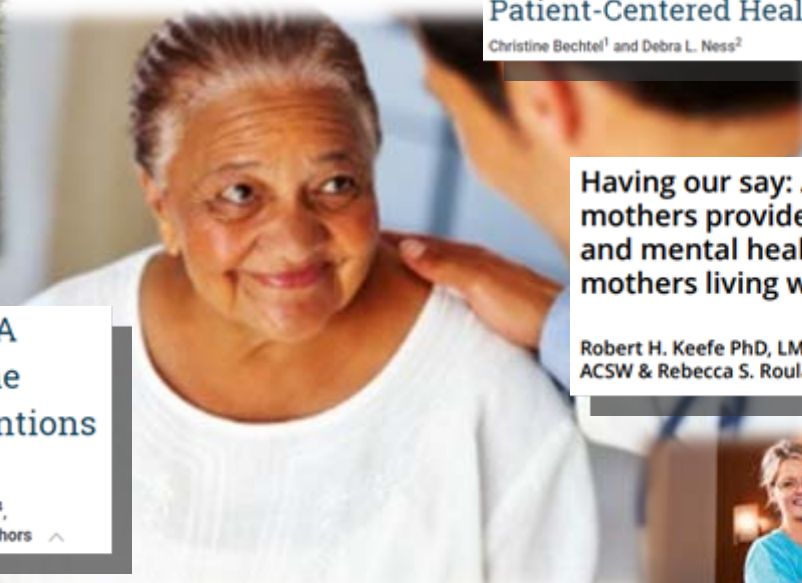
Christine Bechtel¹ and Debra L. Ness²

Having our say: African-American and Latina mothers provide recommendations to health and mental health providers working with new mothers living with postpartum depression

Robert H. Keefe PhD, LMSW, ACSW, Carol Brownstein-Evans PhD, LMSW, ACSW & Rebecca S. Rouland Polmanteer LMSW

Patient And Family Engagement: A Framework For Understanding The Elements And Developing Interventions And Policies

Kristin L. Carman¹, Pam Dardess², Maureen Maurer³, Shoshanna Sofaer⁴, Karen Adams⁵, Christine Bechtel⁶, and Jennifer Sweeney⁷ See fewer authors ^



Health Serv Res. 2016 Apr;51(2):704-27. doi: 10.1111/1475-6773.12345. Epub 2015 Aug 10.

Patient Preferences for Features of Health Care Delivery Systems: A Discrete Choice Experiment.

Mühlbacher AC^{1,2,3}, Bethge S², Reed SD³, Schulman KA³.

⊕ Author information

Patient-Centered Care



Whole-Person Care

- Emphasize dignity and respect
- Reflect cultural differences and preferences
- Understand non-medical factors



Coordination and Communication

- Identify “go to” person
- Promote robust information sharing with patients and care team



Patient and Family Support

- Build trusting, meaningful relationships
- Encourage shared care-planning



Ready Access

- Provide care and information when and where needed



In Their Own Words



Valuing care and connection:

- ▶ *“I see you the first time, or second time, I may not feel comfortable. But, seeing you, grow a connection, a **relationship with you**, I can answer the questions [you ask me].”*
- ▶ *“The people at the front of the clinic matter too... it’s the front people that have to care to get you in...they make you feel like you can keep your **integrity and respect**.”*

Being treated with dignity and respect:

- ▶ *“What I don’t like is when doctors are overbearing. But I do like when they provide information and allow me to make informed decisions... **I like when doctors act like an advisor** instead of condescending.”*
- ▶ *“I would say stop ignoring me. **I feel invisible**. Is it because I am older?”*

Understanding social influences, cultural preferences:

- ▶ *“My doctor understands what I’m saying in my native language. Biggest thing is that **we have a cultural understanding**. I feel like he respects me and understands me.”*
- ▶ *“I really value the **holistic approach to treatment and educating the patient**. Like here at this clinic, they have a cooking class. I can relate it to whatever I am visiting the doctor for, whether it’s my hypertension or diabetes.”*

Misconceptions of Patient Engagement



- ▶ **Getting consumers to do what we want them to do**
 - ▶ Healthy behaviors
 - ▶ Self-management/“compliance”
 - ▶ Interacting effectively with health care providers/system
 - ▶ Brochures and “education”
- ▶ **Point of care – only**
- ▶ **Patient-focused care**
 - ▶ Doing “what’s best for them”
 - ▶ Doing *to* and *for*, but not *with* patients
- ▶ **Designing patient-centered care systems – without patients**

