2014 Activities and Accomplishments

Year in Review: In 2014, the Consumer Partnership for eHealth (CPeH) achieved major advances and continued to champion the foundational role of health IT to empower consumers to improve health and support health system transformation. CPeH celebrated consumer achievements on the five-year anniversary of the HITECH Act, increased consumer representation on federal committees and other external workgroups, and informed the development of a nationwide survey on consumer experiences with health IT.

Additionally, the coalition continued to leverage the policy transformations occurring through the Electronic Health Record (EHR) Incentive Program ("Meaningful Use"), furthered its signature initiatives on person-centered care planning and reducing health disparities, and provided the consumer perspective via multiple formal comments.

> **As the leading consumer voice on health IT policies and practices, CPeH is a vital force for ensuring that health IT remains a catalyst for patient and caregiver engagement, coordination of care and better health outcomes.**

Looking Ahead: 2015 will be another significant year for the Meaningful Use program with proposed requirements for the third and final stage of incentive payments on the horizon. The coalition will redouble its efforts to protect gains and advance recommendations that improve patient engagement, electronic access to and sharing of health information, disparities reduction and health and care planning.

Looking forward, we anticipate an increased focus on the issue of interoperability. To ensure progress of consumer priorities, we plan to frame our key issues through the lens of *consumer* interoperability, because interoperability must include patients and their caregivers as equal partners in electronic access to and use of their own health information. **We look forward to working with coalition members and allies to advance the consumer vision for health IT and deliver tangible benefits to patients and families across the nation.**

EHR Meaningful Use Incentive Program:

The Meaningful Use Program is currently one of the most significant venues for presenting and advocating consumer needs and interests in health IT. The Consumer Partnership was active and effective in 2014.

- **Stage 3**:
  - **The Consumer Partnership secured significant advances for patients and families by advocating criteria that the HIT Policy Committee adopted and recommended to the National Coordinator for Stage 3**, including the inclusion of patient-generated health data, the availability of patient education resources in language other than English, the capture of more granular demographic data, and the stratification of clinical quality measures by disparity variables.

- **Calls for Delay**:
  - In 2014, major stakeholders, including trade associations and some members of Congress, continued to call for delaying aspects of Meaningful Use. Throughout these calls, CPeH was often **the sole consumer voice strongly opposing delaying the key benefits for patients and families, and urging the administration to stay the course**.
  - In May, CMS and ONC released a Notice of Proposed Rulemaking (NPRM) formalizing changes to the timeline of Meaningful Use, as well as proposing changes to the required

certified technology providers must use for 2014. CPeH submitted a **comment letter** expressing disappointment with the continued delays.

- **Voluntary EHR Technology**:
    - In February, ONC issued an NPRM for the next edition (the "2015 Edition") of EHR technology certification criteria. The proposed rule launched ONC's new regulatory approach that includes more frequent rulemaking for the technological criteria that certified EHR technology providers must use to demonstrate Meaningful Use.
        - Importantly, the NPRM proposed a number of essential criteria which would build the technological capacity to support policy requirements that are important to patients and families. **Accordingly, CPeH devoted considerable time to analyzing the rule, gathering members' input, consulting with various experts on numerous technology issues and preparing extensive comments**.
        - In September, ONC issued a final rule on EHR technology certification criteria. To our surprise, the agency reversed course and decided not to adopt the proposed 2015 voluntary criteria. However, ONC acknowledged the coalition's comments on several proposed criteria and indicated plans to consider them in subsequent rulemaking.

- **Consumer Representation**:
    - When ONC reorganized the Federal Advisory Committee workgroups over the summer, we successfully advocated maintaining a standalone Consumer Workgroup. Ultimately, CPeH members and National Partnership staff increased their representation on several of the committees, workgroups, and subgroups of ONC's Health IT Policy and Standards committees influencing Meaningful Use and other federal health IT policy.

HITECH Five Year Anniversary:

February 17 was the fifth anniversary of the Health Information Technology for Economic and Clinical Health (HITECH) Act, the law that created Meaningful Use.   The Consumer Partnership celebrated five years of progress in giving patients and families online access and tools to manage their health.

- To thank President Obama, HHS Secretary Kathleen Sebelius and National Coordinator for Health IT Karen DeSalvo, CPeH sent them an anniversary card. **Eighteen CPeH member organizations and more than 2,600 consumer activists from all 50 states and Puerto Rico signed the "Happy HITECH Anniversary" card on February 12-14, 2014.**
- Later that month, Dr. DeSalvo included the coalition's card in a high-profile keynote presentation before more than 37,000 health care IT professionals, clinicians, executives and vendors from around the world at the HIMSS14 conference in Orlando, Florida.

Consumer Interoperability:

Health information is only useful if the end user can access and understand the information received. Interoperability is the ability for two systems (or people) to electronically exchange and use data. Over the summer, ONC released a paper outlining its 10-year plan to achieve an interoperable health IT infrastructure in an effort to reduce costs while improving population health and patient engagement.

- On September 12, the Consumer Partnership submitted comments on ONC's Interoperability Vision Paper highlighting the role of consumers in advancing interoperability efforts.

