A Framework for Patient- and Family-Engagement

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About us

- **National Partnership for Women & Families**
  - Non-profit, consumer organization with 40 years’ experience working on issues important to women and families
  - Labor, health care
  - National and local work

- **Signature Health Initiative: Campaign for Better Care**
  - Engage patients and consumers in re-design of our health care delivery and payment system
  - Particular focus on meeting the needs of high need/high cost populations – older adults, complex chronic conditions
  - More than 150 national, state, and local organizations
Can you describe the concept of “patient- and family-engagement”?

Do you think your colleagues would describe it the same way?

"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.)
Levels of Engagement

- **Direct Care** – patients and families are part of the care team, and their values, experiences, and perspectives are integrated into their direct care.

- **Organizational Design and Governance** – patients are partners in the design and governance of health care organizations.
  - Enables integration of patients’ and families’ values, experiences and perspectives into health care operations.

- **Policy Making** – patients and families collaborate with policy makers and community leaders to solve community and social problems, shape health care policy, and set priorities for the use of resources.

Factors Influencing Engagement

- **The Patient**
  - Knowledge, attitudes, and beliefs
  - Experience with health care system
  - Functional capacity
  - Self-efficacy – ability to reach goals
  - Caregiver status

- **The Organization**
  - Demonstration that patient’s participation and leadership are central to the achievement of improvement goals
  - Responding positively to patients’ efforts (e.g., inviting and welcoming)
  - Organizational policies or practices (e.g., patient/family participation in QI, training etc)

- **Society**
  - Social norms (PCPCC Consumer Center)
  - Purchasers’ regulations (NCQA PCMH criteria, Medical Home Demo requirements, etc.)
  - National, state, and local policies (HIT Policy Committee)
Framework for Engagement

Levels of engagement

- Direct care
  - Patients receive information about a diagnosis

- Organizational design and governance
  - Organization surveys patients about their care experiences
  - Public agency conducts focus groups with patients to ask opinions about a health care issue

- Policy making
  - Patients' recommendations about research priorities are used by public agency to make funding decisions

Continuum of engagement

- Consultation
  - Patients receive information about a diagnosis

- Involvement
  - Patients are asked about their preferences in treatment plan

- Partnership and shared leadership
  - Treatment decisions are made based on patients' preferences, medical evidence, and clinical judgment
  - Patients co-lead hospital safety and quality improvement committees

Factors influencing engagement:

- Patient (beliefs about patient role, health literacy, education)
- Organisation (policies and practices, culture)
- Society (social norms, regulations, policy)

For more information

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