Consumer Priorities for Health & Care Planning in an Electronic Environment

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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

- **Consumer Partnership for eHealth**
  - More than 50 consumer organizations advancing health IT in ways that benefit patients and families
  - *Making IT Meaningful: How Consumers Trust & Value Health IT*
    - In-depth survey detailing consumer experiences with both electronic and paper medical record systems
  - *Leveraging Meaningful Use to Reduce Health Disparities: An Action Plan*
    - Evidence-based action plan for leveraging the EHR Incentive Program to reduce health disparities and make a positive life-altering impact for the nation’s underserved and vulnerable populations
Patient- & Family-Centered Care
Patient-Centered Health IT

- Health IT implementation & use that meets the needs of patients & families
  - Timely, online access to comprehensive health information
  - e-tools and applications to collect, use, & share health data
- Linguistically & culturally appropriate
  - Diverse languages, need for linguistic competency and translation
  - Range of literacy in reading, health care, and electronic technology
  - Diverse cultures and communities, need for cultural competency
- Via diverse and accessible technology platforms
  - Differing needs of older people and younger people
  - Diverse abilities and disabilities
- For promise of health IT to be realized, consumers must both trust & value it

Areas of Focus

- CPeH amplifies the consumer voice to ensure that health IT initiatives and policies are implemented according to the needs of patients and families

Reducing Disparities
Health Information Exchange & PGHD
Care Planning
Consumer Access & Blue Button
Policy Presence (Hill & Admin)
Public Education / Media
Meaningful Use
Care Plans 2.0
The Next Generation

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.
Consumer Principles for Health & Care Planning

1) Care plans should be goal-oriented, dynamic tools.

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 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:
- 85 years old, widow
- Bruce, Mississippi
- 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.

- Reference and consider race, ethnicity, culture, language, faith, and disability status

- 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
  - Environmental barriers
  - Social assessment information

- Include arrangements for additional information and supports necessary
  - Transportation, interpretation, child care, health education, etc.
#4: Secure Access

- 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
#5: Care Planning for All

- **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
  - 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

- Challenges
  - Technical
  - Policy
  - Cultural

- Role of *Consumer Principles*
Thank You!

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