Patient & Family Engagement Across the Care Continuum

Erin Mackay
Associate Director, Health Information Technology Programs

Courtney Roman
Outreach Manager

Alliance for Home Health Quality and Innovation
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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
    - Health and care, workforce, anti-discrimination

- **Signature Health Care Initiatives:**
  - *Campaign for Better Care*
    - Engage patients and consumers in re-design of our health care delivery and payment system, focused on older adults, multiple chronic conditions
  - *Consumer Purchaser Disclosure Project (CPDP)*
    - Leading collaboration of consumer and employer groups focused on improving care and reducing costs through performance measurement and payment
  - *Consumer Partnership for eHealth (CPeH)*
    - More than 50 consumer organizations advancing health IT in ways that benefit patients and families
What is Patient- and Family-Centered Care?
Model of Patient and Family Engagement
Influencing Delivery System Reform, CMMI Initiatives
  - Role of Home Health
Patient- and Family-Centered Health IT
Care Planning
  - Role of Home Health
Q & A
What is Patient- and Family-Centered Care?

- **Institute of Medicine (IOM)**
  - Care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions.

- **Planetree**
  - An approach to the planning, delivery, and evaluation of care grounded in mutually beneficial *partnerships* among providers, patients, and families. It redefines relationships in health care.
What Do Consumers Want?

- “Whole person” care
- Coordination and communication
- Patient support and empowerment
- Ready access
We All Want The **Same** Things

Patients and Families Want What We All Want

- Better care
- Better health outcomes
- Better experience
- Lower costs

Patients and families care about:
- Clinicians
- Getting better
- Waste and inefficiency
An effective strategy: “Patient and Family Engagement”

How do we get patients and families to tell us what they need us to do?

*We must redefine the ways we engage with them.*
What Patient and Family Engagement is NOT

- Getting patients to do what we want them to do
- Educating them to be “better” patients or “compliant”
- Doing things *for* patients, doing *what’s best for them*, doing things *to* them
- Patients aren’t seen as agents of change
Defining 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.”

Levels of Patient & Family Engagement

- **Engagement in Care**—Partnership to better manage care and improve health status based on patient’s own goals
  - Shared decision-making, joint goal-setting, developing care plans
- **Engagement in Re-design**—Working to re-design care within the facility
  - Care coordination, wait times, improving patient experience, signage
- **Engagement in Governance and Policy**—Setting policy for initiatives and organizations; being engaged at the Board level
  - Members of Quality Improvement, Patient Safety, Patient and Family Advisory Councils, and other workgroups and advisory boards; drafting job descriptions; identifying policies to review, modify, or re-write.
- **Engagement in Communities**—Working with community groups in redesigning care and governing systems/organizations/policies
  - Advising on community resources, serving on governing boards, etc.
Patient & Family Engagement: On-the-Ground

- CMS Innovation Center Demos:
  - Pioneer Accountable Care Organizations (ACOs)
  - Comprehensive Primary Care Initiative (CPC)
  - Partnership for Patients (PfP)

- All partnering with patients and families as a strategy for achieving quality improvement goals

- NP providing technical assistance to providers/clinicians, executive leadership, other staff, patients, and families
Team-based patient- and family-centered care at home
- Authorized by Affordable Care Act (ACA)
- Care planning
- Recognition of patients’ goals
- Care includes what is typically done in hospitals—tests, x-rays, imaging, etc.

House Calls National Advisory Network
- Over 900 operating house calls programs nationwide
- Identifying best practices, creating standards and measures
- Advisory group consisting of consumers, physicians, policy makers
  - National Partnership participates as a consumer representative
Patient- & Family-Centered Care

- Ready Access
  - Expand access beyond 5-minute phone call or 7-minute office visit
  - Patients receive medication, lab results, etc.
  - Keeping wait times brief, allowing care team members available when needed
  - Accommodating limited physical mobility, cognitive impairment, language, and cultural differences

- Patient-Centered Care
  - Patients viewed as whole person rather than collection of body parts
  - Treatment recommendations align with patient’s values, life circumstances, preferences

- Whole Person Care
  - Clinicians understand full range of factors affecting a patient’s ability to get and stay well

- Patient Support & Empowerment
  - Providers organized in teams
  - Clinicians take time to really know and remember patients
  - Help choosing specialists and getting appointments via a timely manner
  - Ensuring other providers have patient’s information ahead of time through health information exchange

- Coordination & Communication
  - Patient partnership with clinicians choosing treatment options, goals, plans, team members, etc.
  - Trust and respect patient preferences, physical and emotional comfort, and privacy
  - Expanding patients’ and caregivers’ capacity to get and stay well (efficacy)
  - Go-to person to navigate system and help patients understand their condition and what they need to do

What do patients want?

- Their doctors to talk to each other.
- To know that all the members of their care team have the information and support they need to do the best job they can.
- Information that helps them better understand their conditions and care effectively for themselves and their family members.
- A health care provider who really knows them enough to recommend treatments that make sense based on their unique needs, preferences and life circumstances.

Health IT = enabler of patient- & family-centered care delivery
What is Health IT?

