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Introduction

This document describes the Consumer Consortium on eHealth. It is a working draft and will be revised as needed as the project evolves, based in part on feedback from members of the Steering Committee and participants in the Consortium. This document sets forth the intended project scope, goals, rationale, benefits of participation, roles and responsibilities of participants, and initial work plan.

Project Scope

The ambition of this project is bold. We hope to begin to alter our society's conversation about what is possible and what should be possible in healthcare. This will only be achieved through collaborative, grassroots, industry-wide work, and effective and ongoing engagement with consumers, and ultimately, providers and other stakeholders.

The scope of this project is to convene a broad, cross-section of stakeholders to develop and coordinate a program to encourage individuals to become more engaged in their health and healthcare through the use of health information technology (IT). The Consumer Consortium on eHealth will serve as a collaborative forum for sharing best practices, initiatives, tools, resources, ideas, and experience related to effective consumer engagement on health IT. The Consortium will build on the collective wisdom, expertise and credibility of the participants and aim to reach consensus on strategies, tactics, approaches, and an overall program for consumer engagement in eHealth. This will allow participants in the Consortium to engage with their constituents within the context of a broader coordinated program, thereby increasing its impact. Ultimately, we hope this program will lead to better communication between individuals and their providers to support further development and use of health IT to improve health and healthcare.

The Consortium will strive to complement and support rather than replicate other efforts. The Consortium will not focus on policy issues.

Goals

- Convene a diverse group of stakeholders to share best practices and develop a coordinated program for effective consumer engagement in eHealth
- Engage and empower consumers on the applications, tools and benefits of eHealth within their lives so that they can make better decisions, receive better care, and have a better experience
- Cultivate better communication and collaboration between individuals, their providers, and their healthcare teams to support further progress in adoption and use of health IT in a manner that will result in better outcomes
- Identify obstacles to the adoption of eHealth and brainstorm methods for overcoming them
- Create a communications infrastructure that enables two-way communication/interaction with millions of consumers nationwide which, in addition to the goals of this project, may have important future uses we aren't yet imagining
- As the public and private sectors invest billions in health IT, we aim to bring the voices and needs of consumers to the forefront in the early stages of developing this new generation of health IT infrastructure so that it can best serve this constituency
- The program developed and implemented by the Consortium will be culturally appropriate/sensitive and accessible by all populations

Rationale

- Studies show that people:
 - Are increasingly using IT to enrich other aspects of their lives
 - Want electronic access to their health information
 - Want their providers to share information to better coordinate care, reduce costs, and avoid errors

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- Want to communicate electronically with their providers
 - Want assurances that their information is protected
 - Are dissatisfied with many aspects of healthcare that eHealth can address
- Better health information in the hands of consumers and providers should lead to better health decisions, which, in turn, should lead to better health, saved lives, reduced costs, etc.
- The Office of the National Coordinator for Health Information Technology's (ONC's) recently released Strategic Plan emphasizes empowering individuals with health IT to improve their health and the healthcare system as one of its top 5 goals
- Under HITECH, the Federal government is investing an estimated \$30 billion to encourage meaningful use of electronic health records (EHRs) as well as supporting programs and infrastructure development, and patient engagement is an important component of meaningful use of EHRs
- ONC is also launching a nationwide outreach campaign and would like to improve and leverage it by collaborating with other interested stakeholders
- Health reform efforts offer a timely opportunity to reshape healthcare in ways that include designing and providing financial incentives for patient-centric models of care and for shared decision making among providers and patients
- We have an opportunity through consumer engagement to help the use of health IT to catch up with other consumer uses of IT (e.g., banking, travel, shopping) – and begin to accelerate a transformation that is already underway

Benefits of Participation

- Be a part of an industry-wide, multi-stakeholder, coordinated effort working to:
 - Help individuals be more engaged in their health and healthcare through eHealth tools
 - Encourage communication between patients and providers on health IT
 - Continue to transform the views of the professionals who deliver healthcare services and the people who receive them regarding the full benefits of health IT
 - Begin to transform the healthcare system with goals aligned with the Administration, HHS and ONC
- Tap into a national brain trust of best practices, initiatives, tools, resources, wisdom and experience for engaging and motivating consumers
- Through collaboration and coordination among many stakeholders with a shared vision for consumer engagement in eHealth, have greater reach and impact than any single organization could have on its own

Roles and Responsibilities of Participants

This initiative is intended to be inclusive and to encourage participation among all interested stakeholders. There will be multiple levels of participation, including but not limited to, a convener, Steering Committee, Founding Member, and general participant. All stakeholders who participate in the Consortium will be expected to be respectful of others' perspectives and opinions, be open and willing to share their perspectives as well as their relevant experience and initiatives, and to offer constructive feedback and advice.

National eHealth Collaborative (NeHC) – NeHC is a public-private partnership dedicated to tackling barriers and accelerating progress regarding health IT and health information exchange (HIE) to improve health and healthcare. NeHC is serving as a neutral convener of the Consumer Consortium on eHealth to bring together experts and interested stakeholders. We believe that multi-stakeholder collaboration and coordination among leaders from interested organizations is the best way to have a large scale and meaningful impact on consumer engagement. In its role as convener and as part of its mission, NeHC is covering the initial costs of pulling the group together. Given its limited resources and depending on how the work of the Consortium evolves, it may be necessary to raise additional funds to cover the costs of the project.

Consumer Consortium on eHealth Steering Committee – The Steering Committee is made up of 12 nationally known health IT experts who share a passion for consumers. The Steering Committee will provide leadership and expertise to plan the effort and will actively participate in the Consortium. The following organizations have representation on the Steering Committee: Office of the National Coordinator for Health IT, National Partnership for Women and Families, Consumers Union, National Patient Advocate Foundation, Continua Health Alliance, National Association of Community Health Centers, AARP, American Association of People with Disabilities, Dossia Consortium, ePatient Dave DeBronkart, Kanter Family Foundation, National Health IT Collaborative for the Underserved, and National eHealth Collaborative. Participants on the Steering Committee are offering their time and expertise as an in-kind contribution to the Consortium. For example, the Joseph H. Kanter Family Foundation and Health Legacy Partnership contributed in-kind services in conducting and synthesizing research.

Consumer Consortium on eHealth Founding Members – A wide range of healthcare stakeholders have been invited to join to Consumer Consortium on eHealth as founding members. Those who agree to join as founding members will be recognized for their commitment to the initiative and will have the opportunity to offer input and advice to the Steering Committee.

Consumer Consortium on eHealth Participants – All interested stakeholders are welcome to be participants in the Consumer Consortium on eHealth. Participants will have the opportunity to leverage the Consortium's program to engage with consumers on eHealth, tailoring the approach as needed for their key audiences.

Revised as of April 15, 2011

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