Care Plans 2.0

Consumer Principles for Health and Care Planning in an Electronic Environment

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Care Plan 2.0: A multidimensional, person-centered health and care planning process facilitated by a dynamic, electronic platform that connects individuals, their family and other personal caregivers, paid caregivers (such as 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.

The lack of coordination and communication is one of the most ubiquitous consumer complaints about the US health care system,[1] and is a key driver of poor quality and unaffordable care. A major contributor to this problem has been the failure to plan and communicate effectively across settings and clinicians, with active engagement by all members of the care team – including individuals and their family and other designated caregivers.

Care plans are gaining increasing attention among federal health policy makers[2] as a tool to enhance care coordination and optimize health outcomes. While the concept of a care plan is not new, there is little uniformity in what these plans look like or how they are used. To achieve robust and effective planning and communication, we must move beyond our mental construct of a care plan as a document fixed in time, to a multidimensional, person-centered health and care planning process built on a dynamic, electronic platform.[3] This next generation of care plans –Care Plans 2.0 – should function as a 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) **Tools that facilitate care planning should enable all members of the care team to securely access and contribute information, according to their roles.**
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) **Care planning and tools should facilitate decision-making and specify accountability.**
5) **Every individual would benefit from care planning and tools.**

As the health care system moves toward a focus on wellness, these next-generation care plans offer the opportunity for patients and their loved ones to play leading roles with their care team in identifying and pursuing the health and wellness goals most meaningful to them. Of course, early efforts to develop care plans will, and should, focus first on those with the greatest need – individuals needing more complex care, such as those with chronic conditions. However, our approach to care planning should evolve from episode- or illness-based care planning to proactive, all-encompassing wellness planning, from which all individuals stand to benefit. Proactive development of a care plan for all individuals who want one will require a shift in cultural norms and expectations. To begin the transition, the process could build upon pre-established interactions with the health care system, such as childhood immunizations, annual wellness visits, or pneumonia vaccinations for seniors.

While human interaction drives the process of care planning, technology can help make necessary information more readily available and actionable, connect all people who have a role in an individual's care plan, and provide a shared platform for the ongoing maintenance and management of an individual's care and wellbeing. Electronic platforms also make it possible to scale plans according to individual needs and various stages of life – supporting, for example, a woman during her childbearing years, helping to manage chronic or debilitating conditions, and ultimately guiding her advance directives toward the end of life.

If the care plan depends on having a family caregiver, the caregiver's own needs for information and training should be identified in the planning process to ensure that the caregiver has the capacity to meet the expected responsibilities in the care plan and achieve better outcomes for the individual's goals. Proactively and explicitly engaging an individual's family and caregivers in the development of a care plan helps to ensure the individual's abilities, culture, values, and faith are respected and care instructions and action steps are more likely to be understood and followed.

The Electronic Health Record "Meaningful Use" incentive program offers an immediate opportunity to advance the technological foundation for care plans, and the process of care (and ultimately wellness) planning. The following set of overarching principles is a consumer-directed starting place for building the functionality to support care planning into health IT.

Consumer Principles

1. Care plans should be goal-oriented, dynamic tools (not static documents).

- Care plans should be centered on the achievement of goals identified by the individual (or designated caregiver), supported by appropriate clinical goals.
    - Information about an individual's needs, preferences, and values should be captured as part of the care plan and updated as needed.
    - Care plans should address the unique needs of individuals and diverse populations.
- Care plans should contain specific and measurable action steps necessary for meeting agreed-upon goals.
    - Longer-term goals should be broken down into short-term, incremental steps.

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- Care plans should be flexible and accommodate real-time updates based on changing circumstances and previous experience. This may include revision of the goals themselves, as well as the individual steps in the plan.
- Care plans should reflect actions for healthy living, and should not be developed exclusively from a medical perspective.

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

- Relevant information from care plans should be accessible across health care settings and to non-health care supports in the community to enable refinement and updating at the point of care.
    - Care plans should allow individuals to select and share selected information with different care team members, as the patient chooses.
    - A list of care team members and contact information should be included.
- Individuals, family and other designated caregivers, and health care providers granted access by the patient should be able to initiate modifications and record progress related to care plans, including new barriers to achieving goals and changes in circumstances or lifestyle.
    - A record of when the care plan was last updated and who made modifications should be kept.
- Care plans should be organized or customizable into different views in order to enable each care team member to see clearly what his or her assigned actions are, relative to the comprehensive plan.
    - Care plans should be displayed to patients and families in non-medical language and leverage accessible, consumer-friendly interfaces.

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.

- Care planning should reference and consider race, ethnicity, language, culture, faith, sexual orientation, gender identify, and disability status, which may inform an individual's perspective on health and health goals and influence the development and implementation of care plans.
- Information about an individual's knowledge, skills and confidence related to managing their own health and care, needs for reasonable accommodation, as well as health and health IT literacy needs, should be captured as part of the care plan and updated regularly.
- Care plans should take into consideration both barriers and facilitators to achieving stated goals.
    - Social assessment information and environmental barriers relevant to an individual's ability to achieve the agreed-upon goals should be integrated into the care plan.

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    - Arrangements for additional information and supports necessary to address barriers should be included in the care plan. This may require coordination with and management of non-medical community resources and supports ("enabling services"), such as transportation, interpretation, case management, child care, and health education, in concert with medical interventions.

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

- Care plans should include a method of monitoring both patient and care team member progress in completing action steps, as well as in meeting agreed-upon goals to improve health outcomes and maximize functionality.
- Care plans should clearly reflect what action is to be taken, by whom, and when, in order to ensure clarity of responsibility and support coordination of care.
    - An initiation or revision of a care plan should always be followed by mutual confirmation of each relevant actor's understanding of the plan and his or her role in the plan.
- Care plans should connect to clinical decision-support (CDS) tools so that clinicians are able to receive automated prompts based on patient-specific goals, preferences, and clinical information.
    - Identification of high-risk behaviors or adverse health events should trigger the modification or addition of action steps in the care plan.

5. Every individual would benefit from care planning and tools.

- Every individual should have the ability to initiate the care planning process and care planning should be advanced as a routine activity.
    - Development of care plans should initially be prioritized for individuals with needs that would most greatly benefit from better care coordination and planning, such as individuals with disabilities or multiple chronic conditions.
- Care plans should be established prior to a crisis situation, when possible. Care plans should be scalable to support individual needs and stages of life.
    - Care planning may not be a priority for every individual at any given time. Individuals should be able to initiate (and suspend) the care planning process consistent with their needs and priorities.

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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. More information is available at www.NationalPartnership.org.

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1 Campaign for Better Care Focus Group Report, Lake Research Partners, 2009.

2 National Quality Forum, ONC HIT Policy & Standards committees, Standards & Interoperability Framework.

3 For purposes of brevity, we refer in places to "patient" and "care plan," though these terms to some could imply a medical model with a focus on episodes of illness. The independent living movement uses the terminology "integrated person-centered planning" in lieu of "care planning," which we support. Choice of terminology is particularly important for purposes of care planning and care coordination, when the worlds of independent living and health care provider intersect.