- Collecting, sharing, and using electronic health information for communication and decision-making\(^1\)
  - Electronic Health Records
  - e-Prescribing
  - Computerized Provider Order Entry (CPOE)
    - Secure Messaging
  - Personal Health Records/Patient Portals
  - Clinical Decision Support
  - Medication Management Technologies
  - Implantable and/or Monitoring Devices
  - Telehealth

\(^1\) Thompson, T. and Brailer, D. Health IT strategic framework. DHHS, Washington, DC, 2004.
What is Health IT?

- Health IT has the potential to revolutionize the way our health care system operates.
  - Facilitates provider access to necessary information about their patients and the latest science pertaining to their care
  - Improves quality and safety of care
  - Integral to new models of care delivery and payment
    - To achieve full potential, must connect to the full continuum of health delivery & payment settings
What is Patient-Centered Health IT?

- Health IT implementation & use that is meaningful to patients & families; they experience a real difference in the way care is delivered:
  - Timely, online access to comprehensive health information
  - Secure online messaging with providers
  - Patient reminders
  - Education materials
  - Summaries of care, treatment recommendations, discharge instructions
  - E-tools and applications to collect, use, & share health data
  - Shared Care Plans**

- Linguistically & culturally appropriate; via diverse and accessible technology platforms
  - For promise of health IT to be realized, consumers must both trust & value it¹

Care Plans

- Nursing Care Plan
- Cancer Survivorship
- Medicare Home Health
  - Services needed
  - Recommended health care professionals
  - Frequency of services
  - Medical equipment needed
  - Results expected
Consumer Vision:

- A multidimensional, person-centered health & care planning process facilitated by a dynamic, electronic platform that connects individuals, their family and other personal caregivers, paid caregivers (such as direct care workers and home health aides), and health care and social service providers, as appropriate.

- The care plan supports all members with actionable information to identify and achieve the individual’s health and wellness goals.
  
  - Roadmap for patients, families, and health care providers to follow toward the best possible health or functioning.
1) Care plans should be goal-oriented, dynamic tools (not static documents).

2) Care planning and tools should facilitate decision-making and specify accountability.

3) Care plans should identify and reflect the ability and readiness of an individual (and caregiver) to successfully meet their goals, as well as potential barriers.

4) Tools that facilitate care planning should enable all members of the care team to securely access and contribute information, according to their roles.

5) Every individual would benefit from care planning and tools.
Care plan examples are a work of fiction...

But inspired by my great Aunt, Bai:

- 85 years old, widow
- Bruce, Mississippi
- Sharp as a tack, storyteller extraordinaire
- Type II diabetes, family history of high cholesterol
- Fear of falling, repercussions

  **GOAL:** *Live independently as long as possible*

Key Factors

- Active & engaged caregiver support
- Strong primary care team (coordinating with community resources)
- Lack of transportation (no longer driving)
- Southern diet
#1: Goal-Oriented, Dynamic Tools

- Care plans should be goal-oriented, dynamic tools (not static documents).
  - Centered on the achievement of goals identified by the individual
    - Captures information about individual’s needs, preferences, and values
  - Contain specific and measurable action steps
    - Long-term goals broken down into incremental steps
  - Flexible and accommodate real-time updates
    - Goals, action steps based on changing circumstances, previous experience
  - Reflect actions for healthy living
    - Not developed exclusively from a medical perspective
#2: Specify Decision-Making & Accountability

- Care planning and tools should facilitate decision-making and specify accountability.
  - Monitor both patient and care team member progress
    - Completing action steps, achieving goals
  - Clearly reflect what action is to be taken, by whom, and when
    - Initiation, revision of care plan must be acknowledged
  - Connect to clinical decision-support (CDS) tools
    - Trigger modification of care plan, addition of action steps
Care plans should identify and reflect the ability and readiness of an individual (and caregiver) to successfully meet their goals, as well as potential barriers.

- Take into account differences in culture, language, and faith
- Capture information regarding an individual’s:
  - Knowledge, skills, and confidence
  - Needs for reasonable accommodation
  - Health and health IT literacy needs
- Consider both barriers and facilitators to achieving goals
  - Social assessment information
  - Environmental barriers
- Include arrangements for additional information and supports necessary
Tools that facilitate care planning should enable all members of the care team to securely access and contribute information, according to their roles.

- Accessible across health care settings and to non-health care supports to enable refinement and updating at the point of care
  - Allow individuals to share selected information with different care team members
- Individuals granted access by the patient should be able to initiate modifications and record progress
- Organized or customizable into different views
  - Non-medical language
  - Consumer friendly, accessible interfaces
Every individual would benefit from care planning and tools.

- Every individual should have the ability to initiate the care planning process
  - Initially prioritized for those with the greatest needs for care coordination and planning
- Advanced as a routine activity
  - Integrate planning process into wellness visits
- Scalable to support individual needs and stages of life
  - Ability to initiate (and suspend) the care planning process consistent with individual needs and priorities
Next Steps

- **Formal release of Consumer Principles**
  - Fall 2013

- **Challenges**
  - Technical
  - Policy
  - Cultural
If you build it *with* them – They will already be there!

Questions?
For more information

Contact me:
Erin Mackay
emackay@nationalpartnership.org

Courtney Roman
croman@nationalpartnership.org
(202) 986-2600

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