- On September 19, CPeH received a **[letter from National Coordinator Dr. Karen DeSalvo](#)** **thanking the coalition for its thoughtful comments and acknowledging the Consumer Partnership as a valued partner in national health IT efforts.**

Congressional Education and Outreach:

- **Disparities Action Plan**
  - o In March, Senator Baldwin led a Senate letter sent to ONC and CMS in support of leveraging Stage 3 of Meaningful Use to reduce health disparities. The letter was signed by Senators Menendez, Baldwin, Brown, Blumenthal and Warren. **The letter highlighted the Disparities Action Plan released by CPeH in 2013 and called particular attention to CPeH's recommendations to improve data collection and use, health literacy and communication, and patients' access to health information.**
  - o The Senate letter was a companion to a February letter led by Representatives Capps and Takano and signed by twenty-four members of the House of Representatives. **Both letters were the result of our extensive outreach to educate Congressional members on the intersection of health IT and health disparities.**

- **Care Planning**
  - o In June, six U.S. Senators sent a letter to ONC and CMS in support of improving advance care planning in Stage 3 of Meaningful Use. The letter, led by Senator Bill Nelson, was the result of extensive efforts to educate members of Congress on how health IT can help to ensure that patients' wishes are respected and their voices heard. **The letter made two requests that are directly aligned with CPeH's vision for Stage 3.**

- **The Health Equity and Accountability Act (HEAA, H.R. 5294)**:
  - o The National Partnership co-led the health IT title (Title XIII) in HEAA, which addresses the use of health IT in the legislation's broader effort to eliminate health disparities.
  - o In July, National Partnership staff briefed the Congressional Tri-Caucus staff on the bill's health IT provisions. In November, the National Partnership participated in the HEAA Day of Action urging Members of Congress to support the bill.

- **Other Digital Health and Data Initiatives:**
  - o **21st Century Cures:** On July 21, the National Partnership submitted comments responding to the House Energy & Commerce Committee's Digital Health Care white paper, which sought ideas about how to improve the digital health care landscape. The comments called for Congress to expand the Meaningful Use program, leverage health IT to advance health and care planning, continue funding to foster innovation, and include consumers in innovation efforts.
  - o **Wyden-Grassley Health Care Data Transparency:** On August 8, the National Partnership submitted comments in response to a request from Senators Wyden and Grassley on data transparency and accessibility. The comments encouraged Congress to weave patient and consumer perspectives throughout efforts to increase data transparency and accessibility.

Consumer Survey:

In December, the National Partnership for Women & Families released a comprehensive survey that probes consumer experiences with and attitudes toward health IT and EHRs, [Engaging Patients and Families: How Consumers Value and Use Health IT](#). Much has happened in the health IT landscape since

the National Partnership fielded its baseline survey in 2011, so the organization conducted a follow-up survey in 2014 to gauge the impact of this evolution from the perspective of patients and families. The new survey offers an in-depth look at how patients value and use health IT, and which functions are important to them.

- **The survey included additional questions in 2014 to gather information on issues important to coalition members—such as caregiving, care planning, goal setting and mobile access—and better understand patients' demand for more robust features in these areas.** The survey oversampled three different populations who are frequently underserved in the U.S. health care system today — African American, Hispanic and Asian American adults – to assess their perceptions and experiences of health IT. We also collected new data on sexual orientation and gender identity, as well as from individuals with a major disability.
- The survey not only yielded extensive findings to support patients' and families' policy proposals, but they also disclosed seven key strategies for effectively engaging patients and families in their care. **The survey will inform and reinforce the coalition's advocacy to implement health IT policy and practices that provide the tools all consumers need to promote better care and better health.**

Advocacy Materials:
We created fact sheets that explain health IT, its importance for patients and families, and federal policy initiatives in relatable terms, and made these and other documents available online for advocates and the public to use.

- Five Years of HITECH: Progress and Opportunities
- Health IT: Foundation of Health Reform
- Consumer Benefits of Health IT
- What Health IT Means for Women

Coalition Meetings and Communications:
We continued regular communication with emails and webinars to educate coalition members on hot topics and gather their feedback, experience, and expertise to inform our ongoing advocacy. For the first time, we offered a number of online demonstrations of electronic tools that engage patients throughout the care of themselves and their family members, including those that engage consumers in genetic research, provide electronic tools for non-English language access and improved communication, and connect patients and caregivers with community services and supports.

- **CPeH Meet & Greet:** Virtual Open House (*January 21*)
- **Meaningful Use 101:** Back to Basics (*February 5*)
- **Leveraging Meaningful Use:** Disparities Action Plan (*February 10*)
- **Meaningful Use Technology:** The Next Edition (*March 18*)
- **Engaging Consumers in Research:** Platform for Engaging Everyone Responsibly (*April 15*)
- **Improving Patient Communication & Understanding:** Meducation Demonstration (*May 21*)
- **Mid-Year Check-Up** (*June 18*)
- **Sneak Peek:** Health IT Landscape (*September 18*)
- **Connecting the Dots:** Healthcare, Social Services & Community Supports (*October 1*)
- **Consumer Health IT:** Trick or Treat? (*November 3*)