

Getting on the Same Page: Patient- and Family Engagement A Multi-Dimensional Framework



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— HEALTH —



Patient- and Family-Engagement

- Are you confident that you can define “patient engagement?”
- Are you confident that the person sitting next to you would define it the same way?





Common Misconceptions re: Patient Engagement

- Most people think of patient education, behavior change, etc.
 - Getting patients to do what we want them to do.
- Big focus on education campaigns, compliance/adherence, “good patients,” “taking responsibility”
- Getting consumers to do what we want them to do, because “providers know best”



What is effective Patient- and Family-Engagement?

“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.”

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



Level of Engagement	Consultation	Involvement	Partnership & Shared Leadership
Direct Care	Patients receive information about a diagnosis	Patients asked about preferences in treatment plan	Treatment recommendations based on patients' preferences, medical evidence and clinical judgment
Organizational Design & Governance	Organization surveys patients about experience of care	Hospital involves patients as advisors or advisory council members	Patients co-lead hospital safety and quality improvement committees
Policy Making	Public agency conducts focus groups with patients	Patients' recommendations about research priorities used by public agency to shape funding decisions	Patients have equal representation on agency committee that makes decisions about resource allocations



Why **NOT**?

- Why is the old approach **ineffective**?
 - Often focus on education only, and not done well; no partnership.
 - Solutions are designed by providers and staff, without patient input.
 - Often ineffective due to misunderstanding barriers and challenges patients face, or their workflow.
 - Old medical model of doing for patients or to them, but not with them



Examples of Partnership: Engagement in Care

- Care plan that is centered on the patient's life goals
 - Co-created with patients and families, where clinical goals are aligned/serve as milestones along the way
- Assessing patient activation and self-efficacy, then designing self management support that is rooted in partnership between the care team and the patient
- Group and peer-led education – shared medical appointments, etc.
 - Provider/clinician led or patient-led; multi-modal; effectively building a peer support network, activating patients.
- Shared decision making



Values Underpinning Engagement in Care

- Whole person orientation
 - What matters to you, vs. what's the matter with you
- Partnership and Shared leadership
 - Collaboration, support and accountability (on both sides!)
- Trust
 - Honesty, communication, access



Engagement in: Design and Governance (e.g. Partnership)

- Put patients on QI/project teams
- Form patient and family advisory councils
- Hold focus groups
- Ask a handful of individual patients and/or family members for feedback
- Involve patients/families in staff orientation/training, hiring, job descriptions.
- Walk-through a partner PCMH to assess care delivery or operations from patient and family perspectives
- Patients on Boards of Directors, shaping planning, etc.
 - Different from advisory councils



Values Underpinning Partnership in Design/Governance

- Meaningful participation and impact
 - Solving important problems, shaping decisions, seeing results
- Partnership and shared leadership
 - Support and accountability (on both sides!)
- Trust
 - Transparency, communication, respect (on both sides!)



Engagement in Policy Making:

- Public comment periods
- Focus groups
- Public opinion surveys
- Town halls & constituent meetings
- Technical Expert Panels
- Online forums
- Etc.



Why Aren't We There Yet?



Common Myths Get In The Way Of Partnering with Patients....

- Patients always want everything.
- What patients say they want is nice (like better experiences) but we don't have time – what matters is clinical outcomes.
- Doctors/clinicians know what patients want/need.
- We can't deliver on what patients ask for, so why ask.



The Essential Equation

Better health and care requires changes in...

- How patients are cared for.
- How care is paid for.
- How patients are engaged.

The Essential Question:

If You Build It, Will They Come?

To Be Continued!