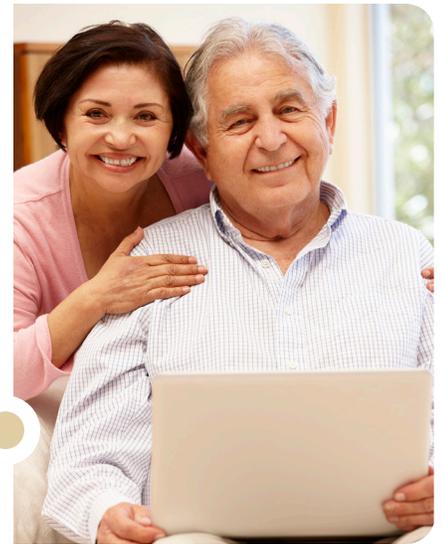


# 2016 Activities and Accomplishments

JANUARY 2017



## Year in Review

Health information technology (health IT) can enable the access, engagement and partnership that individuals and families need for better care coordination and better health. In 2016, the Consumer Partnership for eHealth (CPeH) successfully integrated person-centered health IT into new national initiatives designed to transform the way care is delivered and shift the emphasis from quantity of health services to quality and value.

This year saw increasing attention to health IT issues — particularly consumer access to health data — at the highest levels of government, from congressional hearings and legislation to rulemaking proceedings to the president's Precision Medicine Initiative. CPeH was often the sole consumer voice championing key benefits of health IT for patients, families and communities across the nation and urging policymakers to incorporate those benefits and digital tools into health care transformation initiatives.

## Looking Ahead

2017 will be another significant year for consumer health IT, given the new administration, the onset of the Quality Payment Program, further rulemaking and implementation of the 21st Century Cures legislation. The coalition will redouble its efforts to protect gains and advance meaningful patient access to health data and person-centered uses of health IT.

## Health Care Transformation

### MACRA and the Quality Payment Program

CPeH remained a critical and successful voice in efforts to integrate person-centered health IT into new programs under the Medicare Access and CHIP Reauthorization Act (MACRA), which changes how Medicare pays clinicians and replaces the Meaningful Use program for eligible professionals. In 2016, the proposed and final regulations to implement MACRA reflected CPeH's strategic impact by integrating key patient engagement and care coordination policies that CPeH had championed in the Meaningful Use program.

In April, the Centers for Medicare & Medicaid Services (CMS) released the much-anticipated proposed rule outlining the new Merit-Based Incentive Payment System (MIPS) and Alternative Payment Models incentive. CPeH launched a webinar series to educate its members on the program, solicit input and prepare detailed comments and recommendations. In June, CPeH submitted comments to CMS on numerous health IT aspects of the program with the support of 34 coalition members and allies. The coalition enthusiastically supported CMS' focus on patient and family engagement, care coordination and health information exchange in the MIPS Advancing Care Information performance score and supported the new Clinical Practice Improvement Activities performance category, which includes innovative uses of health IT.

CMS published the final rule in October; the renamed Quality Payment Program preserved much of the health IT structure but reduced the number of required measures in MIPS to offer providers even more flexibility. CPeH hosted an educational webinar for members and prepared a fact sheet on the health IT aspects of the Quality Payment Program. The final rule included a public comment period and the National Partnership shared talking points and recommendations for members to use in their organizational comment letters.

### MACRA and Interoperability

MACRA also declared achieving widespread interoperability to be a national objective, and CPeH has been the leading voice calling for interoperability efforts to include patients and family caregivers as well as providers. In April, the Office of the National Coordinator for Health Information Technology (ONC) requested public comment on how to measure progress toward



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nationwide interoperability. CPeH submitted comments that encouraged ONC to measure interoperability more broadly, to include individuals as equal partners in electronic access to and use of their health information, as well as to make connections to community-based health and social service settings.

### **Meaningful Use**

The Electronic Health Record (EHR) Meaningful Use Program remains in effect for eligible hospitals. This program has been the most significant policy lever for catalyzing health IT adoption and use and advancing consumer access to electronic health information. Its provisions for patient engagement and patient-centered uses of health IT would not look anything like they do today without CPeH's leadership and work. Stage 3 of the program, and the 2015 Edition of Certified EHR Technology, include consumer wins such as access for family caregivers, the ability of individuals to contribute *patient-generated* health data, and the collection of social determinants of health. Stage 3 is scheduled to take effect on January 1, 2018.

In July, CMS proposed modifying Meaningful Use requirements for Stages 2 and 3. These modifications would lower the threshold for several patient and family engagement measures in the next several years, including by requiring eligible hospitals to show that only one patient has used online access. CPeH submitted comments and encouraged CMS to recommit to meaningful thresholds for critical measures of patient and family engagement and health information exchange. On November 1, CMS released the Hospital Outpatient Prospective Payment System final rule, which finalized changes to Meaningful Use, among other programs. CMS considered the comments from CPeH but, unfortunately, reduced several patient/family engagement measures.

