

The Problem

The HITECH investment of \$22.6 billion dollars and the ACA investment of \$940 billion will fail without designs and implementations that are directly focused on engaging patients and their caregivers.

Project Overview

A 2 to 3-year pilot program with a minimum of 3 states designed to support patients and caregivers following post-hospital discharge, with the aim of improving recovery and reducing hospital readmission. This project will leverage emerging HIE infrastructure and create multiple means for patients and their advocates (i.e., caregivers, providers, and community-based organizations) to better understand patients' care needs and resources available through a shared information and support gateway that takes advantage of available patient specific clinical information (starting with the hospital discharge summary).

The system design will include a caregiver website, caregiver hotline, and local care coordinators to identify or clarify support needs and coordinate local healthcare and community services options for both caregivers and patients. Caregivers are a critical untapped and too often unsupported patient resource. The project will fortify the estimated 42.1-61.6 million family caregivers in the U.S. that provide care to an adult with limitations in daily activities during the year.¹

The project is designed to meet or exceed the Partnership for Patients' goal of 20% reduced hospital readmissions by 2013 and achieve the strategic goal of empowering patients and caregivers with Health IT. The project will anticipate the outreach and education tools and content needed to make patients and caregivers aware and engaged in their automated clinical information. The project will also transform clinical information, including online discharge summaries and instructions, into accessible, understandable and actionable consumer information.

Project Design

A shared patient-centered eHealth Literacy (eHL) gateway will either stand alone or work under the umbrella of state-level or community-based HIEs. The platform will help patients and caregivers use the communication channels they choose and, gain access to needed health status and health care information. The shared services model used to implement the eHL gateway will make the total cost more affordable, cost-effective and scalable.

The project design is flexible and can build upon existing and emerging health care delivery improvements in a given community, including patient centered medical homes, home-based care initiatives, Beacon communities and ACOs. The platform will use the best available interpretive, education and support tools related to targeted post-discharge health needs. It will leverage emerging best practices for consumer outreach and education regarding health IT, privacy and security, and the relevant consumer-oriented health information.

Each participating state or community will select the reform or healthcare delivery initiative in their state that could most benefit from the reinforcement of consumer and caregiver-facing support. The project

¹ National Alliance for Caregiving, and AARP. *Caregiving in the U.S. 2009*. Rep. MetLife Foundation, Nov. 2009. Web.

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builds upon the recognition that “only 10-20% of health outcomes are determined by health care”². This project will focus on the remaining 80-90% that are largely determined outside of the healthcare system and use the combined support structure to augment targeted interventions selected by the state or community to help inform patients and caregivers’ understanding and actions during the time they are not readily influenced by their providers.

The eHL Gateway and Caregiver Support System

The eHL gateway will be the one-stop secure access point for individuals or their designees/caregivers to access health information and tools that are written in plain language. The vast majority of patients discharged from the hospital to home have someone acting on their behalf in a caregiver capacity. The project will help support the caregiver such that s/he can assist the patient post-discharge and readily navigate information resources on behalf of the patient in addition to resources that can uniquely assist the care e.g., respite services. Key components of the eHL and caregiver system include:

- Consumer website with health, HIT and patient-specific health information and support needed for the targeted post-discharge patient population
- Caregiver website with resources for local healthcare and services options and caregiver access to the eHL platform for patient advocacy
- Call center support with warm transfers to specific state resources and health and tech support for patients/caregivers
- eHL and call center providing caregiver to local care coordinator connectivity
- Navigational tools enabled with preferred means of communications
- Linkages to the HIE, EHRs and PHRs as appropriate to the state designs
- Provider links including case managers, nurse call centers, and home health services with patient/caregiver permission.
- Consumer advocacy and community-based organization interfaces that support linkages and downloading of patient/caregiver support resources.
- Content from government and leading disease organizations, including best practices.
- Multiple language options
- mhealth connectivity and cell phone messaging via the website and call center to support communication and tracking of early risk indicators
- Monitoring device information tracking and needed feedback
- Local staff resources trained to serve in the role of care coordinator and form a care coordination network

² Presentation from Lygeia Ricciardi, ONC’s Senior Policy Advisor on Consumer eHealth “Engaging Consumers with HIT” NeHC University September 16, 2011
October 2, 2011