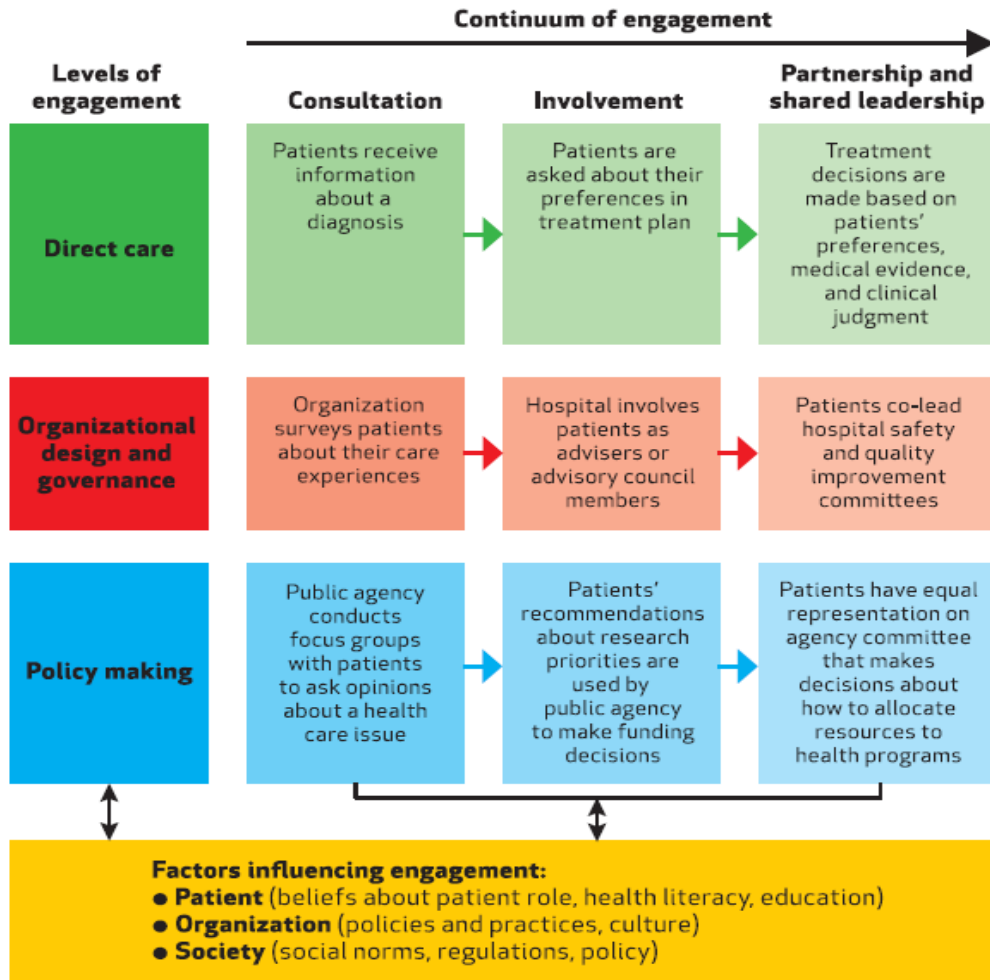
Engagement **Redefined**



- ▶ “Patients, families, their representatives, and health professionals working in active **partnership** at various levels across the health care system – direct care, organizational design and governance, and policy making – **to improve health and health care.**”

- ▶ **SOURCE:** Carman, Kristin; Dardess, Pam; Maurer, Maureen; Sofaer, Shoshanna, Adams Karen; Bechtel, Christine; Sweeney, Jennifer. “Patient and Family Engagement: A Framework for Understanding The Elements And Developing Interventions and Policies.” *Health Affairs* 32 No.2 (2013): 223-231.

Continuum of engagement



- ▶ Striving for partnership and shared leadership
- ▶ Beyond point of care
- ▶ Occurs at every level and throughout the process

SOURCE: Carman, K. L., Dardess, P., Maurer, M., Sofaer, S., Adams, K., Bechtel, C., & Sweeney, J. (2013). Patient and family engagement: a framework for understanding the elements and developing interventions and policies. *Health Affairs*, 32(2), 223-231

Concerns



- ▶ “This work is too technical for patients.”
- ▶ “What patients say they want is nice but we don’t have time – what matters is clinical outcomes.”
- ▶ “Doctors and clinicians know what patients want.”
- ▶ “The payment system doesn’t support it, so it can’t be done.”
- ▶ “If we just build the system the right way, patients will come.”
- ▶ Other examples...?

How to Get Started



- ▶ **Leadership commitment**

- ▶ Identify champions (clinicians and staff)
- ▶ “Walk the talk” – culture/integration

- ▶ **Careful selection**

- ▶ “Right fit” – applies to all stakeholders

- ▶ **Training and coaching**

- ▶ Patient- and family-centered care (PFCC) skill development for staff
- ▶ Ongoing support for patients and families

How to Get Started cont.



- ▶ **Operating principles/”good practice”**
 - ▶ Expectations – scope, rules, responsibilities
 - ▶ Transparency
 - ▶ Trust & relationship building

- ▶ **Making a difference**
 - ▶ Evaluation and showing impact

- ▶ **Authentic partnership – genuine change process**
 - ▶ From the beginning
 - ▶ Everyone changes together

Examples of Partnering in Redesign



- ▶ Include patients and families in quality improvement, safety, research, and redesign efforts; create patient/family advisory councils
- ▶ Jointly develop solutions, in response to patient/family experience surveys and other feedback data
- ▶ Engage patient and family council (PFC) advisors in developing and vetting patient information, educational materials, websites/portals, care planning and support tools and assuring cultural/linguistic appropriateness
- ▶ Involve PFC advisors in “walk-about” to assess care delivery from patient and family perspectives
- ▶ Involve PFC advisors in staff orientation/training
- ▶ Engage PFC advisors in priority-setting at the governance level

For more information



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