## **Consumer Access to Health Data**

### **Health Insurance Portability and Accountability Act (HIPAA)**

This year marked the 20<sup>th</sup> anniversary of the Health Insurance Portability and Accountability Act (HIPAA), the law that gives individuals a right to see and get a copy of their medical records. Unfortunately, confusion persists among both patients and providers, and too often consumers face barriers to getting their health information. Building on CPeH's successful work, the National Partnership's GetMyHealthData initiative continued championing greater consumer access and use of their health data and amplifying the stories of consumers who faced insurmountable and inexcusable barriers. HHS's Office for Civil Rights issued two sets of guidance explaining how to implement HIPAA's right of individual access, including electronic access, and clarifying when and how consumers may be charged fees for their health data. CPeH celebrated the guidance and routinely shares GetMyHealthData findings to promote policies that make

access and use of electronic health information easier for patients and families.

### **Data Portability**

This fall, the White House Office of Science and Technology Policy requested public feedback on whether and how to increase consumers' ability to get and use their data — otherwise known as data portability. CPeH submitted comments in November highlighting that consumers want and need increased portability of their medical records and other critical health data. Better health data portability is critical to the success of initiatives like the Precision Medicine Initiative and learning health systems that advance better care, better health and better value nationwide.



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### **Model Privacy Notice**

The Model Privacy Notice (MPN) is a voluntary, openly available resource to help technology developers provide transparent notice to individuals about how consumers' health data are used, protected and shared. In 2016, ONC revised the model notice and invited public comment in light of the much-expanded universe of smartphones, mobile applications (apps) and devices. CPeH submitted comments in April, encouraging ONC to consider issues important to consumers, including sale of data, language and disability access, and information portability.

Drawing from the public comments, ONC released a proposed template in September and requested review and input from the HIT Policy and Standards Committees' Consumer Task Force. As an active member of the Task Force, the National Partnership advanced CPeH's suggestions to ensure the template's clarity and usefulness for patients and families. The Task Force's formal recommendations incorporated many of these suggestions. In December, ONC released the revised Model Privacy Notice, which reflects CPeH's recommendations across all data sharing categories.

### **Health Data Stakeholder Commitments**

At the 2016 Healthcare Information and Management Systems Society (HIMSS) Conference, Health and Human Services Secretary Sylvia Burwell announced three commitments from leading health care stakeholders to make health data work better for consumers: (1) consumer access to electronic health information; (2) no blocking of electronic health information; and (3) national interoperability standards and policies. Building on CPeH's

advocacy, the National Partnership was the sole consumer group invited to sign the pledge.

## Health IT on the Hill

### 21<sup>st</sup> Century Cures

In 2016, Congress continued work on a 21st Century Cures innovation package to change medical research procedures and the FDA's drug and device approval process, support the Precision Medicine Initiative and Cancer Moonshot, and spur the interoperability of electronic medical records, among other issues. In January, the Senate Committee on Health, Education, Labor & Pensions (HELP) released a discussion draft of health IT provisions. The National Partnership submitted comments echoing CPeH's recommendations and urging the Committee to consider changes that reflect the full spectrum of patient and provider priorities and needs regarding access, exchange and use of electronic health information.

In late November, House and Senate health committee leaders released the final 21<sup>st</sup> Century Cures bill. Title IV reflects the National Partnership's feedback to the Senate HELP Committee, and includes several provisions related to EHRs and interoperability, as well as provisions to empower and improve patients' access to their electronic health information. On November 30, the House passed the 21<sup>st</sup> Century Cures Act (H.R. 34) by a vote of 392-26. The following week, the Senate passed the bill by a vote of 94-5, and President Obama signed it into law on December 13.

### House Roundtable and Testimony

The House of Representatives' Committee on Oversight and Government Reform invited the National Partnership to represent the consumer and patient perspective at a roundtable on health IT in February and then a formal hearing in March. The National Partnership's written and oral testimony provided detailed recommendations on how health IT can advance access to care and consumer access to health information, improve communication and care coordination, and enhance the privacy and security of health information. Subsequently, the National Partnership shared a memo on the Meaningful Use program and how best to advance patient-centered health care based on CPeH's many public comments, and submitted comments on harmonization of privacy laws.

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Editorial Note – 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](http://www.NationalPartnership.org).

Editorial Note – The Consumer Partnership for eHealth (CPeH) is a coalition of more than 50 consumer, patient, and labor organizations working at the national, state, and local levels to advance private and secure health information technology in ways that measurably improve the lives of individuals and their families. The combined membership of CPeH represents more than 127 million Americans.

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